Interfederal Centre
for Equal Opportunities

Human Rights of Older Persons and Long-Term Care

Monitoring Report on The Human Rights situation of Older Persons in Belgian Residential Care Settings

March 2016

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Het boek (Rechten en plichten)[1]

Boek, wat bent gij groot, boek, wat bent gij dik.

Waarom verberg je toch die schat aan recht en wet?

Wat goed dat u bergt voor de mensen staat.

't Is goed te lezen wat U ons hebt te geven:

Vrijheid, goedheid en liefde, zelfbeschikking?

al zijn we oud zelfs heel oud .....

blijven of zijn, wij zijn nog steeds burgers en hebben ook dezelfde rechten.

Een bijbel van mensenplicht en wensen, een baken van licht voor oude mensen.

Gij hebt dat alles in vorm gegoten,

hoe ze ons dekken, door onze plichten.

Een weegschaal met gelijk gewicht om de waarden en noden, van de mens te meten.

Bejaarden zijn noch niet dood, ook niet te vergeten!

X - 1 March 2016

The book (rights and obligations)

Book, how big you are, book, and how thick.

Why do you hide your wealth of laws and rights?

So good of you to store them for people.

It's good to read what you have to offer:

Freedom, goodness and love, self-determination?

and old or even very old .....

as we are or remain, we are still citizens and have the same rights.

A Bible of human obligations and hopes, a beacon of light for the old.

You have given a form to all of this,

the way that we are covered, through our obligations.

A well-balanced scale to measure the values and needs of mankind.

After all, the elderly aren’t yet dead, don't forget!

X - 1 March 2016

[1] This poem was e-mailed to us by a 93-year-old resident in response to the ENNHRI interview.

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Executive Summary

Context

The care sector finds itself not in an era of change, but rather, in a change of era. The sector has reached a crossroads in the quest for accessible, affordable care that is high-quality and based on human rights, at the same time as contending with the demographic trends that will profoundly influence the demand for (residential) care. Thus, on 1 January 2015 Belgium had a population of 11,209,044, of whom 2,692,514 were over the age of 60. This makes up approximately 24% of the population.[2] Based on the forecasts of the Federal Public Service Economy (FPS Economy), by 2050 there will be 3,909,373 people over the age of 60 in Belgium, including 1,252,507 over the age of 80.[3]

The residential care sector is one of the most highly regulated sectors in the country. In order to be certified, a residential care centre must meet a number of standards and rules. These have to do with the quality of the care and assistance provided, personnel and competencies, information provided, safety, freedom and respect, among others. Many human rights aspects are protected through these standards and rules. However, the regulations and standards and rules are not uniform throughout Belgium. The policy on ageing is currently undergoing a profound transition in Belgium. An institutional State reform entails the phased transfer of federal authorities to the federated entities.[4] as a result of one of these transfers, the federated entities have had responsibility since 1 July 2014 for the policy on ageing, which therefore also includes the residential and long-term care. The federated entities are each taking a different approach to their new powers, using different instruments and working at different speeds, in order to ultimately guarantee a human rights-based approach to residential care.

Implementing a human rights-based vision of care will involve shifting from a traditional medical model of care to a citizenship based model in care. After all, the citizenship based model assumes the fundamental equality of all citizens and therefore, that older persons have equal rights and obligations. The emphasis is on the quality of life, inclusion, self-determination, empowerment, integration and participation in society.[5]

Findings on the Human Rights Situation of Older Persons in Residential Care in Practice

Entry into Long-Term Care: Equal Access and Free Choice: in order to guarantee this right, not only does a non-discrimination policy need to be in place, but any positions of disadvantage need to be remedied in order to arrive at an approach based on equal opportunities. Guaranteeing equal and free access necessitates this twin-track approach, certainly if one takes into account the relationship between the socio-economic profile [6] of the

[2] FPS Economy, Directorate-General Statistics - Statistics Belgium, 1 January 2015.
[3] FPS Economy, ‘’Sectorstudie rusthuizen”, 2009, p. 11.
[4] http://www.belgium.be/nl
[5] GPS 2021, werkboek. Nieuwe navigatie voor ouderenzorg. Zorgnet Vlaanderen, Acco. P 60.
[6] We regard this in a broad sense: origin, education, employment, beliefs, financial capacity, age, etc.

person requiring care and the respective need for care. This may lead to a compounding of barriers and an increased risk of combined discrimination.

Rights in Care: Quality of Life and Quality Care Services: The human rights identified in relation to care in residential care centres are: The Right to Life; Freedom from torture, violence and abuse; Dignity; Choice and autonomy; Freedom of Movement and Restraint; Participation and Social Inclusion; Privacy and family life; Freedom of expression, freedom of thought, conscience; Highest attainable standard of health; discrimination; An adequate standard of living; Education, training and life long learning; Redress and Complaints and Palliative and end-of-life care. Observations during the monitoring indicate - although aspects do differ from one residential care centre to the next - that these fundamental human rights are generally applied and respected.

The residents and family members interviewed often find it difficult to come up with a concrete example or clear definition of human rights in residential care. Although the staff and management are able to identify the human rights, they have more difficulty in translating this into the care that is provided in a residential care centre. Residents feel that they are safe and valued and treated with respect in the residential care centre and have not personally experienced or heard of any abuse. The staff and management are alert to signals of mistreatment or abuse and are aware that this is an important area for attention in the residential care sector. Mistreatment or abuse by family members was also mentioned by the staff. Figures from the various reporting centres and authorities confirm the existence of mistreatment and abuse of the elderly, and this also occurs in residential care residential care centres. There are, for example, various organisations that can be contacted by residents, family, staff, management or other stakeholders with complaints, but it is notable that complaints are rarely submitted by residents.

Having freedom of choice and autonomy is an important right in the context of services for the elderly, from a policy point of view as well as for the sector itself. In certain cases, restrictions to this choice and autonomy are reported by residents, family, staff or management, chiefly with regard to meals, daily schedule and activities. Freedom of movement was approached in two areas during the monitoring: free intra and extramural mobility and ‘the restraint policy’ within a facility. Except for residents with a specific care profile (dementia, etc.) free access and free mobility is possible within the facility. For these residents, this is sometimes constrained by transport options and location, which also leads to a restriction of the freedom of movement. The residential care centres investigated apply a ‘low restraint policy’ for the residents who are subject to a safety risk (e.g., residents with dementia). In this case, restraint is only permitted in carefully considered situations and the decision to apply restraint is the exception rather than the rule. However, the workload and the many (technical) possibilities for applying restraint can lead to an increased restraint policy encroaching on a low restraint policy.

Some residents also mentioned the lack of personal and social networks within the residential care centre. Others participate as much as possible and maintain good relationships with fellow residents. Furthermore, the right to privacy in a residential care centre is not always given maximum expression. Despite the general satisfaction of the residents, there are many (minor) restrictions to this right that can be observed. This is an area that requires further attention and certain adjustments would be desirable.

The freedom of expression, thought and (religious) conscience and the right to express them in the residential care centre is a right that was confirmed by all stakeholders interviewed. The limitations associated with this freedom are the legal restrictions that apply elsewhere in society as well. The cultural and religious diversity of the resident population remains low, however, and is in contrast to that of the staff population which is increasingly diverse. Attention for discrimination unfortunately remains necessary. With regard to care receivers and care providers, we should therefore pay specific attention to the vulnerability of those who may experience discrimination through a combination of factors, such as age and disability (multiple discrimination).

For the right to the highest attainable standard of care, critical feedback was received and improvements were suggested. The factors that could improve the physical and psychological situation are highly diverse, ranging from infrastructure to aspects of care. Residents, family and staff regularly complain about the shortage of personnel, despite the fact that many residential care centres employ more staff than is officially required. The staff interviewed indicate that they do have access to the necessary training options. A training on human rights in care could further optimise the knowledge and skill of the staff. The right to life long learning is a fundamental right, but unfortunately this is not so for all senior citizens. The gulf between different residential care centres is somewhat larger here. More extensive intra and extramural cooperation could safeguard this right for the residents.

For palliative care, in the residential care centres investigated, care designed to increase comfort was primarily applied, with the care based on the patient's wishes. In Belgium euthanasia is in fact legally possible under certain conditions and according to a specific procedure. Residential care centres must follow these legal regulations and must attempt to make clear agreements with the residents in this regard through the early planning of future care.

The monitoring included random sampling in 9 residential care centres. The observations with regard to human rights differ from one residential care centre to the next and therefore absolutely cannot be generalised.

Introduction

The ageing of the population is having a major impact on the demand for care, the specific need for help and care facilities and the ability for our society to meet this demand. In the meantime, the context of the care sector for the elderly is changing. Thus, the residential care sector for the elderly is becoming increasingly fragmented, in terms of both supply and in the distribution of authority. For example, residential care facilities for the elderly may assume numerous forms: service flats, assisted living, expertise centres for dementia, short-term residential centres, residential care centres, nursing homes, etc. which are distributed across a number of levels of authority.

Moreover, elder care and long-term care are undergoing a (r)evolution in Belgium. This represents a decisive point for the vision and policy on human rights for the elderly in the context of care relationships. It is difficult at this time to make binding analyses, but this does not make our observations any less relevant.

Despite the many international treaties and rules concerning the 'right to care', such as the International Covenant on Economic, Social and Cultural Rights (ICESCR), the European Social Charter (ESC) and the European Union Charter of Fundamental Rights, the International Covenant on Civil and Political Rights (ICCPR), the UN Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW) and, of course, the European Convention on Human Rights (ECHR), the associated human rights in care are often under pressure.

Human rights in long-term care have therefore long been an area for attention for Unia. Reports are processed, projects are initiated and recommendations drafted with an eye to discrimination. Thus, our investigations into the issue of discrimination and diversity within the care sector have included an approach based on the four Care-phases as defined by Joan Tronto:[7] phase 1 – 'caring about': recognising the need; phase 2 – 'taking Care of': taking responsibility with regard to the specific need; phase 3 – 'Care giving': meeting the need via work requiring a certain skill; phase 4 – 'Care receiving': checking the match between the need-response.[8]

In addition to the right not to be discriminated against and the right to equal opportunity, human rights in care encompass a wide spectrum of rights. The right to privacy, the right to choice and autonomy, the right to dignity … etc. are fundamental rights in long-term - and thus also residential - care for the elderly. Within the framework of the ENNHRI project '**Human Rights of Older Persons and Long-Term Care**', Unia carried out monitoring in a number of residential care centres in Belgium in relation to these rights.

The results of this research are discussed in this report: '**Monitoring report on The Human Rights situation of Older Persons in Belgian Residential Care Settings'**. During this

[7] TRONTO J., Un monde vulnérable – pour une politique du Care, 1993.
[8] Care en transculturele vaardigheden. Centre for Equal Opportunities and Opposition to Racism. 28 October 2011.

ENNHRI monitoring a random sample was made in 9 residential care centres. The observations with regard to human rights should therefore by no means be generalised.

Purpose of report

The aim of this report is on one hand to contribute to a coherent and informed European policy with regard to a human rights-based approach to long-term care, and specifically to the residential care of older persons. To this end, elements from this report will be included in the global report that the ENNHRI secretariat will present in European fora.

On the other hand, the report is intended as a starting point for greater focus by Unia on promoting knowledge of and respect for human rights in care relationships in Belgium, with particular attention for antidiscrimination laws.

Mandate of the Monitoring

Unia, Interfederal Centre for Equal Opportunities

Unia is the successor of the Centre for Equal Opportunities and Opposition to Racism which had a type B-status as National Human Rights Institution (NHRI).

Unia is independent interfederal public institution specialised in equal opportunity policy and promoting non-discrimination. Its mission, based on the goals established in a joint operating agreement between the Federal Government, the Regions and Communities, is made up of three major areas of focus:

- Promoting equal opportunities and participation for all, regardless of their origin, age, disability, sexual orientation, religion or beliefs, ... in all areas of society (labour market, housing, education, well-being, leisure, culture and citizenship).
- Collaboration with the various players in society, at the local, regional, national and European level: political and public authorities, citizens, civil society, the professional sector, social partners, the academic world, international organisations, etc.
- Promoting the knowledge of and respect for human rights, with particular attention for the antidiscrimination laws to ensure that these rights are applied and respected in Belgium. In addition, Unia is an independent body responsible for the promotion, protection and monitoring of the application of the UN Convention in Belgium.

Towards a national human rights mechanism?

Together with 11 other institutions with a mandate and expertise in the field of human rights, Unia drew up a report for the United Nations Human Rights Council. This Universal Periodical Review (UPR) lists a number of recommendations with regard to combating racism, the incarceration of minors, the importance of inclusive education and the reduction of preventive detention.

Although Belgium has a number of authorities – at the federal, regional, subregional and inter-federal level – that are active in the field of human rights, Unia is of the opinion that it is high time for a national human rights mechanism to be established. Before setting up an institution of this kind with an A status, civil society bodies and the various Federated entities should first be consulted. The federal government must follow through on its promise and put plans on the table as soon as possible to effectively realise this long-awaited institution.

Methodology and ethical principles

Methodology

In order to be able to approach the residential care sector in all its diversity, also taking into account its complexity, it is necessary to use a number of different methodological tools.

These tools should help us to understand the reality of the residential care centres, in order to find out what may be happening but which is difficult to discuss. When those active in the long-term care sector are approached, the research protocol provided by the ENNHR-secretariat is followed [9], which is adapted to the cultural and temporal circumstances of each individual involved, and to his or her background and identity characteristics (language, interview techniques, etc.).

The tools need to meet a combination of requirements… :

- with regard to the collection of objective (the legal framework…) and subjective data, to simultaneously assess the facts and the experiences of the subjects while taking into account all the human rights related problems with which the residential care sector is faced,

- with regard to the analysis, to be able to draw the significant correlations between the realities observed in practice.

The monitoring is made up of two different methods which are adapted to the specific characteristics of the employees in the sector, the residents and their families. Depending on the availability of the various stakeholders, their habitual schedule in the residential care centre and their degree of vulnerability, the monitoring may use:

- individual interviews or double interviews;

- collective interviews or focus groups

In total, 9 residential care centres were monitored, including centres in Flanders, the Brussels Capital Region and the Walloon Region. Residential care centres from the German-speaking Community were not included in the sample. The selected residential care centres differ from one another in size (from +/- 330 beds to +/- 70 beds) and type of supplier (public residential care centres, private residential care centres or 'private for profit' and vzw-residential care centres or 'private for non-profit').

In the 9 residential care centres, 124 people were interviewed, including 36 residents, 19 family members, 54 members of staff and 15 members of the management team (the senior management, the executives and the policymaker(s) responsible for the care policy in the residential care centre.)

In addition, the following actors were consulted:

[9] Human Rights of Older Persons and Long-Term Care: Monitoring Methodologies Report. ENNHRI – permanent secretariat, July 2015.

- Representatives of the competent authorities;
- Senior citizens' organisations and (residential) care organisations from civil society;
- Umbrella organisations and consultative platforms from the care sector, both from the supply and demand side;
- Representatives of educational institutions for care specialists and nurses;
- Experts and academics.

Ethical principles

All of the Unia staff are subject to a code of ethics that forms part of their employment contract. This creates a clear ethical and deontological framework: *'… We treat colleagues, partners in dialogue and the public with respect, courtesy, openness and a sense of justice'*, and furthermore '… *We strive to ensure impeccable professional ethics. All members of the staff must conduct themselves with integrity, honesty, sincerity and incorruptibility. Decisions must be taken independent of personal interests and preferences, …* .'[10]

Furthermore, during the entire monitoring process, the ethical principles and code of conduct, established by the ENNHRI secretariat, were observed: Do no harm; Show sensitivity; Exercise good judgement and seek advice; Be credible; Be impartial; Be visible; Know and respect your mandate; obtain consent from study participants and protect confidentiality.[11]

[10] Unia, BIJLAGE ARBEIDSREGLEMENT nr. 1: Deontologie
[11] Human Rights of Older Persons and Long-Term Care: Monitoring Methodologies Report. ENNHRI – permanent secretariat, July 2015

Terminology

Long-term care: What's in a name?

The term 'long-term care' encompasses a wide range of meanings[12]: prevention, rehabilitation and self-reliance, healing, care and palliative care. It involves a combination of healthcare and social care in 'activities of daily life' (ADL) such as eating, washing, dressing, grooming and housekeeping. These services may also cover the 'instrumental activities of daily life' (IADL) such as managing personal finances and running errands.

These carer services can be provided within diverse care frameworks, from care in the home setting via intermediary care formulas such as home care or family-based care, to (semi)-residential care facilities such as day care centres, short-term residential centres, residential care centres and nursing homes.

Residential care facilities for older persons: What's in a name?

Different terminology is used to refer to residential care facilities for older persons, which can take different forms. Currently, in Flanders the term residential care centres (which may or may not be certified as nursing homes) is increasingly used, while in the French-speaking part of Belgium, the terms residential care centres and nursing homes are used. The residential care for older persons takes numerous forms: short-term residential centres, day care centres, day care centres for palliative care, residential recovery centres, service flats and assisted living.

However, in this monitoring we have focused on the residential care centres (ROB/MR which stands for *Rustoord voor Bejaarden* or *Maison de repos*) and nursing homes (RVT/MRS which stands for *Rust- en Verzorgingstehuis* or *Maison de repos et de soins*).

A residential care centre with only RVT beds may only admit older persons with a significant need for care, in order to be eligible for the care subsidy. The degree of care required is determined by means of a score on the Katz-scale.[13] People with a O and A score will not be given a place in a RVT bed. In a facility with a strictly RVT status, therefore, only older persons from the categories B, C and Cd will be allowed. The most important difference is in the number of staff eligible for subsidy. For a RVT bed, the government awards a higher care subsidy. This means that the residential care centres can assign more personnel for the care and nursing tasks. However, if a residential care centre does not have any RVT beds, this does not mean that it cannot admit and treat older persons with significant care needs.

[12] WEDO **Europees Kwaliteitskader voor Langdurige Zorg.** Uitgangspunten en richtlijnen voor welzijn en respect voor ouderen met a zorg- of hulpbehoefte. (European Quality Framework for long-term care services Principles and guidelines for the wellbeing and dignity of older people in need of care and assistance) P. 6 http://www.belgianageingstudies.be/file/WeDo_brochure_A4_48p_NL_BE_WEB.pdf

[13] See also: Legislative and Policy Context

A (Flemish) residential care centre offers permanent housing and care to older persons. Anyone who is aged 65 or older may be admitted to a residential care centre. In practice, a residential care centre is primarily intended for individuals who are truly unable to stay at home any longer. It is therefore only if other care formulas such as informal care and home care are no longer sufficient and there is a need for virtually permanent care and assistance or supervision for living, that people will move into a residential care centre. The vast majority of the residential care centres are certified as nursing homes or RVT (*'Rust- en verzorgingstehuis*'). The remaining places in a residential care centre are identified by the National Institute for Sickness and Disability Insurance (*Rijksinstituut voor Ziekte en Invaliditeitsverzekering* or RIZIV) as '*Rustoorden voor Bejaarden* beds' (ROB-beds).

There are three types of providers: public residential care centres, private residential care centres (private for profit) and the vzw-residential care centres (private for non-profit)

The public or OCMW facilities (run by the *Openbaar Centrum voor Maatschappelijk Welzijn,* the Public Social Welfare Centres): in most municipalities and cities, there is a residential care centre that is managed by the OCMW. These tend to be larger facilities with over 200 beds, although there are quite a few smaller facilities as well. Sometimes they only accept people who are domiciled in their municipality or region. A vzw-facility is a residential care centre that is managed by a *vzw* (non-profit organisation), such as a religious community. The private residential care centres make up the third group. These private residential care centres are managed by one or more private individuals. There are different types, ranging from small to large facilities, as part of a commercial – national or international – group. In some cases, they may also have a non-profit (vzw)-structure.

For the sake of clarity and in order to guarantee anonymity, in this report we have chosen to use the term 'residential care centre' wherever possible. Other terms that may also be used are 'facilities' or 'residential (care) facilities for older persons'

Findings I: Focus

1.1 Ageing people with disabilities and looking after people with disabilities in residential care centres

Just like the rest of the population, the number of ageing people with a disability is increasing.

Two studies carried out by the 'Observatoire de l'accueil et de l'accompagnement des personnes handicapées' (Observatory for the care and support of people with disabilities) in 201010[14] and the thematic working group '*ouder wordende personen met a beperking*' (older persons with a disability) in 2008[15] respectively, examine the needs and solutions offered to elderly people with disabilities both by specialised services for people with disabilities and residential care centres or nursing homes. Ageing people with disabilities are taken care of in both residential establishments and day centres, and in residential care centres.

In the sector for people with a disability, there is a belief that it is best for ageing individuals with a disability to remain in their familiar living environment for as long as possible, instead of making the move to the sector for the care of the elderly. If ageing people with disabilities[16] are looked after in day centres and residential establishments, the following adaptations should be provided:

- An individualised approach in a collective context: this approach must take into account the person's own pace, and focus on interaction and listening to the person, etc.
- The development of specific activities: less activities where you are passively involved with the person and more activities where you are actively involved with the person
- A specific project and reorganisation at an institutional and educational level (forming an older people's group, creating a serene and calm environment, etc.)
- Different organisation of time (getting people up at different times, late lunches, etc.)
- Mobility support and making accommodations in the infrastructures (technical support, presence of a professional to help people move around, etc.)

[14] Observatoire de l'accueil et de l'accompagnement des personnes handicapées, Cocof, Service Phare, Study on the suitability of care, support and accommodation services for ageing people with disabilities, Phare activity report, 2010, p.10-29.
[15] Thematic group 'Ouder wordende personen met a beperking' (older persons with a disability), *Synthesenota*, May 2008, http://www.west-vlaanderen.be/kwaliteit/welzijn_/wegwijzerennetwerking/rog/documents/synthesenota_themagroep.pdf
[16] The study examines the situation of ageing people with disabilities and not ageing people who develop a disability.

- A medicalised approach and coordination of medical monitoring (medical care provided in the centre, making medical appointments, etc.)
- Collaboration with external services (nursing service or private nurse, etc.).

However, there are also people with a disability who are housed in the sector for care of the elderly. Looking after people with disabilities in residential care centres falls into two major categories:

Either the disabled person is accompanying one of their ageing parents, who is already living in the establishment.

Or, owing to a shortage of places, the disabled person hasn't found a care solution in a specialised residential establishment. It is mainly brain-damaged or mentally disabled persons who are concerned by this type of default solution.[17]

In both cases, these disabled people don't go into a care home for reasons associated with their ageing (in general, they don't have any geriatric conditions). These people have often been living in a family and don't have any experience of living in an institution.

The Observatory's study found that an increasing number of vulnerable populations, including people with a disability, are being placed in unapproved establishments with no clear legal structure.

Furthermore, the study reveals a number of obstacles that residential care centres are faced with when they have to take in people with a disability:

Looking after a disabled person in a care home is subject to derogation: the majority of approved and recognised establishments are subject to a maximum standard concerning the intake of elderly people under the age of 60.

Secondly, the categories of dependence determining the funding granted to residential care centres don't take into consideration care for a slightly or moderately disabled person.

Thirdly, residential care centres have very long waiting lists; therefore, residential care centres don't have a quota of free places to able to take in ageing people with a disability.

Finally, staff at residential care centres don't benefit from specific training to take care of disabled people.

1. A few figures: people with a disability living in a residential care centre

It is currently very difficult in general, and even impossible, to collect overall information on the number of disabled people in residential care centres, their profile, and their registration with a regional service.

[17] In particular, see the report of the Centre Fédéral d'Expertise des Soins de Santé, no. 51B, Chronic care needs among persons aged 18 to 65 years old suffering from acquired brain injury, p.105

Flemish Community

Persons with a disability in nursing homes[18]

The most recent figures on the number of people with a disability in nursing homes are from 2011. However, according to the Minister of Welfare, we can assume that these figures will have remained more or less stable.[19]

In 2011, there were 1 242 people with a disability recognised by the *Vlaams Agentschap voor Personen met a Handicap* (Flemish Agency for Persons with a Disability) in nursing homes. That corresponds to just under 2% of the total number of residents in the nursing homes in Flanders. Of these people with a disability, 27% were under the age of 60, 16% were between 60 and 64, and 57% were 65 or older.

People younger than 65 in residential care centres or nursing homes

Based on the figures from the *Vlaamse Zorgverzekering* (Flemish public care insurance), each year some 1,700 people under the age of 65 are housed in a Flemish residential care centre or nursing home.[20] Some 30% of these individuals have a disability that is recognised by the Flemish Agency for Persons with a Disability. There is no information available about the remaining 70%.

Walloon Region

In the Walloon Region, no official data is available regarding the number of disabled people looked after in residential care centres. However, despite a lack of figures, some documents indicate the presence of disabled people with no geriatric conditions in residential care centres.[21]

Brussels-Capital Region

[18] A residential care centre (RCC) (*woonzorgcentrum, WZC or a Rustoord voor Bejaarden* or *Maison de repos*) offers permanent housing and care to older persons. A nursing home (*rust- en verzorgingstehuis, RVT* or *Maison de repos et de soins, MRS*) is an RCC that is certified for the care of older persons requiring extensive care. Most RCCs have this certification, but not all of them: http://www.vlaanderen.be/nl/gezin-welzijn-en-gezondheid/gezondheidszorg/woonzorgcentra-vroeger-rusthuizen

[19] Answer from Jo Vandeurzen to question no. 413 of 23 February 2015 from ELKE VAN DEN BRANDT, http://docs.vlaamsparlement.be/pfile?id=1127319; Answer from Jo Vandeurzen to question no. 48 of 10 October 2014 from BART VAN MALDEREN, http://docs.vlaamsparlement.be/pfile?id=1122116

[20] Agency for Care and Health, *Zorgzwaarte in de ouderenzorg*, http://www.vitalink.be/v2_default.aspx?id=31050#bewoners; Answer from Jo Vandeurzen to question no. 413 of 23 February 2015 from Elke Van Den Brandt, http://docs.vlaamsparlement.be/pfile?id=1127319

[21] On this subject, see in particular, *Manque de places en hébergement et Budget d'Assistance Personnelle: Façades de bonnes intentions?*, proceedings of symposium of 2 February 2010.

In Brussels, residential establishments are faced with a population that is older than that found in day centres: the percentage of people over 45[22] years old that they look after is higher than 50%, whereas barely 33% of these people attend a day centre.[23]

Moreover, there are no official figures concerning the number of disabled people looked after in residential care centres and nursing homes.[24] Researchers and inspection services subsequently contacted 50 approved establishments, on an exploratory basis, to provide them with the number of people under 60 years old being looked after there, including recognised people with a disability or people benefiting from a disability allowance. Out of these 50 establishments, there are 87 people under 60 years old, 42 of whom are recognised as people with a disability.

A survey carried out by the Brusselse Welzijns- en Gezondheidsraad within the framework of research on people with a disability residing in resdential care centres and nursing homes in the Brussels-Capital Region, revealed that 55 establishments reported 239 people with a disability in their care. Among them, 49.4% were between 45 and 60 years old and 68% were less than 60 years old.

2. A few points of attention regarding adapted care for ageing people with a disability

In an effort to provide an appropriate response to the needs of ageing people with a disability[25], the study carried out by the 'Observatoire de l'accueil et de l'accompagnement des personnes handicapées' issued the following recommendations, among others[26]:

On the one hand, the answers must be individualised in order to take into account the person's specific needs, and there must be a diverse offer of places to live: keeping the person at home, keeping the person in a residential or care structure, creating places in centres or residential establishments for elderly people with a disability, creating specific projects in residential care centres and nursing homes, development of sheltered housing, etc.

On the other hand, collaborations between the disability sector (specialised services) and the residential care centres and nursing home sector must be developed according to different perspectives: training staff in care homes on how to communicate with people with a disability; sharing the care of disabled people between a residential care centre and a specialised day centre, or monitoring by a specialised support service, etc.

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[22] The Study on the suitability of care, support and accommodation services for ageing people with disabilities, conducted by the 'Observatoire de l'accueil et de l'accompagnement des personnes handicapées' (Cocof), specifies that the age of 45 is often used as the risk threshold concerning the ageing of disabled persons, p. 10.
[23] Study on the suitability of care, support and accommodation services for ageing people with disabilities, 'Observatoire de l'accueil et de l'accompagnement des personnes handicapées', 2010, p.12
[24] In these establishments, personalised data on residents are either collected by the inspection services (Cocof, Cocom), or by INAMI through an assessment of the person's dependence. This assessment doesn't include specific information on the person's disability, according to the study by the 'Observatoire de l'accueil et de l'accompagnement des personnes handicapées', Cocof, p. 13.
[25] It is essential to remember that a care home isn't a place of residence adapted to young people with a disability. The recommendations given below only concern ageing people with a disability or people with geriatric conditions.
[26] Study by the 'Observatoire de l'accueil et de l'accompagnement des personnes handicapées', Cocof, p. 40 and ff.

Furthermore, the scales used to assess the level of dependence in order to qualify for aid from the healthcare fund, must imperatively take into account the requirements in terms of support and care specifically needed for the care of a person with a disability.

Fourthly, places for ageing people to socialise and engage in leisure activities must be developed in order not to reduce the intensity or the frequency of social relations once the disabled person has been placed in a care home.

Finally, a system to identify the number of people with a disability in care homes / nursing homes must be set up so that these people are known to administrative and private services specific to the disability sector, and can benefit from the support and aid that these services offer.

1.2 The fundamental rights of elderly migrants

Elderly migrants are faced with many obstacles which particularly affect them in terms of access to care, access to nationality and social rights. These are all obstacles that affect their right to age with dignity.

Unia recommends taking into account the difficulties specific to elderly migrants and calls upon the authorities concerned to guarantee them equal access to their rights in law and in practice.

In the past few years, the literature on the ageing of migrants has increased in Belgium as have the number of initiatives to raise awareness among the public authorities on the stakes involved. It was a long time before the question of ageing was raised in Belgium, and it was only in the 2000s that initiatives appeared and found their way onto political agendas. For public authorities and migrants alike, everyone is required to review their analysis since immigration is no longer closely linked to work. Retirement is no longer associated with a return to the country of origin, even though this used to be the dream of many immigrants.

For a large majority of first generation migrants (of Turkish and Moroccan origin), this reality has been replaced by toing's and froing's between the two countries. These chosen or forced trips between two countries in order to deal with old age seems to be becoming more common among many men and women, thus raising new questions concerning justice: access to care and reimbursement for care received abroad, exportability of pensions, GRAPA. Even if the majority of elderly migrants remain invisible and silent, this doesn’t alter the fact that they have real needs and expectations regarding the public authorities, just like the elderly in general. They currently remain under-represented (even almost absent) in structures for the elderly and in geriatric services.

Concerning the issue of fundamental rights, we believe it is important to take into account certain realities.

Elderly people don’t represent a homogenous group.

This is what we recommend in favour of the “elderly migrant” population:

- Considering demographic change and new migrations, Unia recommends taking into account the heterogeneousness of the “elderly migrant” group, since the realities of every group is unique and strongly conditioned by the circumstances of their immigration. The aim is to gain increased knowledge on the actual needs of these ageing immigrant populations, which are increasingly isolated, especially among women. Unia suggests carrying out more censuses that are more precise, studies that are more focused on their state of health (victims of early ageing, strenuous occupations and subsequently exposed to various conditions and diseases such as diabetes, high blood pressure, depression, etc.). By knowing more about elderly migrants, it would be possible to take into account certain inequalities and traumas linked to exile (shame of not being able to return to the home country, impression of being useless, feeling empty with no work identity, discrimination, exclusion of certain public and private spaces, etc.).

Up until now, Unia has devoted significant attention to the ageing of first generation immigrants of Turkish and Moroccan origin, which comprise two large groups in Brussels. These are people who came to work here within the framework of bilateral agreements between Belgium and their country of origin. Although these groups represent a significant proportion, there are others, such as new arrivals (Sub-Saharan Africa). The latter also encounter specific health problems linked with the trauma of exile, war, etc.

Among the studies and research on this issue, all describe the difficulties common to all elderly Belgians although they do have certain specificities. Two studies are in fact references in the matter, one being ‘Migrations et Vieillissement’ conducted by the Fondation Roi Baudoin in 2007, and the other ‘Ouder worden in Vlaanderen’ and the research carried out by the Kenniscentrum Woonzorg Brussel. The authors of these scientific works emphasise the characteristics linked to migration, which dictate how people age.[27]

- Unia recommends developing tools to make information accessible to elderly migrants. This means targeting people who don’t have a good command of the language (or none at all) and who don’t know their rights.

The seminar organised by the Interfederal Centre in September 2014 (cf. symposium proceedings), which paid tribute to elderly first generation migrants, revealed two major problems: the vulnerability of women and access to rights.[28]

Owing to a particular migration trajectory, women may find themselves in a very precarious situation. Some who have had fragmented careers marked by frequent interruptions and part-time work, and others, who have done undeclared work, find themselves with a very low pension, thus plunging them into relative poverty. An increasing number of them have no partner and in the majority of cases, they receive a modest survivor’s pension. Besides the financial uncertainty in which they find themselves, they are subject to social precarity accentuated by a lack of knowledge of the support and aid structures. Associations that

[27] Cf the FRB’s report, 2007, Ouder worden in Vlaanderen, 2007, Onderzoek zorgnoden en behoeften: de kijk van de Brusselaar, Kenniscentrum voor Woonzorg, 2012.
[28] Cf annex of the proceedings of the symposium organised by the Interfederal Centre on 16 September 2014, "Vieillissement et immigration", Brussels.

endeavour to set up adapted and specific social support, as well as cultural actions to overcome their isolation, have few means.[29]

- Finally, Unia recommends encouraging the use of interpreters or intercultural mediation in order to provide quality care in establishments. The access to rights and services for elderly migrants could thus be facilitated. Being able to communicate in one's mother tongue reassures and establishes a certain level of trust. Faced with illness and long-term care, migrants must be able to understand the treatments and care in their own language and be supported in their suffering and questions concerning end-of-life issues.

Besides religious practices (food, prayers), the issue of death in exile must be approached from the point of view of fundamental rights. There are many concerns in this respect.

For the Turkish and Moroccan populations, religion may play a far more important role in daily life as these people grow older. It is important to ensure that the freedom to practice their religion is guaranteed and facilitated. Furthermore, aspects associated with death must be considered within the context of fundamental rights because they raise a lot of questions: will or won't it be possible to practice the necessary Muslim rites at the time of death? Will it be possible to ensure a proper Muslim burial? Concerns regarding burial have been partially met with the creation of Muslim parcels or plots in some graveyards... But some wish to be repatriated to their country of origin.

Hence, the issue of old age among migrants inevitably raises the question of interculturality, particularly in residential care centres, and the contact with carers and other health professionals. And in this case, it is important to ensure that fundamental rights don't forget these vulnerable groups of elderly people.

[29] Accounts of elderly women from the not-for-profit association "Seniors sans frontières" in Saint-Gilles.

Findings 2: Legislative and Policy Context

2.1 Introduction

The residential care sector is one of the most highly regulated sectors in Belgium. In order to open - and to keep open - a facility for older persons, it must be certified by the government. This certification is obtained by meeting a number of standards and regulations, which have to do with the care and aid provided, financial aspects, infrastructure, personnel and competences, framework of agreements, information supplied, safety, freedom and respect, etc.

Checks are carried out by authorities such as the inspection departments, which monitor compliance with these rules. As necessary, the facility may lose its certification and closure then becomes inevitable.

However, the regulations are not the same throughout Belgium. The policy on senior citizens in Belgium is currently undergoing a profound transition. An institutional State reform is transferring this policy area from the federal level to the federated entities.[30] One of these transfers has given authority to the federated entities, since 1 July 2014, over the policy on senior citizens, and therefore also over the residential and long-term care of older persons. It goes without saying that the different regulations and standardisation measures related to elder care are currently under development, as a result. We therefore consider that in addition to a demographic portrait of the Belgian (senior citizen) population, it would be useful to present a brief overview of the authorities and a number of basic concepts.

2.2 The ageing of the Belgian population and life expectancy

The demographic changes and the increasing age of the population forms an important point for attention for the care sector, and this also applies to the European community as a whole.

The Belgian demographic development shows that the over-60 age group continues to grow. On 1 January 2015, the Belgian population was 11,209,044, of whom 2,692,514 were over the age of 60, which represents 24% of the population.[31] Based on the forecasts of the Federal Public Service Economy (FPS Economy) 'in 2050 in Belgium there will be 3,909,373 people over the age of 60, of whom 1,252,507 will be over the age of 80.[32]

In 2009 the life expectancy from birth in Belgium was 77.7 for men and 82.9 for women. Men in 2060 would have a life expectancy of 86.2, while for a woman this would be 88.8. In 2060 the life expectancy for women would be 2.6 years higher than for men, as compared to 5.2 years in 2009.[33] Whereas in 1990, 546 senior citizens reached their 100th birthday, in 2010 they were already 1,556 centenarians and in 2015, 2,001 people aged 100 or over were counted.[34]

[30] http://www.belgium.be/nl/over_belgie/land/geschiedenis/belgie_vanaf_1830/vorming_federale_staat/zesde_staatshervorming
[31] FPS Economy, Directorate-General Statistics - Statistics Belgium, 1 January 2015.
[32] FPS Economy, ''Sectorstudie rusthuizen", 2009, p. 11.
[33] Federal Planning Bureau, ''Bevolkingsvooruitzichten 2010-2060", December 2011, p. 6
[34] Federal Planning Bureau, http://statbel.fgov.be

Of course this has an impact on the profile of the average Belgian residential care centre resident. The average age of the residents is 84, at 85 for the women and 79 for the men, with 3 out of 4 residents being heavily dependent on care [35]. Three quarters of the residents are women. The average age is 84: 63% of them are entitled to increased benefits, and in Flanders their share is 73%. Three out of four residential care centre-residents are heavily dependent on care (care profiles B, C, Cd of D). In Flanders their share is even higher (4 out of 5).

Taking all of these developments into account, the challenge is to guarantee the fundamental rights of the elderly with regard to care in Residential Care Settings.

2.3 Available facilities

The Belgian Health Care Knowledge Centre (Federaal Kenniscentrum voor de Gezondheidszorg) published the following figures on the available facilities: 'Between 2011 and 2013 we observed an increase in Belgium of the number of facilities certified as nursing home (*Rust- en Verzorgingstehuis, RVT*). Their numbers have increased from 1,161 to 1,205 and the number of beds available to the residents has increased from 65,325 to 69.705. With regard to the ROB's[36] or residential care centres (*Woonzorgcentra*), however, a decrease was observed in the number of certifications from 1,556 to 1,518 and the number of beds fell from 64,255 to 62,545. This inversely proportionate trend can be explained in part by the reconversion of ROB-rooms into RVT-beds.[37] This trend, that began in the previous decade, can also be explained by another element, which is the appearance of a diversified range of care services. For example, the home-care services have increased by over 40%, while the number of users of family help has increased by over 20%.'[38]

2.4 Authorities and policy

2.4.1 General

Belgium is a federal state which is made up of Communities and Regions: Flanders, the Brussels Capital Region, the French-speaking Community, the German-speaking Community and the Walloon Region.

The matters referred to as 'land-based' (such as economy, infrastructure, town and country planning) are Regional matters and the more 'person-based' matters (such as education, culture and welfare) are subject to the authority of the Communities. The overarching Federal Government is in charge of matters such as justice, defence and social security.

The Flemish Community has been merged with the Flemish Region into a single entity, Flanders.

In the Brussels Capital Region, the authorities are distributed between Regional institutions and Community institutions. The Community powers are exercised by the French

[35] http://fr.scribd.com/doc/305195405/Rusthuisbarometer-2016
[36] *ROB: rustoorden voor bejaarden = rusthuizen*, now referred to as *woonzorgcentra*, residential care centres
[37] RIZIV, Evolution in the number of beds, 1996-2012. http://www.riziv.fgov.be/nl/riziv/
[38] Belgian Health Care Knowledge Centre, *Soins résidentiels pour les personnes âgées en Belgique : projection 2011-2015 .2011*, p 10.

Community Commission (Commission Communautaire Française, COCOF) for policy initiatives of the French-Speaking Community; by the Flemish Community Commission (Vlaamse Gemeenschapscommissie VGC) for community powers for the Flemish Community; and by the Joint Community Commission (Gemeenschappelijke Gemeenschapscommissie, GGC) for community powers that do not fall exclusively to one or the other of the Communities. These are generally social and health issues such as the care policy within and outside of the care institutions, pensioners ('third age'), social policy, family policy, etc. It is also important to point out that the COCOF has transferred the Brussels residential care centres under its authority to the Joint Community Commission.

2.4.2 Changing authorities

Currently, the authority over the residential care centres can still be described as a shared authority. Each government has specific powers but there are overlaps, e.g.: the Communities have authority for the standards for the residential care centres and the Federal Government for the standardisation of the residential care centres and nursing homes. Generally, residential care centres are combined structures with both residential care beds and nursing home beds, all of which is monitored by the inspection departments of the Communities; Furthermore, the federal government is in charge for a significant part of funding the costs.

As mentioned, as a result of the sixth State reforms, many federal authorities and measures have been transferred to the federated entities. The federated entities now have the power to pursue a complete health care and welfare policy with regard to aspects such as standardisation, the certification of care sector workers, elder care and mental health care.[39] This is given concrete form in the pricing policy for facilities for older persons, the funding and standardisation of residential care centres and nursing homes, the centres for day care and non-congenital brain disorders, as well as for the Indemnity for Help to the Aged, (*Tegemoetkoming voor the Hulp aan Bejaarden*,THAB), sheltered living facilities and psychiatric nursing homes and certain rehabilitation agreements and specialised hospitals.

In the following chapter, we shall present the core elements of the respective (residential) policy on the elderly per region. The aim is not to provide a complete picture of the policy applied, as this is in a state of tremendous flux, but rather to highlight elements that may be important for a Human Rights-based approach to long-term care and specifically for residential services for older persons.

2.4.3 The Federal government

As mentioned above, as a result of the State reforms, the powers concerning long-term care and elder care are being transferred. However, not all authorities are being transferred to the federated entities. For example, the oversight of the care professions will remain a federal matter, as will home healthcare and geriatric hospital care. Furthermore, certain physical therapy services will remain under the authority of the federal government, in the form of the RIZIV (National Institute for Sickness and Disability Insurance). The other policy aspects will be gradually transferred by means of a transitional measure between 2014 and 2017.

An important federal instrument is the KATZ-scale: The KATZ-scale is a form that is used by home healthcare and nursing homes to measure the degree of dependency on care of the

[39] http://www.vlaanderen.be/nl/vlaamse-overheid/staatshervorming/staatshervorming

patients or residents. The criteria have to do with Activities of Daily Life (ADL). The form must be completed by the attending physician or by the nurse. This involves assessment of 6 to 7 important areas:

- washing oneself
- dressing oneself
- mobility
- toilet use (with or without help)
- incontinence
- eating
- orientation in time and space (dementia)

A score is assigned for each area depending on the amount of help the patient needs. The outcome can vary between 4 scores, ranging from 'no need for any help whatsoever' to 'fully dependent on help'. The result of this scale system gives a care profile, the degree of the need for care. On this basis, the facilities will receive funding.

For the sake of completeness, we should also mention the BelRAI. The BelRAI project is a Belgian pilot project commissioned by the FPS Public Health, Food Safety and Environment, for a uniform and web-based registration of client data. It is based on the interRAI-instrument, an assessment instrument for measuring the care situation and degree of well-being of the elderly in a standardised and structured manner. The aim is to create a better and more individualised care plan and to optimise quality control. The interRAI instrument, which is the result of an international project, has been adapted in the BelRAI-project both in terms of content and structure to the Belgian situation.[40] The goal is to replace the Katz-scale with the BelRAI.

2.4.4 Flanders

The institutional shifts concerning policy on senior citizens are occurring in parallel with a number of major social changes and areas of focus that will be integrated into the policy on senior citizens in Flanders. Here, we shall present an overview of some of them, based on the *draft memorandum 'Vlaams welzijns- en zorgbeleid voor ouderen. Dichtbij en integraal. Visie en veranderagenda van de Vlaamse minister of Welzijn, Volksgezondheid en Gezin*[41]*:*

Thus, the target group for the long-term care policy is becoming better educated, more vibrant and assertive. Various studies show that the higher the level of education, the better the health. At the same time, it is also clear that the more active one's lifestyle, the better one feels and the better the sense of well-being. The increased level of activity will lead to a desire for freedom of choice and the possibility to clearly express needs and expectations.

Secondly, the diversity in our society will continue to make itself felt in the policy on senior citizens. Financial resources, physical and mental aspects, religious beliefs, etc. will necessitate a more individual approach, with respect for the individuality and potentials of all. A diversification and increase in the range is a necessary condition for fulfilling this need. In

[40] *Naar een getrapt gebruik van de BelRAI met de BelRAI-screener*. Bram Vermeulen, Liza Van Eeno, Dirk Vanneste and Prof.dr. Anja Declercq. Lucas, Centrum voor Zorgonderzoek en consultancy, KULeuven. March 2015, p.13.

[41] Draft memorandum on Flemish policy on welfare and care policy for older persons. *Dichtbij en integraal. Visie en veranderagenda*. Flemish Minister for Welfare, Public Health and Family, 5 February 2016, p.9 - 15

the following chapters, we shall also examine in greater detail the importance of this inclusive approach to care.

Changing family composition and family relationships are leading to additional areas for attention. Single individuals are increasingly becoming a focus of the policy, within the context of an ageing population with a growing proportion of women. Isolation, loneliness and neglect form the key challenges in this area.

The shift from a residential to an outpatient system of care and assistance will be further discussed and defined. The management of the care is increasingly in the hands of the person requiring the care and should preferably be started from the basis of the home situation. All resources and possibilities for long-term home care and home help should be exhausted first before the step should be taken to a residential facility. Technological and medical developments will expand the possibilities for care as well. Using these new methods and treatments will bring both opportunities and challenges. The electronic care file, electronic 'wandering' prevention methods, fall detection, etc. will make providing care more efficient, but will have a direct impact on the organisation and funding of the sector.

The commercialisation of care is another important point for attention. The increasing influence of the private sector is resulting in a transition in the supply and demand. Aspects such as cost-effectiveness, competition in care and freedom of choice will become increasingly important.

An important element in this draft memorandum 'Vlaams welzijn- and zorgbeleid voor ouderen' is the clear acknowledgement of a Human Rights-based vision in the policy on senior citizens: '*A guiding principle in the creation and realisation of the policy on senior citizens is the Universal Declaration of Human Rights (UN, 1948) and the recommendation CM/Rec (2014)2 of the committee of the Ministers of the Council of Europe to the European member states on the promotion of human rights for senior citizens.*'[42]

The Residential Care Decree

On 1 January 2010, the Residential Care Decree of 13 March 2009 came into effect in Flanders.[43] The aim of this decree is to encourage the sector to better respond to the individual needs for care. In addition, 'customised care' and 'guaranteeing the continuity of care' are central aspects. The decree sets a number of priorities that may have an influence on the human rights of care receivers and care providers:

- offering **customised care** to the user and creating a high-quality continuum of care, through the correct and professional use of self-care, informal care and professional care, in a way that is customised to the individual;
- **updating** the regulations for care, housing and welfare and better **coordinating** them, with the goal of facilitating and encouraging collaboration between home care, care in support of home care and residential care;

[42] Draft memorandum on Flemish policy on welfare and care policy for older persons. *Dichtbij en integraal. Visie en veranderagenda*. Flemish Minister for Welfare, Public Health and Family, 5 February 2016, p.6.

[43] http://www.codex.vlaanderen.be/Zoeken/Document.aspx?DID=1017896&param=inhoud

- increasing the **quality of housing and care** by responding appropriately to the individual physical and psychological needs of the person requiring care, with sufficient attention to social inclusion and the sense of well-being for the person in need of care.[44]

General guidelines of the decree

The decree regulates the registration, certification and subsidy of facilities in the organised residential care sector and establishes a number of general guidelines that are directly linked to several of the stipulated Human Rights in long-term care[45]:

- guaranteeing the accessibility of the residential care without discrimination on the basis of ideology, religion or philosophical beliefs, membership or any other criterion which could form grounds for discrimination;
- requested and accepted by the user (or by the informal caregivers);
- take into account the entire care situation, including palliative care;
- be optimally adapted to the nature, timing, location, duration and intensity of the user's need for care;
- respect the privacy of the user and the informal caregivers without discrimination on the grounds of ideological, religious or philosophical beliefs, membership or any other criterion which could form grounds for discrimination;
- supporting and stimulating the personal autonomy and self-reliance of the user and the informal caregivers;
- making maximum use of the user's ability to care for himself and to be self-reliant, as well as that of his informal caregivers, taking their capacities into account;
- informing the user and his informal caregivers of the possibilities and limitations of the residential care and any other aid and services;
- streamlining the communication between the user, informal caregivers and facilities in order to be able to guide the user and his informal caregivers to appropriate care;
- paying special attention to users with an increased risk of reduced opportunities for well-being;
- paying special attention to diversity;
- paying special attention to specific target groups;
- respecting the pricing for the users as determined by the Flemish Government,
- developing a policy on ethically responsible care;
- stimulating volunteer care, organising or setting up joint operating agreements with organisations that provide volunteers;
- organising the opportunity for users to provide feedback;
- reporting inhibitory factors in the ability to offer residential care, with an eye to policy-making;
- developing programmes for education, training and systems of peer-to-peer coaching in order to enhance the expertise of the staff and management.

Regulation, certification and standardisation based on a Human Rights vision?

[44] http://zorg-en-gezondheid.be
[45] http://www.codex.vlaanderen.be/Zoeken/Document.aspx?DID=1017896&param=inhoud

These residential care facilities must always receive certification from the *Agentschap Zorg en Gezondheid* (Agency for Care and Health) of the Flemish government before they can be allowed to begin operations. This certification is obtained through a procedure with clearly defined rules and standards which builds further on the general guidelines and which must be met as minimum conditions (minimum number of staff; minimum number of hours of training; minimum room size; but also the integration into the local society; etc.). As mentioned above, these conditions for certification are often related to aspects that frequently overlap with Human Rights or aspects that encompass a risk of violation of these Human Rights. They are broken down as follows:

- The residents are aged 65 or older (exceptions to this rule are possible);
- One year after the date of the decision for certification, the facility must meet the stipulations for quality of health and welfare facilities;
- The residential care centre must actively communicate with the resident and his entourage with regard to any strategic policy decisions of the management which have an impact on the day-to-day functioning of the centre, on the cost of the residence or the nature of the aid and service provided;
- The residential care centre must involve family members, informal caregivers and volunteers in its operations;
- The centre must integrate as fully as possible into the neighbourhood;
- A residential care centre must be able to use the services of a quality coordinator. This function does not necessarily have to be assigned to a single centre exclusively;
- During the night, in any residential care centre there must be one active night shift organised per segment plus any partial segment of 60 residential units;
- The residential care centre must develop an education, training and instruction policy for the personnel. Every member of staff, with the exception of the cleaning and kitchen staff, most complete at least 20 hours of continuing education over a period of maximum two years. Each year, the director must complete 8 hours of continuing education;
- The residential care centre must be able to present, for every member of staff and every member of the Board of Directors, an extract from the national judicial files;
- The residential care centre must meet fire safety standards;
- The entertainers must meet the requirements for qualification;
- Since 1 January 2014 a residential care centre may not provide rooms for more than 2 people (deviation is possible and an application must be made supported by the reasons for the request).

How to guarantee high quality care with respect for Human Rights? [46]

In order to further guarantee the quality in residential care facilities, the Quality Decree of 2003 is applied.[47] The decree requires the facilities to provide users with responsible aid and services - based on the quality standards - and to demonstrate this! The facilities must take steps such as creating a quality manual and an annual quality plan (with annual report) in

[46] http://www.zorg-en-gezondheid.be/kwaliteit-in-woonzorgcentra
[47] http://www.codex.vlaanderen.be/Zoeken/Document.aspx?DID=1011700&param=inhoud

which they demonstrate how they intend to meet these quality standards. An umbrella organisation has published a handbook and a digital file in order to help the affiliated members with this.[48]

The minimum quality standards for care facilities are broken down into headings which in turn can often be directly translated into Human Rights in residential care facilities. The headings are:

1. **User oriented**: The degree to which the organisation, buildings, equipment, aid workers, procedures and working instructions are tailored to the specific needs of the users of the facility, in order to ensure their well-being. **The criteria** for this well-being are: privacy, dignity, autonomy, feedback, freedom of choice, self-fulfilment, integration, homelike atmosphere, security, the right to redress and information.

2. **Continuity**: the aid and service provided by the facility must be continuous and must be provided coherently. The **criteria** are staffing, follow-up and referral.

3. **Social acceptability**: the aid and service provided must be offered on the basis of accepted social values and rights (political and civil rights) which are minimally described in the constitution and the International Declaration on Human Rights. **Criteria** are: rights of the user and inspection.

4. **Effectiveness**: the degree to which the facility achieves the goals that it has set. **Criteria** are: the mission statement (mission, vision and values), core processes and evaluation

5. **Efficiency**: the aid and service provided and the functioning of the facility for senior citizens is provided and organised in such a way that the resources expended are in proportion to the results. The **criteria** for these are as follows: structure, internal and external dialogue, personnel qualifications, training, employee review, resources and material and financial policy, volunteers, trainees and students

These minimum quality standards form an important measuring instrument for assessing our findings with regard to Human Rights. This will be discussed further in the following chapters.

Quality indicators

Residential care centres must also measure and record various aspects of their service annually. These are what are known as quality indicators for residential care centres. These indicators concern the care provided, safety, their carers and the organisation and can once again be directly linked to Human Rights in long-term care. The indicators are monitored throughout the year by the facility and these are then sent to the *Agentschap Zorg en Gezondheid*. The fact that this monitoring is constantly under discussion in the field will become clear in the following chapters.

Based on their records, the facilities will receive a report from the government (*Zorg en Gezondheid*) twice a year with their data, this evolution and a comparison with others in the

[48] http://www.zorgneticuro.be/content/prezo-woonzorg

sector. Currently, the data cannot be made public because this is in a test phase and these indicators may still be revised.[49]

The indicators on the quality of care and safety are:

- decubitus (bedsores)
- unintentional weight loss
- incidents involving falls
- daily physical restriction of movement
- incidents involving medication
- flu vaccination
- medication use
- place of death
- end of life care plan

Indicators on the quality of the care providers and the organisation of the care:

- absenteeism (short-term per staff member)
- care staff who have left the residential care centre
- volunteers (number of hours worked)

A quality survey

The government has contracted a three-year project with the market research agency TNS Dimarso to conduct a survey of residents and family members in all residential care centres in Flanders. This survey, which will run from 2014 to 2016, will specifically measure the 'quality of life' and will therefore form a very useful source and benchmark for our observations within our ENNHRI assignment.

In 2014, 250 residential care centres were visited, at which 6,949 residents without cognitive difficulties were questioned in a face-to-face interview. The residents with cognitive difficulties were questioned via their respective personal contacts by means of a survey form. However, the response rate was less satisfactory in these cases. Although 3000 forms were sent back to us, the response per residential care centre differed too widely and was too low to arrive at reliable conclusions.[50]

In this overview, we shall present the summary of the results as shown on page 6 of the indicator report in question. Their relevance for the ENNHRI plan speaks for itself. [51]

(The 'quality scores' were calculated by first assigning all answers to the questions a score from 1 (never) to 5 (always) and then calculating an average.)

The residents of the residential care centres personally report that they have a high quality of life.

[49] http://www.zorg-en-gezondheid.be/vlaams-indicatorenproject-voor-woonzorgcentra-vip-wzc

[50] Vlaams Indicatoren Project Woonzorgcentra: *Meting van kwaliteit van leven in Vlaamse woonzorgcentra* (2014). Agency for Care and Health, June 2015, p.3.
[51] Vlaams Indicatoren Project Woonzorgcentra: *Meting van kwaliteit van leven in Vlaamse woonzorgcentra* (2014). Agency for Care and Health, June 2015, p.6

Residents are very satisfied in the areas of 'privacy', 'safety' and 'respect', with average scores of respectively 4.64, 4.53 and 4.28. We can conclude that the fundamental human rights of the residents in our residential care centres are respected: their privacy is respected, the residents feel safe and they are treated with respect.

The topics 'feeling comfortable', 'demand driven', 'autonomy', 'meals' and 'information o about the RCC' received fairly moderate scores (between 4.20 and 3.59). These topics largely concerned the care, the environmental factors, the freedom and independence, the homelike atmosphere, the food, receiving sufficient information… We can conclude that most residents scored the environment and the care as satisfactory to good.

For the topics related to personal relationships and use of time, there is room for improvement. The 'personal interaction between residents' received an average score of 2.66. The residents experience little opportunity for closeness or romance. Even maintaining good friendships and doing fun activities together is generally absent. Also the topics 'feeling connected with the staff' (M=2.98) and 'choice of activities' (M=2.99) score relatively poorly. The relationships with the employees and caregivers of the residential care centre are under (time) pressure. Also the way that they spend their days could be improved for many residents.

Conclusion: overall, the most significant finding of this survey is that the residents themselves report that they have a high quality of life. They are highly satisfied when it comes to 'privacy', 'safety' and 'respect'. The environment and the care receive good scores. In the area of personal interaction with the residents themselves and with the caregivers, and with regard to the way that the time is spent during the day, the quality of life could be further improved. (Flemish Indicators Project for residential care centres: measuring quality of life in Flemish residential care centres or *Vlaams Indicatoren Project Woonzorgcentra* : *Meting van kwaliteit van leven in Vlaamse woonzorgcentra*. Agency for Care and Health, June 2015, p.6).

In the following sections of the ENNHRI report, where relevant, we shall compare the various results with the results of our interviews conducted within the context of the ENNHRI research.

Tracking the results

The Flemish government has a follow-up plan in place for this quality monitoring. The aim is to give feedback to residential care centres about their care performance and to offer concrete ideas for improving the care of the residents. This will be done through an analysis of the figures and by drawing up improvement plans.[52]

2.4.5 The Brussels Capital Region

Brussels residential care centres have been certified either by the Joint Community Commission or by the Flemish Community and therefore fall under the standards (legislation) of the respective governments. In addition, there are the standards imposed by the RIZIV

[52] http://www.zorg-en-gezondheid.be/vlaams-indicatorenproject-voor-woonzorgcentra-vip-wzc

(federal government). As mentioned above, in the period 2016 – 2018 further changes will be made.

A total analysis of the differences between the JCC and the Flemish facilities would be far beyond the scope of this report. However, by way of example we would like to mention a few differences: one of the most important conditions for a JCC certification is that the care and information provided must be offered in Dutch or in French, depending on the resident's language choice. For Flemish certification, care and information is only necessary in Dutch. The age requirement in a JCC facility is 60, in the Flemish Community, this is 65. We shall discuss this further below.

Each government has specific authorities in Brussels, but there are overlaps as mentioned above:

- ✓ The Flemish Community and the Joint Community Commission have powers in Brussels for the standardisation of the residential care centres and the Federal Government for the standardisation of the nursing homes,
- ✓ The residential care centres in Brussels are usually mixed structures with residential care beds and nursing home beds which are monitored as a whole by the inspection of the Flemish Community and the Joint Community Commission.

As a result of the State reforms, in 2017 or 2018 the funding via the RIZIV will stop and the Flemish Community and the Joint Community Commission will set up their own institution for organising the funding.

Kenniscentrum Woonzorg Brussel (Brussels Residential Care Knowledge Centre)

We would also like to mention the Kenniscentrum Woonzorg Brussel here. They strive to respond to the increasing demand for care in Brussels. For this purpose, working under the motto 'stabilise the housing, mobilise the care', the organisation develops residential care concepts whereby lifelong 'living at home 'is stimulated and (semi-) residential care is offered if necessary.

In 2012 the Knowledge Centre published the results of the study of the housing situation and the care options for the elderly and those needing care in Brussels: *'Zorgnoden en – behoeften: de kijk van de Brusselaar. Analyse van sterktes, zwaktes, kansen en bedreigingen van de Brusselse woonzorg.'* This has therefore been a valuable source against which to compare our findings. The complete study is available on the website of the Knowledge Centre.[53]

In the period November 2011 – June 2012, through group discussions nearly 300 people were questioned: senior citizens (both those living at home and residents of a facility), people with a disability, informal caregivers, care providers, and (para) medics, managers of home care and residential facilities and finally experts and specialists.[54]

The questioning was focused on four main questions:

[53] http://www.woonzorgbrussel.be/sites/default/files/BehoeftenonderzoekBrusselseZorgVolledig.pdf
[54] Kenniscentrum Woonzorg: *'Zorgnoden en – behoeften: de kijk van de Brusselaar. Analyse van sterktes, zwaktes, kansen en bedreigingen van de Brusselse woonzorg'.* 2012, p.5.

- What is the housing situation and housing environment like in Brussels?
- What are the experiences or possible future perspectives for housing with care?
- What are the experiences or needs with regard to the service and care provided?
- What is the place and the role of informal caregivers and support from the immediate surroundings?

In the overall analysis, the study provides a brief overview of the results. These are presented schematically in the form of Strengths, Weaknesses, Opportunities and Threats. We shall present this schematic overview below and in the following chapters of this report, we shall compare the findings from the analysis of the target group of residential care centre residents with our findings and those of other organisations (e.g. the quality surveys of the Flemish government).

Needs and requirements for care: the view of the Brussels residents. Analysis of strengths, weaknesses, opportunities and threats in residential care in Brussels.

Strengths	**Weaknesses**
• Ability to decorate room according to taste • Natural light, view of the street, • Own bathroom • Ability to go outside • Activities • Contact with fellow residents	• Shortage of space • Lack of own space and privacy, certainly in sharing the bathroom • Limited living space • Disruptive behaviour / noise • Timing of evening meal • Limited choice /variation of meals • Unprepared transition to the residential care centre • Telephone costs
Opportunities	**Threats**
• General satisfaction • Positive choice for the residential care centre: good care and combating loneliness • Understanding for the situation • Residents support one another • Involvement of volunteers for (more) entertainment and activation	• Limited space for leisure and socialising • Passivity/resignation should not be equated with satisfaction • shortage of suitable homes for people with a disability • No room / attention for cultural / religious identity • Boredom

2.4.6 The Walloon Region

Regulations applicable to accommodation and looking after the elderly in the Walloon Region

In this chapter, we shall endeavour to highlight the main elements of the regulatory framework surrounding the policy concerning the elderly in the Walloon Region. This evolving policy helps to protect the fundamental rights of elderly people. We shall only focus on explaining four key areas associated with our theme: the standards of practice concerning residential care centres, control and sanctions, combating abuse of the elderly and resident representation: the residents' advisory board.

1. Standards applied to residential care centres

To be able to open its doors to residents, a residential care centre must acquire approval from the competent Walloon minister and consequently satisfy the standards imposed by the Walloon government. The request for approval aims to ensure the well-being and protection of the elderly. The Inspection Service verifies that the standards are respected. These standards cover several aspects, in particular[55]:

1.1 The residents

- Costs
  - the services covered by the accommodation costs
  - the terms of adjustment of the accommodation costs

- *Quality of life and fundamental rights*
  - food, hygiene and healthcare
  - *internal regulations*. A non-compulsory model is established according to the terms set by the government, which must respect the following principles:
  - respect for the residents' privacy as well as their ideological, philosophical and religious beliefs
  - free choice of doctors
  - free access to the residential care centre by family, friends, ministers from different faiths and lay advisors requested by the residents or, if necessary, by their representative
  - the greatest possible freedom to go out.
- establishment of a *life plan* for the elderly and its implementation in response to the residents' needs in order to ensure their optimum well-being and maintenance of their autonomy.

[55] Walloon public service, department for the elderly and the family, "regulations applicable to the accommodation and care of the elderly in Wallonia'', 5/01/2015. http://socialsante.wallonie.be/?q=aines/legislation/maison-de-repos

This life plan must at least include:

- measures taken relating to the care of residents with the goal of respecting their personality, helping them to overcome the feeling of loss experienced by them and their family when they go into a home, and detecting the elements that will help highlight their aptitudes and aspirations during their stay

- measures relating to the stay allowing residents to enjoy a living environment as close as possible to their family setting, especially by encouraging their participation in decisions concerning community life and by developing occupational, interactive and cultural activities in an effort to encourage the residential care centre to open up to the outside.

- *housing agreement* between the manager and the resident, or their representative. The non-compulsory model is established according to the terms set by the government.

1.2 Staff qualifications

- experience and qualifications, as well as the minimum requirements regarding activity and presence required to exercise the role of director

- number, competence, qualifications, effective presence and morality of the people exercising their activities in the residential care centre

1.3 External collaborations

The terms of the collaboration to be established with one or more coordination centres for care and home help or, if necessary, with a nursing home and with the organisaiton for palliative care covering the geographic area concerned, if the residential care centre doesn't have any nursing home beds.

1.4 The building

The building, in particular the regulations concerning fire safety and panic, in that they complete and adapt the standards decreed at federal level.

These principles are included in the charter relating to the quality of the accommodation and care of the elderly in Wallonia. The funding of residential care centres and nursing homes depends on the respect of these standards. They must have their own salaried and statutory nursing staff and carers. The number of workers depends on the residents' level of dependence (see page above).

2. Control and sanctions

Every residential care centre and nursing home is required to respect accreditation standards, as mentioned above, ensuring the residents' quality of life in their care package. There are also the following controls carried out by INAMI to check:

- the data and documents sent by the residential care centres in accordance with the funding provided by INAMI

- the content and quality of the care

- application of the Katz scale which determines the level of dependence of each resident and therefore the amount allocated to the residential care centre.

The Walloon government can suspend or withdraw a residential care centre's approval following the recommendation of the Commission Wallonne des Ainés if it doesn't respect the regulations in the matter. It can also authorise the emergency closure of an establishment for the elderly for health and safety reasons. Inspectors are appointed by the Walloon government to ensure the rules and standards are respected. They are also responsible for following up complaints regarding the abuse of elderly people in residential care centres. A Walloon agency to combat abuse was thus established by decree on 3 July 2008.

3. Combating the abuse of elderly people

The Walloon government has given the agency four missions:

- assistance for the elderly regarding abuse, in particular by setting up, managing and monitoring a freephone helpline;

- organising actions, providing information and raising awareness of abuse among the general public, in particular through the creation of a website;

- organising training for professions that are likely to be confronted with cases of abuse;

- sharing information, statistics or good practices with similar associations or organisations in border regions or communities, or in other countries.

In 2014, 1,740 (i.e. 57.14 % of all contact with staff from the agency) cases of actual abuse or fear of abuse being committed against a person aged 60 years and over were reported to the agency. These figures show that the majority of elderly 'victims' of abuse, i.e. 69.61 %, are women. It should also be noted that 21.82 % of cases of abuse are committed against elderly people living in an institution.[56]

4. Resident representation: resident advisory board

In Wallonia, every residential care centre and nursing home must have a Residents' Board (RB), which gives opinions, makes requests or suggestions. This RB is, of course, composed of residents, their family, staff and management representatives.

During board meetings, everyone may speak freely. This opportunity to express one's opinion aims to improve communication within the residential care centre between the various parties who live and work there. In general, the Residents' Board and how it operates are explained in the life plan given to every new resident in the residential care centre.[57]

[56] Agence Wallonne de Lutte contre la Maltraitance, Annual Report, 2014, p. 25-31
[57] Article 341 of the Walloon Code for Social Action and Health.

Findings 3: Human Rights Situation of Older Persons in Residential Care in Practice

In this chapter, we shall explore the results of the ENNHRI monitoring in greater detail. We shall first present some of the general results of the monitoring: 'what are human rights according to you? What does the term bring to mind? We shall then examine the vision and mission that is upheld at the facilities with regard to human rights. Later, we shall take a closer look at various human rights that can be identified as relevant to access to the residential care sector: Equal access to health services for all persons; the affordability of healthcare services and the choice of Long-Term Care Service. The bulk of the monitoring involves discussing human rights during the stay in the residential care facility for older persons: The Right to Life; Freedom from torture, violence and abuse; Dignity; Choice and autonomy; Freedom of Movement and Restraint; Participation and Social Inclusion; Privacy and family life; Freedom of expression, freedom of thought, conscience; Highest attainable standard of health; discrimination; An adequate standard of living; Education, training and life long learning; Redress and Complaints and Palliative and end-of-life care.

3.1 What are Human Rights according to you? Selection of responses.

What are human rights? What does the term bring to mind? Can you name some human rights? What do they mean? … And what about human rights in (residential) care?

Resident

- ✓ No idea.
- ✓ What do human rights have to do with a residential care centre?
- ✓ Human Rights are guideline: what society asks of me and what can that society do for me? I believe that most people don't know this.
- ✓ Treating others as you would wish to be treated yourself, that's the basis for care with respect for human dignity.
- ✓ These are the things that I have a right to as a person and that I cannot (or can no longer) achieve myself
- ✓ At this residential care centre, I can say and do anything I could at home. So I don't think that my human rights have changed.
- ✓ Being honest with us, the residents, that's a human right, isn't it? And humour? Humour is so important but it's often forgotten as a right
- ✓ Free choice of your doctor; The right to rest after having worked, and therefore also the right to work; The right to a decent pension; the right to food; Freedom and freedom of religion; privacy; a roof over your head; etc.

Family

- ✓ Human Rights are about being treated with dignity, you have to take the wishes of the residents into account
- ✓ To be heard, and to receive an answer to your questions. Being there to listen to the needs and desires of the residents.

- ✓ It's about little things: not lowering the bed after care so that you can't see the TV; being a bit rougher and faster with washing; not knocking before entering, etc.
- ✓ Freedom of expression; Freedom; housing; not being abused; good food and drink; etc.

Staff

- ✓ I do not have the impression that human rights are a theme at our residential care centre. You are not involved with human rights when you provide care or assistance.
- ✓ Human Rights are not a concern when you're a young care provider. That only comes when you're a bit older. When you start to understand what it means to be dependent on care.
- ✓ Human Rights in care are about empathy. Putting yourself in the situation of each individual resident and helping the resident in the way he or she wishes to be helped
- ✓ Asking the question: what do you want? The difference between hot and warm water, between laying out clothing or allowing you to choose your clothing; getting up at 8:00, 9:00 or 10:00? etc. Letting people do what makes them feel good. And then asking them if that was all right!
- ✓ Human Rights are basic needs. They are the rights and obligations related to these basic needs that apply in our society, and therefore also in our residential care centre. In this context, the right to sexuality is often forgotten.
- ✓ Participation; Autonomy; Freedom; Equality; Privacy; care with kindness; dignity; respect; freedom of religion; diversity; freedom of expression; self-determination; no abuse;

Management

- ✓ I think that we incorporate human rights into our care, but perhaps it is a little too often ‘supply driven’ rather than ‘demand driven’. This is an area in which we need to take further steps.
- ✓ If you want to give care based on a human rights vision, then you need to work with permanent teams. Only if you know your resident well can you safeguard his or her human rights.
- ✓ A residential care centre is not a ‘human rights free zone’. We are a mini-society with the same rights and obligations as the society as such.
- ✓ If I want to be sure that the Human Rights of my residents are safeguarded, then I need to monitor everything very closely. For example, I still know all of my residents by name and in 90% of the cases I also know of their medical files, and that is a conscious choice. We could grow larger, but then I would have to make different choices and work in a way that is more ‘anonymous’ and I don't want to do that.
- ✓ Having respect for everyone's social class. After all, an engineer is different from a labourer.
- ✓ The right to be alone sometimes; Receiving explanations and information, that seems to me a fundamental Human Right; housing; freedom of religion; participation and involvement; non-discrimination; right to education; right to care and food; etc.

3.2 Vision and mission

Most of the residential care centres that were visited in the context of the ENNHRI monitoring made an effort to take a human rights-based approach to care. The respect for human rights was sometimes explicitly, and sometimes implicitly, present in the care plan provided.

For example, there are facilities that clearly communicate their values and standards related to care in their mission statement and vision texts. We selected an example:

'… Our mission is to provide housing and care to older persons, in the same way that we would want ourselves or our family to be cared for, with the preservation of their freedom, and respect and attention for the individual…[58]

During the monitoring, this was often confirmed or mentioned by the staff and management: we want to provide care the way we ourselves would like to be cared for, or as we would like to care for our parents.

Within the vision and values of the facility, this can be expressed as follows:

'… we aim to provide a home for older persons…. Where safety, security, individuality, a homelike atmosphere and trust are given a central place. Self-determination will be stimulated at all times … we guarantee an unlimited, individual freedom …we strive to maintain our open and flexible character… we aim to optimise well-being in material, physical, psychological, social and spiritual terms … offer personal assistance until the end of life, including palliative care… Staff will display a respectful, friendly attitude with respect for self-determination, the ability to make decisions, the individuality and experience of each resident … through an interdisciplinary approach, we strive to constantly improve quality … the care for employees is very important… this is expressed in a decent salary, clear labour regulations, employee review meetings, personal attention for staff and an individual work schedule, …[59]

Unfortunately, however the mission as communicated is not always borne out in the workplace. The day-to-day expression and application of the human rights-based approach requires constant attention and a number of 'care leaders' who put a human rights-based approach into practice and positively stimulate other caregivers to provide this form of care.

- ✓ *A few years ago, we signed a human rights charter, but I cannot remember whether this was ever converted into concrete, practical examples. It's something that you sign and afterwards, nothing further comes of it. (staff)*

A human rights-based vision of care implies a citizenship-based model in care. The citizenship based model works from the assumption that all men are created equal and that, consequently, older persons have equal rights and obligations. It places the emphasis on the quality of life, inclusion, self-determination, empowerment, integration and participation in society.[60] In the workbook '*Nieuwe navigatie voor ouderenzorg'* (New navigation for the care of older persons) from Zorgnet Flanders, this model is applied directly to the situation of older persons: 'The older person is not only given the opportunity to choose, but also takes responsibility for his decisions. The voice of (vulnerable) older persons is increasingly being

[58] Mission statement of one of the participating facilities.
[59] Vision text of one of the participating facilities.
[60] GPS 2021, workbook. Nieuwe navigatie voor ouderenzorg. Zorgnet Vlaanderen, Acco. P 60.

heard, in the process of providing care and services as well as in the functioning of the residential care centre. The (vulnerable) older person is no longer relegated to a passive role, but receives the necessary support – taking into account his capacities and limitations – to organise his life and care according to his own wishes.[61] The shift from a traditional medical model to a demand oriented/demand driven citizenship model can be illustrated as follows:

Comparison of a traditional supply driven model and a citizenship based model in care[62]

Traditional supply driven model	**Citizenship based model**
Person with limitations	Person with capacities, rights and obligations
Patient	Client and citizen
Provide care/treatment	Support
The care provider as interventionist	The care provider as coach
Paternalism	Emancipatory
Institute	Simply facilities
Segregation	Normalisation and integration
Exclusion	Inclusion,
One-directional	Mutuality
Older person must adapt	Older person can be himself
Older person has little or no responsibility	Older person is also co-responsible for the care and service provided
Client as object of care. Individual personality and lifestyle are often of less importance	Client as subject of care. Respect and value for diversity in lifestyle
Choices are made by the care provider	Client makes his own choices after receiving thorough information
There are little or no demands placed on the client's own competencies	The client's own competencies are engaged
Social context is often disregarded in the care process	Social context counts in the care and service plan

[61] GPS 2021, workbook. Nieuwe navigatie voor ouderenzorg. Zorgnet Vlaanderen, Acco. P 61.
[62] GPS 2021, workbook. Nieuwe navigatie voor ouderenzorg. Zorgnet Vlaanderen, Acco. P 61.

Those requiring care are guided to the most appropriate available standardised form of care	Based on the need for care, unique or maximally individualised care solutions are sought.

3.3 Entry into Long-Term Care and Residential Care

3.3.1 Equal access to health services for all persons

Equal access to long-term care is a matter of concern that regularly appears on the political and societal agenda. There is an extensive framework set down in the Belgian constitution which provides for the right to a life in keeping with human dignity in article 23.[63] This right includes, in paragraph 2, for example, the right to social security, protection of health and social, medical and legal assistance. However, the 'equal access' is not specified as such. In the policy documents of the federated entities, the importance of this fundamental right appears to be acknowledged: 'Every older person has the right to equal access to the support and care that he/she requires. This support and care is available, financially accessible and high quality.'[64]

Although it is difficult to legally enforce this fundamental social right, it is binding as a standard and it gives rise to a set of laws and (moral and political) responsibilities for the government and policymakers. The right to healthcare therefore encompasses the right to equal access in relation to the principle of equality. This means that there not only needs to be a non-discrimination policy, but that any positions of disadvantage must be remedied in order to arrive at an approach based on equal opportunity. Safeguarding equal access therefore necessitates this twin track policy, certainly if one takes into account the relationship between the socio-economic profile[65] of the person requiring care and the respective need for care. Thus, studies have repeatedly shown that factors such as social and economic status, ethnicity, age, gender, disability and immigration background can have an influence on a person's health and on his ability to access healthcare. Each of these factors can form an additional barrier to access to care. We shall take a closer look at some of the barriers experienced by people seeking care who have an immigration background in Focus 2. It is clear that this right needs to be integrated with another fundamental right: the affordability of long-term and residential care.

- ✓ *That sounds logical, but I believe that there are many people who do not find it easy to receive the care that they need. That has to do with your socio-economic situation, but also with the people you know. (resident)*

The care profile of the older person requiring care (the degree of need for care) can form an obstacle in access to residential facilities since these facilities are funded on the basis of the need for care. This care profile is determined based on the Katz-scale: a resident with a care profile O has the least need for care. Care profiles A, B and C denote increasing degrees of need for care. Residents with a CD profile

[63] https://www.senate.be/doc/const_nl.html
[64] Draft memorandum on Flemish policy on welfare and care policy for older persons. *Dichtbij en integraal. Visie en veranderagenda*. Flemish Minister for Welfare, Public Health and Family, 5 February 2016, p.17.
[65] We regard this in a broad sense: origin, education, employment, beliefs, financial capacity, age, etc.

require care and have difficulties with orientation in time and space (dementia). The profile CC should also be mentioned, as these residents have a non-congenital brain disorder (*niet aangeboren hersenletsel, NAH*). Residential care facilities for older persons are awarded certification and funding based on the degree of severity of the care profile of their residents. And the fact that the care profile of the residents is a determining factor in the business results of the facilities is made clear by the research of Dr. Jozef Pacolet and Annelies De Coninck: '*De financiering van de bewoneriële ouderenzorg. Het perspectief van de voorzieningen*.[66] The research clearly shows that the degree of profitability of the residential care facilities for older persons increases in relation to higher proportions of RVT (nursing home) authorisations (persons needing extensive care). It therefore goes without saying that senior management will keep careful track of these proportions.

If there is no room for the care profile of the applicant (the number of beds for profile X are occupied) then one is placed on a waiting list or is forced to find another facility. Although a waiting list is not by definition an illegal or discriminatory practice, it does form an obstacle in the pursuit of equal access.

- ✓ *We registered our parents at different places. It was a question of simply finding a place, wherever we could. (family)*

This is confirmed in the survey conducted by the consumer organisation 'Test-Aankoop' in 2012.[67] In order to avoid these waiting lists and to somewhat speed up the access, the respondents reported that they contacted the "right" person (63 %), which they ranked as being the most successful approach. Another method that some people used to gain quicker access to a residential care centre was exaggerating the health condition of the candidate (8 %). According to the respondents, the primary criterion for admission to residential care centres in the candidate's degree of need for care, followed by the chronological order of the applications.[68]

Furthermore, the facilities for older persons are geared chiefly towards those requiring care who are from the immediate area, their own care region. For example, they are increasingly working on the basis of residential care zones and residential care districts, whereby the zone or the district can be defined as within a radius of 1 km or may encompass the entire municipality and suburbs. Within this vision, service will be given to the local persons requiring care first and only secondarily, to persons requiring care from outside of the care region.

- ✓ *The residential care centre should be a mirror of its municipality, the connection with the local community is important. (Management)*

Although during the interviews and focus groups it was always emphasised that the facility was open to all, there had not been much experience to date with the access of LGB persons to the care for the elderly. The equal access appears to be guaranteed on paper, but in practice, this has not (yet) been confirmed. Unia advocates an inclusive society, and therefore a society in which LGB individuals can be offered acceptance in care facilities for older persons. This would appear to require further investigation.

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[66] https://lirias.kuleuven.be/handle/123456789/525473
[67] Test aankoop/Budget en Recht nr 227. *Home Sweet home? Niet altijd!* March – April 2013, p.8-13.
[68] Test aankoop/Budget en Recht nr 227. *Home Sweet home? Niet altijd*! March – April 2013, p. 10

- ✓ *You do not see any gays or lesbians here. You see them everywhere except here. And after all, they need residential care too. (Personnel)*

As mentioned above, the changing societal circumstances are also leading to lapses in the equal access to residential care. Other areas for attention are changing family composition and family relationships. For example, not only do persons who live alone form a precarious target group, but also partners (who may or may not be in their 2nd or 3rd relationship or marriage) are looking for access to residential care with appropriate care services.

- ✓ *I would very much like to have been able to live here together with my wife, but I am still too fit and there was no room. I can only come here as a visitor. (family/partner)*

Equal access for persons with functional impairment in facilities for older persons is another area for attention. After all, it is not because you have a disability that this should impair your right as an older person. This was discussed above in 'Findings I: Focus on the ageing of people with a disability and looking after people with a disability in residential care centres.

Selection of responses on the equal access to health services for all persons

Resident

- ✓ I've never thought about that. It might be less accessible only for very poor people or for people who cannot find their way in the range of services available.
- ✓ In this residential care centre, it is mostly people from the neighbourhood. I assume that neighbourhood residents are given priority and if there is room left over, the places are given to people from other regions.
- ✓ If you ask me, the patients from the nearby hospital have an advantage if they want to live in this residential care centre.
- ✓ Everyone has access to healthcare and assistance.
- ✓ In our country, I think it's fine. I think that everyone can receive the care that he or she wants.

Family

- ✓ Anyone can go to a residential care centre. I think there is room for everyone who needs it.
- ✓ I do have the impression that anyone is welcome at this residential care centre. After all, you see people with different backgrounds and different profiles.
- ✓ My father was on a waiting list for three years. He - and we - would have preferred to come to the facility sooner.

Staff

- ✓ You have to know the right people to get equal access, you have to knock on the right doors. I don't know of everyone knows or understands that.
- ✓ Not everyone has the possibility to be admitted to care, whether it is for financial or practical reasons. There is a difference between 'wanting to' and 'being able to'.

- ✓ In our residential care centre there is a resident who would benefit tremendously from an electric wheelchair. But the government won't reimburse him for that because he lives here and not at home. How ridiculous is that!
- ✓ When I started working here, it was a real shock. In my home country, it would be unthinkable for someone to end up in a residential care centre who was still in good condition. Some residents here make me wonder what they are doing here.

Management

- ✓ I think that the range of available care services has a very low threshold.
- ✓ Our residential care centre has to be accessible to all. I know that that is not the case everywhere.
- ✓ Is there equal access if you are granting priority based first on the degree of care required and then based on the waiting lists and then based on the location? And then the family of staff is often given priority as well.

3.3.2 Affordability of healthcare services

The affordability of long-term care and residential care is a sensitive subject. It is not only one of the greatest concerns for the residents and for the sector, but owing to our changing demographics, it is also one of the greatest financial challenges for our government and society. This is clearly shown in the studies and articles that are published on the subject.[69]

It is often a question of the excessive cost of residential care for older persons. In addition, the infrastructure, personnel costs and material costs of the care are also open to debate. For example, the costs have been found to have increased by 20% in 5 years.[70]

Thanks to a study (*De Rusthuisbarometer*) by the research department of the Socialist mutual health insurance fund *Studiediensten van de Socialistische mutualiteiten*, we have recent figures on the average cost.[71] In Belgium the resident pays an average of 1,487 euros per month for the residential care. The vast majority of this (93%, or 1,379 euros) goes to paying for the day fee. The remaining 108 euros (7%) goes to supplements, or the payment for extra amenities and services. However, this is an average figure which masks significant differences. For example, 5% of the residents pay less than 1,045 euros per month and 5% of the residents pay more than 1,973 euros. The price can vary significantly depending on the location of the residence, the type of room and the property structure of the institution where the person lives. For example, a resident in Flanders comes out the most expensive: an average of 1,595 euros per month, of which 1,488 euros is for the day fee and 107 euros for supplements. In Wallonia, a resident of a residential care facility pays the lowest amount, at 1,338 euros per month. In Brussels the cost for a stay is 1,497 euros per month. [72]

- ✓ *I pay about 1,500 euros per month. That's not very much? Or is it?*

[69] http://fr.scribd.com/doc/305195405/Rusthuisbarometer-2016
[70] http://deredactie.be/cm/vrtnieuws/economie/1.2347240
[71] Rusthuisbarometer. Analyse bewonersfacturen in woonzorgcentra residential care facility barometer. Analysis of resident at bills in. Studiedienst/onderzoek en ontwikkeling, Socialistische Mutualiteiten, March 2016.
[72] Rusthuisbarometer, March 2016. P 9.

It is therefore also clear that the average pension, which in Belgium is between 1,000 euros and 1,500 euros, is no longer sufficient to pay the bill for residential care.[73] This is certainly the case if there are additional medical costs, which can quickly add up. In the Rusthuisbarometer [74], based on the EU-statistics on income and living conditions (EU-SILC) an overview is presented of the income available to older persons. (In addition to pensions, this also includes, for example, income from property rental or interest.) When the total cost for living at a residential care facility is compared to the total available income for single persons over the age of 80, the conclusion is that three quarters of these senior citizens do not have sufficient income to pay the bill for the residential care facility.

The residents interviewed also often expressed their anxiety about the affordability of their care. For example, they are worried they will be evicted from their room when their savings run out and will be put out on the street. The frequency of this comment leads us to conclude that much of the information on this is unclear for the residents. In most of the residential settings studied, there is a possibility to pay the bill in instalments, which can keep the cost affordable.

- ✓ *I had to sell my house, otherwise I wouldn't have been able to afford this residential care centre. With my pension, I would only have been able to stay here for half a month. So I have serious concerns about the affordability of all this. What are they going to do with me when my savings are gone? I can keep paying for about 10 more years, but imagine if I live longer than that, what happens then?*

Within the entire spectrum of service providers, for the very top segment, it appears that the 'sky is the limit'. More and more luxury settings in the private segment are specifically targeting wealthy older persons who demand a higher standard of high-quality care. In such cases, the price for the nicest room with an extensive array of services can be as high as 235 euros per day or some 7,050 euros per month. What you get for this price includes an indoor swimming pool, wellness areas, an individual entertainment selection, transport services and meals prepared by a star chef. [75]

The influence of the free market in the residential care sector is considerable. On account of the ageing of society and the insufficient public range, numerous private actors are entering the care marketplace in order to meet the demand for care. The commercialisation of care is in this way playing a role in the pricing, and therefore, also in the affordability of residential care for older persons.

During our interviews, nearly all of the members of senior management indicated that an increase in the day fee would be necessary in the future in order to be able to continue to offer the same level of care. Many of them are looking for alternative sources of income for care via a *Lokaal Dienstencentrum* (local service centre), short-term stays, assisted living or service flats etc. in order to keep the 'residential care centre' affordable.

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[73] http://moneytalk.knack.be/geld-en-beurs/pensioen/hoeveel-moet-je-sparen-voor-a-rusthuis/article-normal-560769.html

[74] Rusthuisbarometer. Analyse bewonersfacturen in woonzorgcentra. Studiedienst/onderzoek en ontwikkeling, Socialistische Mutualiteiten, March 2016.

[75] See i.a.: '*Meest luxueuze rusthuis van het land kost 7.000 euro per maand*', HetLaatste Nieuws, 12 and 13 March 2016, P.11.

- ✓ *We manage to survive thanks to our Local Service Centre. We wonder how long we're going to be able to keep this up? (management)*

From a policy point of view, therefore, there is now much greater focus on –affordable– home care and home assistance or on 'substituting second line care with first-line care.'[76] A multidisciplinary support in the home environment, tailored to the personal needs of the person requiring care, made up of formal (professional) and informal (neighbours, family, friends) care and support will be increasingly used. It is generally assumed that these (current and future) measures will ensure the affordability of long-term care. However, those working in the field have expressed some reservations about this idea. For example, the costs for home care are systematically underestimate because the costs are rarely calculated in total.

- ✓ *Every care provider has his or her own way of working, preferably with a certain tool that needs to be purchased or rented by the person requiring care. Here, the costs for incontinence materials are included in the price, but in home care, that is not the case, you have to buy them yourself. People often say themselves that there is not that much of a difference between the price of care at home and at the residential care centre. (staff)*

Other responses on the affordability of healthcare services

Resident

- ✓ I pay 54 euros per day and I think that's inexpensive if you compare it to other facilities. You receive good care for the price that you pay. But I am afraid that the prices are going to keep going up. In the end, only the 'rich' will still be able to afford a residential care centre and the ordinarily folks will have to stay home.
- ✓ If I'm not mistaken, it costs 2000 euros per month here.
- ✓ We are moving in the direction of a situation like in America: the have's and have not's
- ✓ Among the residents you often hear the joke: 'we're paying a lot to die'.

Family

- ✓ The entire pension of my parents goes to the residential care centre, and then each month they add some savings on top of that. In total, it's about 1,600 or 1,700 euros.
- ✓ I am worried about this: how do less well-off people manage to pay? The prices are really rising out of control.
- ✓ They are flexible with the payments; they understand the financial pressures that all of this brings with it. We have a sort of instalment plan with the residential care centre. I was ashamed to ask for it, but they were quite prepared to arrange it.

[76] Draft memorandum on Flemish policy on welfare and care policy for older persons. *Dichtbij en integraal. Visie en veranderagenda*. Flemish Minister for Welfare, Public Health and Family, 5 February 2016, p.14

Staff

- ✓ A residential care centre is expensive. You can turn to the public social welfare office (OCMW) for support, but then you don't get to choose the facility you go to. Then you have to go to the OCMW care centre.
- ✓ You can receive a subsidy from the OCMW if you cannot afford this residential care centre. They will then make up the difference.
- ✓ We notice that among the residents, that they are worried about the cost. They are afraid we will send them away once their budget is used up.
- ✓ We take it into account when residents have financial difficulties. For them, we will be more inclined to wash something by hand rather than sending it to the external laundry.

Management

- ✓ I suspect that we are a fairly affordable residential care centre.
- ✓ Our prices are average for this region.
- ✓ Our residential care centre is not affordable for everyone. But even those who cannot pay are welcome here, then the OCMW helps out.
- ✓ You have people here who pay a lot and then take advantage of the situation. They ring the bell every 3 minutes and when the staff arrives they say: 'I'm ringing because I pay enough for it'.

3.3.3 Choice of Long-Term Care Service

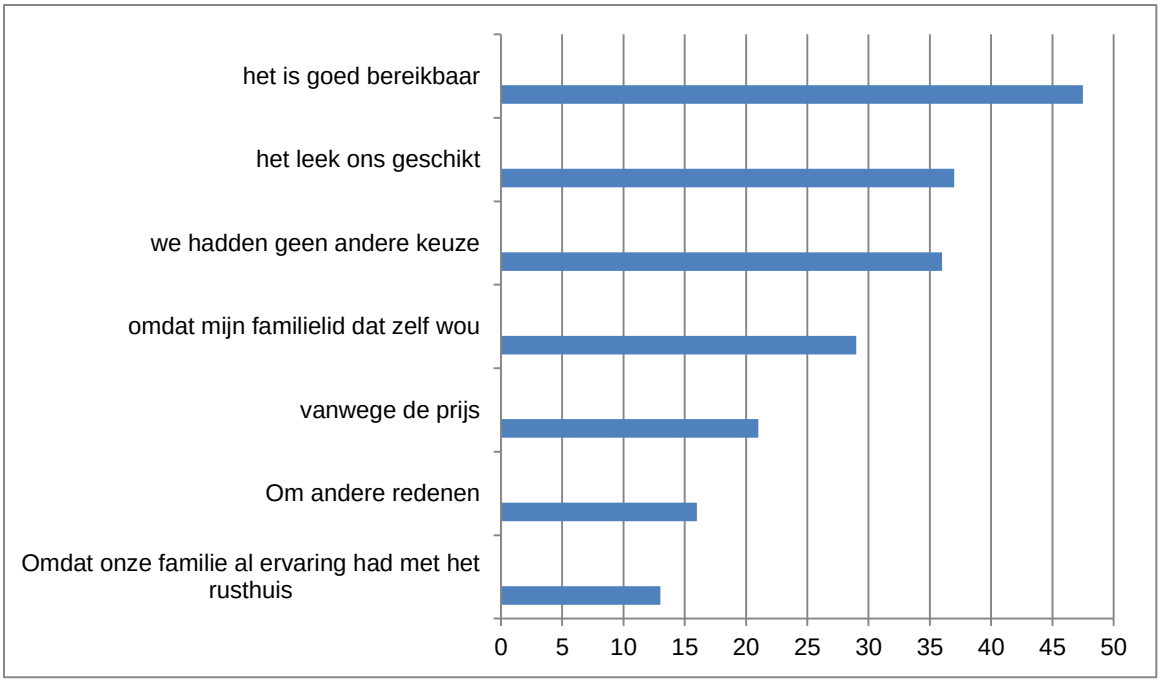
It is clear that this aspect has a direct link with the two rights discussed above. After all, you can only guarantee a free choice in long-term care when everyone has equal access to this care and when barriers such as price are counterbalanced (see above).

In general, in Belgium, the law of 22 August 2002 clearly establishes the rights of the patient and the rights of the person requiring care in the context of the individual relationship that the patient enters into with his professional practitioner.[77] With regard to the freedom of choice, there is a clear reference to the fact that the person requesting care may personally choose a professional practitioner and that this choice can be changed at any time. The law or circumstances inherent to healthcare can sometimes limit this free choice (e.g. in the case of forced institutionalisation of a person with mental illness, in the presence of a specialist in a hospital). On the other hand, any practitioner can refuse to provide a service to the patient for personal or professional reasons, except in emergency situations. There is no specific reference to the freedom of 'form' of service (e.g. the choice between home care and residential care).

In the survey by the consumer organisation Test-Aankoop '*Home sweet home? Niet altijd!' ('not always')*, the following answers were given to the question: Why did you choose the residential care centre.[78]

[77] http://www.health.belgium.be/eportal/Myhealth/PatientrightsandInterculturalm/Patientrights/BillRightsPatient/Whatareyourrights/index.htm#toestemming

[78] Test aankoop/Budget en Recht nr 227. *Home Sweet home? Niet altijd*! March – April 2013, p.8-13.



[it was in an accessible location/it seemed appropriate/we had no other choice/because my family member wanted it/because of the price/other reasons/because our family had experience with the residential care centre]

In our investigation, 3 decision-making pathways were highlighted in response to the question of how the residents ended up in a residential setting or why they specifically chose this residential facility: they chose for themselves, their children decided it, or the choice was made (or advised) by 'third parties', in this case the doctor, the hospital of via centres for short-term or day care.

Residents who had made their own choice mention two main reasons for their decision: their care needs had gradually become too great or it was a solution for their loneliness and isolation. They were often already familiar with the facility through previous contact (family, friends) or they registered for different facilities, and then the decision was taken based on availability.

- ✓ *Everything that had become a little bit out of control at home has been sorted out here in the residential care centre. With home care, that would never have been possible. (resident)*

In many cases, the choice was made by the children, or admission to the facility was organised through the doctor or hospital.

- ✓ *My daughter and the doctor from the hospital decided it, after my heart attack and my wife's stroke. We were opposed to it. It's so sudden, we had to decide within 24 hours whether we would take the room or not. It was difficult for us. It's a bit like leaving your whole life behind. (resident)*

As mentioned above, the policy on care and older persons will have a tremendous influence on the choice in long-term care. The access to residential care centres will become more narrowly restricted to those who need the most extensive care. The funnel effect and the tentacles that pull people towards home care will be expanded for the rest of the older

population requiring care. They will be guided in their choice towards home care or towards other residential care options such as service flats or assisted living. Increasingly, the possibility to opt for admission to a 'nursing home' will become available only at the end of the line of care.

- ✓ *In home care, parents tend to quickly and intensely lay claim to their children, in a residential care centre, they receive help from others which allows you to rebuild a parent-child relationship. (staff)*

- ✓ *We have many residents who fall between categories: there are actually still too fit to live in a residential care centre, but they are not fit enough to stay home alone. These are people who are lonely, frightened, but in fact don't need continuous care or who can do quite a lot independently. (staff)*

- ✓ *Allowing older persons to stay home as long as possible, is that in the best interests of the older person or is it the best for the government? The government will increasingly direct your freedom of choice. (management)*

Other responses on the choice of Long-Term Care Service

Resident

- ✓ I don't know how I ended up in the residential care centre, I had a stroke, and after the hospital I came here. It was all arranged very easily. But I don't know who actually took care of arranging it, my children, the hospital, the OCMW?
- ✓ I had registered for the waiting list at different facilities. This was the first place that had an opening. So, was I free in my choice to come here? Yes and no. It was either this or nothing.
- ✓ When I arrived, I was disappointed and sad, you have to give up your house and your home, even if it is a free choice. But then I put on some music and opened a bottle of champagne, and I was home …. It's important that you can make that switch when you arrive at a residential care centre. You can't go on living in the past, you have to bring your previous life to closure and create something new. This choice has given me my 4th life. It was a conscious choice and in retrospect, it was a good one.
- ✓ We took care of our mother-in-law for 35 years, what they now call informal care. Do you think that would be possible nowadays, 35 years of informal care? Most people don't have that choice.
- ✓ You shouldn't ask residents of a residential care centre: 'do you like it here'? That is a stupid question, nobody likes it here, people live here out of social impoverishment. People want to be cared for at home and to stay at home to die, but unfortunately they don't always have that choice
- ✓ I first lived in an adapted home next door to my son. That was fantastic, with a view of the fields. Unfortunately, I spent all day alone, my kids all work, you see. So I decided myself to move to a residential care centre, here I have company at least.

Family

- ✓ I chose the residential care centre for my mother.

- ✓ Friends of my parents lived here in service flats. They were satisfied and my parents had come and registered – unbeknownst to us – for the service flats that are connected to the residential care centre. They made the choice completely themselves.
- ✓ My parents never looked at any other residential care centres, they knew exactly where they wanted to go. We (the children) have always respected their choice.
- ✓ My mum had been here before for short-term stays and her sister lived here too, that's why she chose this residential care centre.
- ✓ You don't always have a choice. Either you take care of your parents at home, or in a residential care centre. We had no choice, the care had become too demanding. We urgently needed a solution and that's why we didn't hesitate when a place opened up here.
- ✓ I always thought it was a good decision to move my parents to a residential care centre. But now that I am growing older myself and the more time you spend here, I'm beginning to have doubts. At the time the choice was simple and easy to make. Now I see things differently. Now I would rather not go to a residential care centre. We are currently looking for a small apartment or a multigenerational living unit to share with our son.
- ✓ After my husband's accident, we first adapted our house and for a long time I took care of my husband at home myself. But the care became too demanding, I couldn't handle it any longer.

Staff

- ✓ You have people here who don't want to be here and we also have people who leave and go back home.
- ✓ We see a lot of residents take gigantic steps forward after they have lived here for a while, simply by providing basic care and stimulating social contact. It's not their physical or psychological situation that forces them to move to a residential care centre, but their social situation. That’s also something you don't have a choice about.
- ✓ As a staff member, I had my parents admitted to this residential care centre, but in a different department. I suggested it to my parents and they were willing to do it. We didn't visit any other residential care centres. I had and continue to have, faith in the good care that my colleagues provide to them.

Management

- ✓ There is free choice, as long as there is room at the residential care centre
- ✓ People know about us through the Local Service Centre, we have our own circuit for admissions. In other words, they have a free choice, but we define that choice to some extent.
- ✓ The choice between home care or residential care, is that really a free choice? Sometimes you have no choice, because of your financial or social situation.

3.4 Rights in Care: Quality of Life and Quality Care Services

3.4.1 The Right to Life

The right to life encompasses both a prohibition - you may not kill - and a protective measure – making every effort to preserve life and taking the necessary safety or care measures to do so. [79]

This human right was not always clear or known to the people interviewed. The visions and answers were therefore highly diverse and fragmentary. The fact that killing is prohibited was regarded as 'logical' by all respondents. There were sporadic references to a notorious murder case in which a nurse was suspected of illegal euthanasia.[80]

We shall present a number of observations that were mentioned most frequently and/or that we consider to be important. This description is therefore far from exhaustive.

It is often interpreted as a life 'of quality', and this is often after a period of needing extensive care, loneliness, isolation or bereavement. Admission to residential care often results in a 'reawakening' of the resident, stimulated by the (more intensive) care and the opportunity for social contact and participation.

- ✓ *I am coming back to life here. At home, I was becoming numb, I was turning into a vegetable. Now that's all over. (resident)*

Safety was another point for attention in regard to the right to life, the right to a safe life. This applies to both protection against certain potential external dangers as well as to 'care safety' if there would be a sudden need for help or care.

- ✓ *I feel safe in this residential care centre, after all, you cannot get in from the outside, but the other way round, of course! (resident)*

- ✓ *If I were to fall here, they would see it immediately. At home I could lie on the ground for hours without help. So I feel safer here. (resident)*

We see this observation confirmed in the Flemish "Indicator Project" in residential care centres: measuring quality of life in residential care centres. [81]

[79] Human Rights of Older Persons and Long-Term Care Project:
The Application of International Human Rights Standards to Older Persons in Long-Term Care. ENNHRI, July 2015. p 12.
[80] http://deredactie.be/cm/vrtnieuws/regio/westvlaanderen/1.1988808
[81] http://www.zorg-en-gezondheid.be/vlaams-indicatorenproject-voor-woonzorgcentra-vip-rusthuis

Theme: Safety

Average score for this theme: 4.53

(note: the scores are between 1 (never) and 5 (always)

Item	Average score	% always agree	% mostly agree	% Unanswered out of 6949 residents
I feel safe when I'm alone	4.74	79.9%	15.4%	0.3%
I think that my property is safe here	4.56	70.4%	19.7%	0.6%
When I need help immediately, I can receive it	4.29	48.5%	34.5%	1.3%

From the point of view of care, guaranteeing this physical safety is sometimes difficult to reconcile with certain human rights. For example, there were facilities which, on account of their vision of care, equipment and use of infrastructure, used fewer restraint measures but had a higher risk of falling incidents as a result. This then gives a negative picture of the quality indicators that the facilities are supposed to monitor and which are designed to respect the right to life in a human rights-based approach.

The right to life regularly gave rise to critical and cynical comments from the residents. One resident expressed it as follows: '*you have lived, you arrived here, and now life is forced upon you*, or: '*we live here among the half-dead, is that a right?*

Among the staff there was often attention for family disputes concerning the right to life. Disputes in which the right to life of residents in a coma come into conflict with possible arrangements according to a will or statements of the wishes of the resident.

- ✓ *One of our residents is a coma patient. Her family wants us to give her all the care and help that is necessary and possible, and even more, if it were up to them, but her husband wants to commit euthanasia after all these years because apparently that was her wish that she expressed in the past. Who gets to decide about her right to life? Her parents or her husband? I don't find this an easy debate. (Staff)*

Other responses on the Right to Life

Resident

- ✓ When we arrived on the first day at the residential care centre, we were met by a welcoming committee with nurses, the doctor and someone from the senior management. It was a festive beginning for our new life.
- ✓ I convinced my girlfriends to come here. They were just sitting around at home. Now we are here together and now we at least have a little bit of a 'life' again.
- ✓ They do everything possible here to let you live in a safe haven.

Staff & management

- ✓ People are allowed to decide themselves about their death, so it's the same for their life and the quality of their life.
- ✓ We have wall-to-wall carpeting in our hallways, and each hall has a different colour so that our residents with dementia can orient themselves when they walk. We may be increasing the risk of falling incidents that way, it allows us to apply a low-restraint policy.
- ✓ We have residents here who have lived as vegetables for years. The family wants them to keep breathing, so we do what we have to do.

3.4.2 Freedom from torture, violence and abuse

This human right was identified by nearly all the subjects interviewed. Although in the first place there was generally a rejection and denial of such crimes, in some cases there was testimony from staff or family members. The testimony always concerned 'other facilities' where they had worked or situations from the past. Just as often, members of staff had heard 'rumours' about other facilities. The residents questioned had no personal experience or knowledge of abuse.

- ✓ *You don't have that at this residential care centre. (resident)*

- ✓ *We often hear stories about other residential care centres: people who are shaken violently, shouting and screaming at residents, little or no washing, simply turning around incontinence materials and reusing them. (Staff)*

What is the (mis)treatment of older persons?

The World Health Organization (WHO) defines elder abuse as ''*a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.*[82]

In the literature, reference is often made to the definition by Comijs[83]: *'The (mis)treatment of an older person (someone who is aged 55 or over) is understood as the action or failure to act by anyone who is in a personal and/or professional relationship with the older person, whereby the older person (repeatedly) suffers physical and/or psychological and/or material damage, or presumably will suffer such and whereby on the part of the older person, there is a situation of partial or complete dependency.'*

In some cases, elder abuse can be recognised based on the following signs or signals[84]:

–visible injury;

[82] http://www.who.int/ageing/projects/elder_abuse/en/index.html. *Elder abuse can be defined as 'a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person'. Elder abuse can take various forms such as physical, psychological or emotional, sexual and financial abuse. It can also be the result of intentional or unintentional neglect.* (Source: http://www.who.int/ageing/projects/elder_abuse/en/)
[83] Comijs H.C., e.a. 1996
[84] http://www.home-info.be/v4.0/brussels-meldpunt-ouderenmisbehandeling/wat-is-ouderenmisbehandeling

–excessively fearful reaction when touched unexpectedly;

–incoherent explanations of injuries;

–depression or unexplained fear;

–nervous or withdrawn behaviour.

In general, eight types of elder abuse have been identified.[85] Where possible, testimony from the ENNHRI monitoring has been added:

1 Physical or bodily abuse:

Pinching, pushing, shoving, grabbing, hitting, kicking, shaking, burning, pulling hair, allowing to fall, unjustified restraint, inappropriate administration of medicine...

The members of staff questioned testified to the difficulties that can arise in providing care to dementia sufferers. In these cases, it is not only a matter of physical aggression towards the staff or from the staff to the dementia sufferers, but also aggression between residents.

- ✓ *It is not easy to deal with people with dementia, you often have to be very patient, that's for sure. (staff)*

- ✓ *In the department with residents with dementia, we have to be very alert. Some residents can be aggressive towards their fellow residents. Guaranteeing the safety of the resident(s) is the priority then. (staff)*

The family members and staff questioned also mentioned incorrect use of medicines. This included errors in quantity and in timing as well as errors in the duration of the use of the medication. According to the members of staff, this is often a result of the lax follow-up by doctors.

- ✓ *I have encountered cases in which the night-time medication was given during the day, that is a little disturbing. (family)*

- ✓ *You have doctors who do not adapt or assess their pattern of prescription. Sometimes we have to point out that certain residents have been taking the medication for months. Some doctors are shocked when they realise how long the residents have been taking the medication. (staff)*

2 Sexual abuse:

Sexual harassment, molestation, rape, being forced to disrobe unnecessarily, …

3 Psychological abuse:

Cursing, harassment, intimidation, blackmail, threatening, humiliation, infantilisation, ignoring, not allowing family and/or social contacts to visit the older person...

[85] http://www.ouderenmisbehandeling.be/

Verbal aggression is acknowledged and recognised by residents and members of staff. Although it is always mentioned in relation to being impolite or unkind.

- ✓ *A colleague who effectively abused her position of power, e.g. you're being difficult, then I will…. Fortunately, I never experienced it. I sometimes notice aggression in the way of reacting, being brusque, unfriendly. I point it out to my colleagues. (Staff)*

- ✓ *Some members of staff can at times be brusque, but I understand that. They are the people who provide the care and they can get into a bad mood now and then. It's not violence or anything like that. (resident)*

4 Financial and material abuse:

Stealing money or property, abuse of trust, demanding gifts, claiming possessions under false pretences, abuse of powers of attorney, seeking inheritance...

5 Violation of rights:

Unlawful violation of the right to freedom, privacy, self-determination, for example withholding or reading a person's mail without permission, never leaving someone alone, not permitting visitors...

The right to privacy, self-determination, the right to visitors etc. will be discussed further in the paragraphs below.

6 Neglect:

Providing insufficient or inappropriate food, not providing sufficient medical care...

7 Shortcomings in the care:

The older person receives care but it has shortcomings, it is not a situation of neglect

An adequate level of care will also be discussed further in the paragraphs below

8 Multiple problem-situations:

Situations in which various forms (3 or more) of elder abuse are present all at once

By using the term "*oudermis(be)handeling*" ("elder (mis)treatment") the idea is to emphasise that, in addition to intentional abuse, there can be unconscious acts or failure to act that may cause the older person sadness, pain or harm (the result of intentional or unintentional neglect[86]).[87] This can happen when, as care provider, one does not yet know how the person requiring care would like to receive the care, either because he has not yet been asked or because the information has not been passed on. The (electronic) care file that is used in facilities is an attempt to address this issue. Sometimes there is a lack of certain aspects of skills or knowledge. This is a reason to further focus on education, training and guidance.

[86] http://www.who.int/ageing/projects/elder_abuse/en/index.html.

[87] http://www.ouderenmisbehandeling.be/

Elder abuse can also involve answering or deciding in someone's place: you ask a question but you don't wait for the answer. This is a practice that is recognised by many care providers. It was made clear that when the communication skills of the residents begin to decline, the risk of insufficient care or abuse increases.

- ✓ *You don't stop and think about it, but it happens quite a lot. We ask the question but immediately decide on behalf of the resident, before they have even had the chance to answer. (staff)*

- ✓ *If you can no longer be vocal about your needs, you run the greatest risk of poor care and abuse. (resident and staff)*

The staff regularly mentioned elder abuse by children and family members. Most of them suggested that it happens more often than people think.

- ✓ *We see a lot of abuse by the family: children who don't want to install a stair lift because it would damage the wall; it also often involves belittling the parents or taking away their mobile telephone because otherwise the cost for the bill will be too high; Parents who are no longer picked up by their children because they cannot speak clearly or it is 'too much trouble' with the wheelchair.*

It was also mentioned that the current generation of people requiring care is still too inclined to accept inappropriate behaviour.

- ✓ *That's also 'Belgian': 'we'll keep our mouths shut if something is not okay, because otherwise there will be repercussions from the staff'. Of course that's not true. (management)*

A few figures

As example, we shall present a few figures from the 2014 Annual Report of the Brussels Reporting Centre for Elder Abuse (*Brusselse Meldpunt Oudermis(be)handeling*). In 2014, the reporting centre drew up 48 cases (based on 198 reports). Of these, 24 cases (50%) had to do with facilities. In the residential care facilities, 26% concerned problems with the care, followed by violation of the rights (24%), in 19% of the cases the older person suffered physical harm and 14% were confronted with financial/material abuse. In the reports concerning the residential care facilities, the culprits are mostly care or assistance providers (76%). This concerns complaints about senior management (6), care staff (7), administration (2), organisation of the residential care facility in general (6) and food (1).[88]

Other reporting centres are:

- SEPAM (Service d'écoute pour Personnes Agées Maltraitées à Bruxelles / French-speaking Centre for Elder Abuse in Brussels)
- Vlaams Ondersteuningscentrum Ouderenmis(be)handeling (Flemish support centre for Elder abuse)

[88] Annual Report 2014 of the Brusselse Meldpunt Oudermis(be)handeling.

- Agence Wallonne de lutte contre la maltraitance (Walloon agency for combating abuse)

Other responses on freedom from torture, violence and abuse

Resident

- ✓ I never noticed anything like that.
- ✓ I think there is too much control. It would be discovered immediately.
- ✓ I am a member of the residents' council and most of the complaints are about the food, never about abuse or aggression or anything. Usually it's about the amount of salt in the food, too much or too little.

Family

- ✓ They have already given my mother the wrong medication 3 times. Wouldn't you say that is abuse?
- ✓ Neither with my grandparents nor with my mother have I ever seen anything that shocked me. I also think it would be very quickly found out if a member of staff abused someone.
- ✓ I trust that the inspections would show it if there was a case of abuse.
- ✓ There are organisations that monitor that, aren't there?

Staff

- ✓ (Mental) elder abuse is something we sometimes see done by the family. Then we can organise family dialogue, but there is little we can do about it, it's a family matter, after all, isn't it?
- ✓ A woman had to sell her house in order to pay for the residential care centre. But this took longer than expected. They turned her out of the residential care facility and now she lives in this residential care facility. It's surely not possible that in the year 2016 they can kick you out of a residential care centre? That's also a form of mental abuse, isn't it?
- ✓ No physical abuse, but verbal abuse. Unpleasantly cutting off a resident in front of another resident, that shouldn't be allowed.
- ✓ That's something I have never seen, residents who are abused or aggression against residents.… We have taken empathy sessions: they allowed us to experience what it's like to be restrained, to be hanging in a bath lift high above the floor, what it's like to put on incontinence material –to have to wait until the caregiver has had the time – or was too late -to put us on the toilet. The sessions stay with you, it gives you a better understanding of how you can give care worthy of human dignity and above all, how quickly you can lapse into poor care. There are a huge number of pitfalls, little steps that can make a big difference.
- ✓ We have the skills to calm down agitated residents. We do things in a sensistive manner.
- ✓ I am convinced that we don't always realise what effect a certain action may have. Leaving the tray tables for a bit longer, turning off the television at 10:30 PM even if people are still watching, etc.

- ✓ This is often associated with a bad atmosphere among the staff, harassment, etc.
- ✓ In my career, I have seen some things that I find unacceptable. I quickly left my job at that residential care centre. There was a lot of rivalry and jealousy among the colleagues. You received no guidance and were left on your own all the time. I never received any briefing about the residents. In some hallways and rooms, the lights were broken for weeks or months or there was no hot water. Loud hip-hop music was played in the room of a dying resident, etc.
- ✓ During my traineeship at a residential care centre in the 1980s, the residents were insulted with names like 'the shitter', 'the pisser' etc. The residents slept by 10 in a dormitory room and they wore each other's clothing. The residents with the greatest need for care were 'saved' for the trainees: the more care you needed, the more chance you had of being cared for by a trainee.

Management

- ✓ If there is a complaint, it's often about impoliteness by the staff, the unpleasant treatment of/towards our residents
- ✓ You can never be 100% sure that there is no abuse taking place, but still, I would like to think that we would find out about it pretty darned quick and we would do something about it quickly too.
- ✓ That something you have two pay attention to all the time. After all, it can happen so fast: being a bit more rushed, rougher, a bit less polite, etc. Before you know it, you are actually abusing people or treating them without respect

3.4.3 Dignity

The Charter of Fundamental Rights of the European Union provides for a number of personal, civil, political, economic and social rights of citizens (and inhabitants) of the EU. The charter is made up of 7 chapters in which these rights are further specified. In the first chapter, the concept of dignity is discussed: it is about human dignity, right to life, right to human integrity, prohibition of torture and inhumane or humiliating treatment or punishment, prohibition of slavery and forced labour.[89]

Human rights organisations such as Amnesty International specify human dignity as human rights, humanity, human development, human safety and dignity.[90] Also the draft memorandum on a Flemish policy on welfare and care policy for older persons (*conceptnota voor een Vlaams welzijns- en zorgbeleid voor ouderen*) gives importance to a 'long-term care that supports dignity': When the increasing demand for support and care cannot (or can no longer) be met at home, the older person has a need for a residential form of care that is of high quality, and which is provided in respectful way that supports the dignity of the individual… .' [91]

For the people questioned, treatment with dignity encompasses a wide spectrum of aspects. For the residents, this is closely linked with the recognition that they receive as (older)

[89] http://eur-lex.europa.eu/legal-content/NL/ALL/?uri=URISERV%3Al33501
[90] https://www.amnesty.nl/mensenrechten/encyclopedie/menselijke-waardigheid
[91] Draft memorandum on a Flemish policy on welfare and care policy for older persons. *Dichtbij en integraal. Visie en veranderagenda*. Flemish Minister for Welfare, Public Health and Family, 5 February 2016, p.30.

people, in other words, respect for their life and their age. This is further broken down into the infantilisation of residents by using baby talk or a patronising tone, in other words, treating older persons like children. This makes the residents look less competent or as if they have cognitive limitations. There is also mention of caregivers who speak 'over the head' of the resident or when the communication is addressed to the family and not to the resident him or herself.

- ✓ *They call me Louiske, but actually my name is Louis. They are quick to infantilise the residents: Joske, Lucienneke, Mariake. We're not toddlers any more, you know. (resident)*
- ✓ *We pay careful attention to that and we point it out to the staff: if you meet a resident accompanied by a caregiver, then you should speak to the resident. You shouldn't speak with your colleague 'about' the resident. You speak with the residents and with the colleague. Both are necessary if you want to provide care with dignity. (management)*

A second element mentioned by the residents is that care with dignity has to do with high-quality care. Receiving the care and assistance it is necessary to be able to live a meaningful life.

- ✓ *I have everything I could want and the staff works hard and is friendly. When it comes to treatment with dignity, I don't ask for more. (resident)*

We can support these observations via the Flemish "Indicator Project" in residential care centres:[92]

Theme: Respect

(note: the scores are between 1 (never) and 5 (always)

Item	Average score	% always agree	% mostly agree	% Unanswered out of 6949 residents
I am treated with respect by the people who help and care for me	4.61	68.4%	24.6%	0.4%
The staff members pay attention to me	4.24	45.5%	37.1%	0.5%
The staff members have respect for what I like and dislike	4.20	43.5%	37.5%	1.0%

The staff indicate that treatment with dignity is connected with 'a continuation of the life of each individual resident'. The intake interview and the life file that is drawn up per resident are important tools for ensuring care that is provided with respect and dignity. In addition, continuously questioning residents about their wishes, expectations and habits is a

[92] http://www.zorg-en-gezondheid.be/vlaams-indicatorenproject-voor-woonzorgcentra-vip-rusthuis

necessary condition for a well 'negotiated care'. We shall return to the concept of 'negotiated care' below.

- ✓ *We conduct a very extensive intake interview. This provides us with a lot of information about how to best approach the resident. And you gradually flesh out that picture in the course of the care that you give day-to-day. This is how we ensure care with dignity. (staff)*

- ✓ *Asking questions. Asking the question again and again, asking your resident's opinion. That is how you provide care with dignity. (staff)*

Also according to staff, and this was confirmed by family members, further application of 'Small-scale normalised living for persons with Dementia ('*Kleinschalig Genormaliseerd Wonen voor personen met dementia'*)[93] would ensure the dignity of some residents but would restrict the dignity of others.

- ✓ *In the '*small-scale normalised living*' it will all be a lot more homelike, but you will be sitting down at the table to eat with people who have a very unappetising way of eating. The residents who are still able to eat properly become somewhat the victims of this. That which increases the dignity of some, reduces the dignity of others.*

Other responses on dignity

Resident

- ✓ All members of staff know me and speak to me. Even the director addresses me by my first name.
- ✓ They treat me here with great dignity, so I am very satisfied. But I am not happy, that's something different. You're not going to find happiness in a residential care centre.
- ✓ The cleaning staff here work very hard. They make sure that everything is very clean, that we can live in a clean house, that is dignity.
- ✓ This morning, they just gave me a light once-over for a wash, I don't like that. And I have told them several times that I don't consider it hygienic.

Family

- ✓ My father-in-law is very assertive; he would react if they didn't treat him with dignity.
- ✓ I think that they approach people here with a lot of 'warmth'. In a care relationship, you have to be more than a 'technician', it has to go further than the business-like treatment. Is that what you mean by dignity?
- ✓ My wife has dementia and she had smeared her excrement all over her entire body. I rang for help in a panic, but their reaction was: 'we are eating and that's not urgent,

[93] http://www.kuleuven.be/lucas/pub/publi_upload/2009_5_AD_Grote%20kwaliteit%20op%20kleine%20schaal_KGW%20in%20Vlaanderen.pdf

we'll come and wash her in a little while'. Then I got angry and demanded they do it immediately. They did it, but I had to get angry first.
- ✓ My partner is completely naked on the bed when they wash and dress him. I don't think that that is acceptable, they should put a sheet over him.
- ✓ I don't always think it's very clean. And the food isn't good enough. I don't really consider it to have much dignity.

Staff

- ✓ Your senior management is incredibly important. They determine whether the residents are treated with dignity. If this is their policy, then it is up to us to execute it.
- ✓ For each individual resident, the residential care centre must be a continuation of his or her home situation in order to be able to provide care with dignity.
- ✓ I ask the question: how would you like to be addressed? It's only if they insist that I would use nicknames.
- ✓ We work very hard on experiential care
- ✓ We can't be with the residents all day long, even if they feel alone.
- ✓ We haven't got a kitchen so meals are a problem. There are complaints. With the current system, there isn't any pleasure in eating. The residents' board has already reported this problem.
- ✓ I have a hard time with family members who never pay any attention to their mother or father, but come and complain to us extensively twice a year because the care is supposedly not good enough.

Management

- ✓ That is a constant concern for our residential care centre
- ✓ We discuss it during the hiring procedures, we make it clear that it is an essential point for attention in our operations. New staff members have to be aware of that.
- ✓ You can only provide care with dignity if you cooperate with different teams. Multidisciplinary and transversal.
- ✓ You have to treat an older person as a person, not as a care product.
- ✓ Our residents have to continue to be the people they were before they became dependent on care.

3.4.4 Choice and Autonomy

Having freedom of choice and autonomy is an important area for attention in facilities for older persons. It is considered by residents, staff and management to be an essential condition for a good care policy. The policy texts are also based on this freedom of choice and autonomy for persons requiring care. For example, the Woonzorgdecreet (residential care decree) mentions this in its guidelines (safeguard, support and stimulate the personal autonomy and self-determination of the user)[94] and it is a criterion for a high-quality policy on older persons within the Kwaliteitsdecreet (quality decree) of 2003.[95] Also in the draft memorandum for a Flemish policy on welfare and older persons, it is clearly stated that older people of today and tomorrow are growing increasingly capable of expressing and realising

[94] http://www.codex.vlaanderen.be/Zoeken/Document.aspx?DID=1017896&param=inhoud
[95] http://www.codex.vlaanderen.be/Zoeken/Document.aspx?DID=1011700&param=inhoud

their wishes: 'for this reason, freedom of choice and being in charge of their own lives and having control of the care is very important to them. They want to be acknowledged for their competencies, for what they still can do, and not approached in terms of their loss of functions and potential'. [96]

In general, autonomy and freedom of choice are associated with persons requiring care who are still capable - or who still possess sufficient capacities - for safeguarding this. Where it becomes risky, therefore, is when it involves persons requiring care who have cognitive problems.

There are therefore a number of factors that can have an influence on this autonomy:

- physical and mental condition
- level of education and socio-economic status
- the values and norms of the person requiring care and the care provider
- the phase of life that the person requiring care is undergoing
- personal circumstances and living situation

The Flemish "Indicators Project" in residential care centres records the following results concerning autonomy:[97]

Theme: Autonomy

(the scores are between 1 (never) and 5 (always)

Item	Average score	% always agree	% mostly agree	% unanswered out of 6949 residents
I decide for myself how I spend my time	4.67	74.8%	19.5%	0.3%
I choose for myself which clothes to wear	4.62	80.4%	10.0%	0.3%
I decide for myself when to go to bed	4.35	69.1%	14.5%	0.2%
I can go wherever I like	4.25	57.9%	22.4%	0.9%
I decide for myself when to get up	3.48	42.0%	17.3%	0.5%
I can have a bath or shower as often as I like	2.54	17.9%	12.4%	3.2%

[96] Draft memorandum on a Flemish policy on welfare and care policy for older persons. *Dichtbij en integraal. Visie en veranderagenda*. Flemish Minister for Welfare, Public Health and Family, 5 February 2016, p.7 – 9.
[97] http://www.zorg-en-gezondheid.be/vlaams-indicatorenproject-voor-woonzorgcentra-vip-rusthuis

The ENNHRI monitoring clarified several key elements of this fundamental right. Although these are largely in line with the conclusions from the Flemish “Indicator Project”, here and there, concrete limitations were revealed. In general, most of the residents confirmed that they did not experience any disruptive limitation in their autonomy or freedom of choice. Most of them vigorously confirmed their free choice about how to spend their time. No longer being able to have this freedom of choice and autonomy was one of the greatest concerns voiced by the residents.

- ✓ *The loss of my independence has been a disaster. As friendly as the staff may be, it's such a profound thing, knowing that you cannot help yourself, the lack of autonomy, I think that is the most horrible. (resident)*

- ✓ *If I ask for something, then there will always see if they can help me. Up until now, they have been able to comply with all of my requests, so yes, I do think that I have choices. (resident)*

- ✓ *You have choice and a say in everything. The only thing you cannot do is burn candles or hammer nails into the walls to hang things up (you have to let the technical service do that). (resident)*

In some cases, restrictions to this freedom of choice and autonomy were mentioned by residents, family, staff or management. For example, in practice it proved not always possible to wash when desired and there were also strict limitations in the choice of meals. In some of the facilities visited, there were options to choose the food. There were also limitations in the free choice of daily schedule and how to spend one's time, particularly with regard to residents with dementia. This was confirmed by family members.

- ✓ *I do not have a shower in my room. That means I have to use the bathroom in the hall, but it is often occupied. I cannot take a shower when I want to, you always have to take others into account. (resident)*

- ✓ *As staff we take a lot of decisions on behalf of the residents, at least among those with dementia. Now they're going to the hairdresser, now they're going to have a nap, now together in the living area, … We determine how they spend their time. But how else could it be done? (Staff)*

- ✓ *The residents with the greatest need for care are put to bed first, that's the way it is. They don't have a choice in that. (family)*

Other responses on Choice and Autonomy

Resident

- ✓ In this specialised department, there is very little that you get to decide for yourself, more self-determination would be good for us.
- ✓ Before I came here, I was really afraid that we wouldn't have any voice here. But nothing could be further from the truth, you can discuss anything here.

- ✓ In the beginning, it feels strange at the residential care centre, it's all new. You don't know anything, you constantly have to ask for information from the staff, you aren't sure what you're allowed to decide for yourself and what not. In the first weeks, you do feel a little bit lost.
- ✓ I have the impression that they say 'yes' to every request. I cannot recall that I ever made an impossible request. They take care of it.
- ✓ You can compose your weekly menu one week in advance, and you always get three choices.
- ✓ Some residents complain that their self-determination has decreased and they don't like it, they would prefer most of all to all continue to work and to remain active, but that's not possible.
- ✓ There are days when I get into bed at three o'clock in the afternoon. Then I sleep until the next morning. The staff know that and they let me sleep.

Family

- ✓ They have to get up every morning at 7:00 and eat at 8:00. Apparently there is no other way to do it
- ✓ you get a choice here of what you eat. Although it's a limited choice and you have to decide several days in advance, but still, you do have a choice.
- ✓ At this residential care centre they pay a lot of attention to participation and choice. They do their best to offer individual care
- ✓ They take my opinion into account as a daughter, the staff explicitly asks for it.

Staff

- ✓ During the intake meeting, we take a lot of notes, we take into account their life, their personality, (e.g., sociable people or people who prefer to be alone).
- ✓ The residents may choose for themselves when they go to bed. It's often the residents who are still in good physical condition who want this. We therefore let people sleep as long as they want to. You can serve breakfast at 11 AM too, you know, that's not such a problem, is it?
- ✓ The residents decide for themselves if they want to participate in activities. The choice in the evening meal could be a bit wider. After all, eating is an important social event and if you don't respect that, then you're not respecting your people either.
- ✓ There's always room for improvement, but the residents do have a voice here in virtually everything. As much as possible, we listen to people quite a lot
- ✓ The question we have to ask ourselves is: do we give the resident the time to answer when we ask: 'would you like to be washed?'
- ✓ We have a portable shop on wheels. We sell cosmetics, nylon stockings, biscuits and sweets, standard products. The residents appreciate that they are able to choose for themselves.

Management

- ✓ We ask about this when they arrive at the residential care centre or if possible, in advance. What are your expectations, what do you want and what don't you like, what are your hobbies and how would you like to be addressed, etc. After 6 weeks, we evaluate this and make adjustments where necessary and possible.

- ✓ Offering people opportunities, giving the resident a choice whether to participate or not, that's something we emphasise very much to the staff
- ✓ You also need ask the children what they want for their parents. What they consider to be important in the care?
- ✓ Some of the residents have asked me if they can have their steak cooked very 'rare', well, I do that for them. That means I'm taking a big risk in terms of food safety, etc. but what matters most, their choice and taste or the food safety?
- ✓ Zero risk doesn't exist. Age and illness don't prevent people from enjoying life and there is nothing worse than not taking any risks at all. I think that continuing to authorise access to risk is synonymous with maintaining a person's dignity.

3.4.5 Freedom of Movement and Restraint

Based on the ENNHRI monitoring, we can divide this right into two major sections: there was thus a focus on a broad expression of the concept 'freedom of movement', which refers to free access and mobility in the facility, at the same time as more deeply exploring 'the restraint policy' of the facility.

In general, the facilities visited were freely accessible for residents and visitors, which is something that is stipulated in policy texts and regulations. With a few exceptions, the residents questioned were able to freely enter and exit the facility. These exceptions had to do with residents with dementia or residents with an exceptional pathology (e.g. Korsakoff). Thus, the departments for these residents were often secured with a code and in a few cases, there was a code required to exit the facility. This was always justified in terms of the safety of the residents.

Despite the 'open door-policy' of some of the care providers, other restrictions on the freedom of movement were observed as a result of the location of the facility (far outside of the city centre) or because of the lack of possibilities for transport. These restrictions may appear less severe than closing doors, but they nevertheless create a feeling of restriction and enclosure.

- ✓ *We can come and go when we like, you simply have to notify the nurses. The doors of the residential care centre are closed at 9 PM, but you can still go in and out after that. You just have to telephone the nurses. (resident)*

- ✓ *We don't have any restrictions inside the residential care centre, but because it's so far from the centre of town and there are so few transport possibilities, you are a little bit trapped here. (resident)*

- ✓ *If we want to leave the residential care centre with the residents in order to do an activity, the transport problem is always an issue: how are we going to transport our residents? (staff)*

For the theme 'Sense of well-being' from the Flemish "Indicators Project", we see the following result[98]:

[98] http://www.zorg-en-gezondheid.be/vlaams-indicatorenproject-voor-woonzorgcentra-vip-rusthuis

(the scores are between 1 (never) and 5 (always)

Item	Average score	% always agree	% mostly agree	% unanswered out of 6949 residents
I can easily go outside whenever I like	4.16	59.1%	17.5%	1.3%

In the facilities surveyed, priority was given to a low-restraint policy. This means that restraint is only allowed in carefully considered situations and the decision to apply restraint is more the exception than the rule. In all the activities, avoiding restraint must be the priority. The risk of increased falling incidents must be taken into account at the same time. The restraint of residents is regarded in several of the regulatory policy texts as an indicator for quality in care and safety (in this case, the number of measures taken daily to restrict physical freedom).[99]

- ✓ *We apply a low-restraint policy. We only restrain the resident for their own protection. Any restraint is the subject of a multidisciplinary discussion, with the doctor and family. (staff)*

We understand the term restraint policy (or means of restricting freedom) as any method of action, material or equipment on or near the body of the resident that he or she cannot easily remove and that limits the freedom of movement or the normal access to the body. The most frequently used means of limiting freedom are: wrist and ankle bands, body vests, gloves, straps, soft belts and the use of crowd control barriers. Other means are: wheelchairs, geriatric chairs with adapted safety belts and/or tray tables, harnesses, wrapping with sheets, closed departments and room doors.[100] The restraining measures mentioned during the monitoring were: straps, protective restraining blankets, crowd control barriers, tray tables and locking the brakes of wheelchairs. During the discussions with staff and management they admitted that in some cases the low-restraint policy was not always accurately followed. At the same time, they have great hopes for the technological sector which they expect will provide many new – humane - techniques, such as using sensors and bracelets. In one of the facilities visited, this had already been – successfully –tested.

- ✓ *I expect quite a lot from the technological sector. There are going to be more and more techniques invented that will allow older persons freedom without risking their safety. There are already residential care centres where they work with sensors and bracelets, so that will come here as well (staff)*

- ✓ *Some residents are restrained, are given a tray table or a special blanket. I think that for some of them, it is truly necessary, because they would otherwise be a hazard to themselves or to us, the other residents. (resident)*

[99] http://www.zorg-en-gezondheid.be/vlaams-indicatorenproject-voor-woonzorgcentra-vip-rusthuis
[100] http://www.zorgneticuro.be/sites/default/files/ethischadvies09.pdf

- ✓ *They once restrained my partner without permission. Then I was very angry. I personally think that they should try everything before resorting to restraint. But then you have to have enough staff for it. (family)*

Other responses on freedom of Movement and Restraint

Resident

- ✓ As a resident I can and am allowed to go wherever I like here. Except for the kitchen I think, you have to ask permission for that.
- ✓ Although I feel good here, I do miss my freedom. The ability to simply step outside and do whatever I like.
- ✓ We are accompanied if we leave our department, so we're not really free (Korsakoff).
- ✓ They don't do that here. At least I've never seen it. They say that they have a low-restraint policy. Sometimes you see or hear that someone has fallen, but that's preferable to tying people up.

Family

- ✓ I think that my father-in-law can go wherever he likes, I don't know of any forbidden areas or anything here, and we visit each week.
- ✓ They do restrain the people with dementia. I also never see them at activities or in the common areas. But that's surely only allowed if the family approves it?
- ✓ If my mother is restless, then they use a weighted blanket. I understand that.
- ✓ They use tray tables; you see that a lot. I assume it's for safety.

Staff

- ✓ The residents of my department get on the bus in the morning here to go into the city and come back in the evening.
- ✓ It isn't a prison here.
- ✓ Our residents who don't have dementia can go wherever they like. Those with dementia are placed in a closed department with a code.
- ✓ It's sometimes difficult to find a balance between freedom and safety. I think that all of my colleagues would feel the same way
- ✓ At this residential care centre the residents are restrained as little as possible. At first, that was a bit worrying, residents are more likely to fall here than to be restrained.
- ✓ At this residential care centre we use wandering detectors. The resident wears a bracelet and there are sensors in the building, so that we can give the residents a bit more freedom without it creating a risk.
- ✓ For residents with dementia, we tend to use more restraint. Perhaps sometimes a bit too much.
- ✓ For all of our residents with dementia, we use a 'protective restraining blanket' or we install tray tables.
- ✓ I am afraid that we regularly leave the tray tables in place for longer than necessary.
- ✓ The department for people with dementia is closed, but we quite often take the residents with us, for example if we go pick something up in a different department. So that way, they do get to go everywhere. In the summer we also often go for walks

in the garden. They have not chosen to get dementia, that's something that a lot of people forget. Sometimes we do apply a time-out and we keep them in the room for a little while until the situation has normalised.

Management

- ✓ If there is a risk of people running away here, then it's logical that we want to keep an eye on that.
- ✓ Our residents are only restricted in their freedom if there is a danger to themselves or to others.
- ✓ Our residential care centre has a low restraint policy. But by taking this low restraint approach, we increase the risk of falling incidents.
- ✓ Using restraint materials requires a whole procedure. Then we are not only talking about preventive actions: the resident displays behaviour that is unsafe for himself or for others. 'Wandering' is no longer a reason for restraint
- ✓ You mustn't underestimate the pressure from some families. They demand that their parents be protected against falling incidents. Well, basically all you can do then is restrain. But we still always try to convince the family that restraint is not necessary.

3.4.6 Participation and social inclusion

By social (care) inclusion we mean that a person is a fully-fledged member of a (care) community. After all, care and well-being are not something outside of society, but are at the heart of it. Inclusion is thus the point of departure and indicates equality and full citizenship.[101] There is considered to be inclusion if the following conditions are met: people have valuable personal and social networks in society; they make use of facilities that are intended for all; and they live in a caring society with people to whom they feel connected.[102] Within the concept of inclusion, the following key values are therefore highlighted: being available, accessible without discrimination, acceptability (in other words, respecting the diversity of needs and capacities), capacity to adapt (flexibility in the range of care available) and quality.

During the ENNHRI monitoring, this human right was expressed by those questioned accurately but in diverse ways. In most cases, the residents, family and staff confirmed that the facilities took various steps to involve residents in the social life or that there were people at the facility with whom they felt a connection. Unfortunately, residents also testified to the lack of personal and social networks.

- ✓ *I am much more active and sociable here than I used to be at home. (resident)*

- ✓ *I don't have any real friends here - like I used to have. I do know a few other residents with whom I chat now and then, but that doesn't happen often. (resident)*

Some of the observations from the Flemish "Indicators Project" appear to confirm this segmentation regarding the social inclusion of residents.[103]

[101] Draft memorandum on Flemish policy on welfare and care policy for older persons. *Dichtbij en integraal. Visie en veranderagenda*. Flemish Minister for Welfare, Public Health and Family, 5 February 2016, p.20
[102] Kenniscentrum Sociale Innovatie, Jean-Pierre Wilken.
http://www.participatiezorgenondersteuning.nl/Content.aspx?PGID=04ea6cf9-a9bc-40f9-8016-89b3376cf2e6
[103] http://www.zorg-en-gezondheid.be/vlaams-indicatorenproject-voor-woonzorgcentra-vip-rusthuis

Theme: Personal interaction with fellow residents

(the scores are between 1 (never) and 5 (always)

Item	Average score	% always agree	% mostly agree	% unanswered out of 6949 residents
You can easily make friends here	3.36	20.2%	28.9%	1.0%
Another resident here is a good friend of mine	2.97	19.7%	20.1%	0.7%
There are people who want to do things together with me	2.79	11.5%	19.9%	0.5%

For the theme 'sense of well-being' the following scores were recorded:

(the scores are between 1 (never) and 5 (always)

Item	Average score	% always agree	% mostly agree	% unanswered out of 6949 residents
I receive the care and services that I need	4.66	71.8%	23.2%	0.4%
I use the common areas	3.47	25.4%	26.9%	0.2%

For family members, but also for some members of the senior management, the presence of a (well-functioning) cafeteria in the facility was a key to social inclusion. After all, this can develop into a meeting place for the local neighbourhood or municipality. A place where the local community can gather together with residents, family and staff. A member of the senior management expressed it as follows: *our cafeteria is not only the heart of our facility, but also the heart of our neighbourhood. In that case it is important that you have a good system of working with volunteers.*

- ✓ *In the cafeteria my father meets other residents and visitors and we see our childhood friends here who are visiting their own parents. (family)*

Participation, and then more specifically the participation of persons requiring care, appears to be a key to being able to adapt the care to the individual needs and wishes. After all, people requiring care have a different perspective on the care services than the care providers. They have a specific experience and unique expertise in relation to their personal situation. The care facility and the care provider can take optimal advantage of this by coordinating the perspectives of the provider and the person requesting care in organising the care. The residents' council can play facilitating role here, as can a well-developed family

council.[104] In the Flemish draft memorandum for a welfare and care policy for older persons, reference is made to the participation ladder that contains these elements.[105]

1. Informing older persons
2. Consulting older persons
3. Asking older persons for a (binding) recommendation
4. Collaborating with older persons
5. Allowing older persons to (help) make decisions in the care and support process
6. Older persons can take initiative for improvements

In this description, participation is expressed as asking about and coordinating the care plans between the person requiring care and the care provider. In this process, the well-informed care requester has a decisive voice in the care that is offered. During the ENNHRI monitoring the importance of a 'life file' was also mentioned. This is a way of documenting the hobbies, interests and previous activities of the residents. It forms a source of information for individually customising and stimulating the participation of residents.

The theme Information from the Flemish "Indicators Project" explicitly investigates the involvement in creating the care plan:[106] (the scores are between 1 (never) and 5 (always)

Item	Average score	% always agree	% mostly agree	% unanswered out of 6949 residents
I have a voice in creating my care plan	3.12	23.6%	21.3%	3.9%

Although having a voice in the care plan is a highly important and determinant aspect of the participation segment, during the monitoring, participation was also often described as 'offering activities'. In several of the facilities visited, the activities were diverse and available individually. In these cases, an effort was made to work on an individually customised basis as much as possible, according to the 'life file'. In several other facilities, the only possibilities were the standard range of Bingo, knitting or sewing workshops and crafts in group. Offering meaningful activities during the weekend and in the evenings is clearly only just beginning to develop. Activities are offered on weekdays between 9 AM and 5 PM, and after that, the range of available activities utterly collapses. Often the only option left is to watch television. This is an observation that is also reflected in the study '*Zorgnoden en – behoeften: de kijk van de Brusselaar*' by the Kenniscentrum Woonzorg Brussel.[107] In this study, the importance of the volunteers is also brought up in relation to the range of activities, an observation that was virtually unanimously confirmed by the members of the senior management we interviewed: '*In our residential care centre, we have more than 80 volunteers. Without my volunteers, I could not offer all of the activities, it's that simple.'*

[104] the residents' council gives residents a voice and can make recommendations either its own initiative, or at the request of the day-to-day management of the residential care centre, regarding all matters that have to do with the general functioning of the residential care centre.
[105] Draft memorandum on a Flemish policy on welfare and care policy for older persons. *Dichtbij en integraal. Visie en veranderagenda*. Flemish Minister for Welfare, Public Health and Family, 5 February 2016, p. 20.
[106] http://www.zorg-en-gezondheid.be/vlaams-indicatorenproject-voor-woonzorgcentra-vip-rusthuis
[107] Kenniscentrum Woonzorg: *'Zorgnoden en –behoeften: de kijk van de Brusselaar. Analyse van sterktes, zwaktes, kansen en bedreigingen van de Brusselse woonzorg'.* 2012, p.121-123.

- ✓ *We paint and do crafts, we sing and play games, they read the newspaper aloud, we knit. That all happens as a group. (resident)*

- ✓ *There are no activities on weekends. I signed up as a volunteer to organise activities with the residents (movie night, petanque). And in the evenings there are no activities here either, so sometimes the evenings can be very long. (resident)*

The importance of a well-developed range of activities is clear and was confirmed by staff and management. Thus, according to many members of the senior management, the 'entertainment' aspect will play an increasing role in the future care of older persons. Keeping your older persons busy with meaningful activities and keeping them challenged is becoming a central challenge in the residential care for older persons. However, they also pointed out the limitations with which they have been confronted. According to the respondents, the personnel levels and the funding of them are too limited to be able to develop a decent range of activities or there were limitations in terms of infrastructure (or transport). Concerns were very frequently expressed about the changing funding for entertainment within the framework of the 6th State reforms.[108] For many members of senior management, this will lead to costs of entertainment to increase, an increase that they are going to have to pass on to the residents. Another possibility is to (further) limit the range of activities.

The presence of a Local Service Centre (*Lokaal Dienstencentrum, LDC*) can be a possible way to expand the range of activities and to stimulate the participation of residents. At the same time, the respondent emphasised the need for a suitable range of activities for men, since they are often forgotten in the programming of activities. Several family members also mentioned the degree of participation of lonely residents. According to them, residents who receive little or no visitors also participated significantly less in activities. Special attention for this target group is therefore necessary. Activities extending beyond the individual departments are occasionally organised so that residents with similar interests or the same capacities can do activities together. This method can reconcile two important elements: specifically guaranteeing an individual approach within a social group activity.

- ✓ *We do activities that extend beyond the departments so that people who are still at the same intellectual and mental level get a chance to do things together. This could be a type of memory training or simply an enjoyable activity. However, it is a highly time-consuming undertaking for what is often a small group of people.*

- ✓ *We should focus our activities more on the fields of experience of our residents, Tosca for opera lovers, matches for football fans, etc. But the period of just 'bingo' is over. (staff)*

- ✓ *We have developed writing workshops with the theatre, a photo booth with youngsters and music therapy. We have a strong link with artists in the neighbourhood. (management)*

- ✓ *We work together with the Local Service Centre and therefore you can offer more activities. (management)*

[108] The Flemish government is currently revising the meaning and role of 'entertainers'

- ✓ *I don't think that we offer enough activities for our male residents. You don't think about it, but you shouldn't forget your male residents in your range of activities. For example, we have a "repair café" here or we build wooden birdhouses. (staff)*

Various themes and indicators of the Flemish "Indicators Project" refer to the range of activities[109]:

Theme: information

(the scores are between 1 (never) and 5 (always)

Item	Average score	% always agree	% mostly agree	% unanswered out of 6949 residents
I get information about the activities that I can do here	4.53	69.7%	20.1%	0.4%

Theme: choice of activities

(the scores are between 1 (never) and 5 (always)

Item	Average score	% always agree	% mostly agree	% unanswered out of 6949 residents
In the past week, I took part in a meaningful activity	2.88	14.6%	23.1%	0.7%
There are enjoyable things for me to do here on the weekend	2.32	9.5%	14.1%	1.2%

The participation of residents in elections was considered to be important by most of the members of senior management as part of the pursuit of fully fledged participation or citizenship for the residents. Working with powers of attorney, setting up voting offices at the facility or organising transport to the voting office, were mentioned as possibilities.

- ✓ *During elections, I barely have to do a thing. The various representatives cannot wait to come collect the residents with a bus. (management);*

- ✓ *We organise transport to the polling station, while many institutions (at best) simply organise voting by proxy, (at worst) thus institutionalising medical incapacity certificates so residents don't have to go to the polling station. We are prepared to take part in a project that would even bring the polling station to the home. If there was a citizen's debate to explain and support the project, I'm sure that even more residents would vote. (management)*

Other responses on participation and social inclusion (and support to participate)

Resident

[109] http://www.zorg-en-gezondheid.be/vlaams-indicatorenproject-voor-woonzorgcentra-vip-rusthuis

- ✓ I have made a lot of friends here and we laugh a lot, that's important, I think.
- ✓ We have a close-knit little club here of 4 friends, they call us the ‘Golden Girls’.
- ✓ You can do different things here. They also always ask you if you would like to take part.
- ✓ There is enough entertainment here, but it is tailored to older people. Although I am in my 80s now myself, it could still be different. The level of the activities is also not very high; they don't appeal to me. Why don't they take us on more excursions? To take a bunch of the people from the residential care centre into the city, to go shopping like we used to, that would be fun.
- ✓ I would really like to do puzzles, but apparently they don't have any here. I haven't actually asked about it yet.

Family

- ✓ A well-functioning cafeteria should be mandatory at a residential care centre; it can form a central meeting place in the village community.
- ✓ In this cafeteria there are a lot of volunteers, but that's not always appreciated by the visitors. On the counter, there is a pot for donations for the volunteers, but they don't get a lot of tips.
- ✓ They watch a lot of TV in the central area.
- ✓ I have the impression that there are a lot of activities here. I regularly see performances, wheelchair games, singing songs, crafts and painting. I once even saw wheelchair football here, that was great. Unfortunately, my father doesn't want to take part, but that is his own choice, they do ask him to participate.
- ✓ That's something I notice: residents who have no children or residents who don't receive any visitors never take part in activities or rarely come to the common areas.
- ✓ All the families take care of the residents even if they aren’t a member of their family. We support each other.

Staff

- ✓ Participation is not only about the resident, but also about the family. You have to involve them too. That's why we not only have a residents’ council but also a family council. This is where they can discuss questions, etc.
- ✓ There's a lot of dancing and singing here, you see that people really enjoy that, it's a way to have fun. Also contact with animals or working in a vegetable or flower garden works well: you see the residents really open up if you can offer this.
- ✓ There should be more activities, especially in the evenings, everything kind of shuts down after the evening meal.
- ✓ You have a lot of residents who prefer not to take part, they'd rather stay in their rooms. You have to respect that, too.
- ✓ Their requests must be logical, if they want more, they have to go elsewhere.
- ✓ If we can’t set up an activity, we do something else.
- ✓ We involve people with dementia as much as possible in the daily activities, and they really enjoy that, you can tell. The social life for residents with dementia is in fact greater than in other departments, people spend a longer time sitting together in the living area and are often less inhibited about talking to one another

- ✓ You can continue to play the role that you previously did, for example, if you used to go to the Okra (association), then we make sure that you can still do that.
- ✓ We also always try to let residents do activities at other locations, that way you can give them a change of scene. You break the monotony and the routine. As a residential care centre, it is also a way to come out into the world, although you do need a good transport network for that.
- ✓ I can personally join the residents in one major activity per week. The rest of the week I am busy with administration or my own activities: marking which activities I will do, explaining why I am not doing more activities and saying what the starting situation of the residents was before the activity, and what the situation is after the activity.
- ✓ Our cafeteria is freely accessible and this means that many inhabitants of the village come here daily for a drink, so that provides social contact and creates a very pleasant atmosphere.

Management

- ✓ During elections we work with powers of attorney.
- ✓ The elections are held here at the Local Service Centre, so it's fairly easy to organise.
- ✓ Chopping vegetables for the soup is also an activity that you can do as a group. And they enjoy it, too.
- ✓ We do our activities as much as possible as a group and with the supervision of occupational therapists.
- ✓ It's very important to mix care profiles: if you are no longer able to speak, it's pleasant when other residents speak and that you can be part of a conversation.
- ✓ The social restaurant run by the OCMW is also located here and that generate a lot of social contact between the residents and the rest of the village community.
- ✓ We're also very interested in the intergenerational aspect; pupils from a school have been coming to the care home for the past seven years to meet the elderly residents.

3.4.7 Privacy and family life

In our society, in principle, it is easy to protect your privacy. You have a home where you can withdraw to be by yourself, where you as resident decide who may or may not enter your personal living space. You open your door or you leave it closed. Living in a facility is living in a mini-community where this option is not always easily available.

When people enter a facility, after all, this safe and secure environment is exchanged for a room, usually an individual room but sometimes with a roommate. In the study '*Zorgnoden en –behoeften: de kijk van de Brusselaar'* by the Kenniscentrum Woonzorg, the importance of a single private room is highlighted: 'The room is the place where people can be themselves, relax, …, It's the only little piece of privacy that the residents have left. Therefore, many of them don't want to share a room, …. , or they have great difficulty with it… Sharing a room with people you have not chosen requires an adjustment.'[110]

[110] Kenniscentrum Woonzorg: *'Zorgnoden en –behoeften: de kijk van de Brusselaar. Analyse van sterktes, zwaktes, kansen en bedreigingen van de Brusselse woonzorg'.* 2012, p.119.

At the policy level, there is also a lot of attention paid to this basic right. For example, privacy standards are a priority in the sector specific minimal quality standards for residential care centres.[111] Thus, since 1 January 2014, a residential care centre may not have rooms for more than 2 occupants (deviation is possible but must be requested with statement of the reasons).

Moreover, each facility must make clear and appropriate agreements concerning acquiring and sharing information with respect for the privacy of the user. In addition, all facilities must take measures for protecting privacy in the interaction with the users.

It goes without saying that –despite these privacy standards– this right to privacy and the right to family life can come under pressure in a residential care setting. Although during the monitoring, privacy was mentioned as 'self-evident' or 'an acquired right', upon further questioning, it was revealed that it can sometimes bring certain limitations and challenges.

In general, residents reported that privacy was possible. The possibility of closing the door to your room was consistently mentioned as an argument to support the right to privacy.

- ✓ *I have privacy in my room. I close the door and voilà! (resident)*

- ✓ *The residents can lock their doors here, and they do. People have the right to be by themselves, and that right applies here as well. (staff)*

Moreover, the vast majority of the residents and staff confirmed that people have the habit of knocking before entering the room. As we were able to observe ourselves during the monitoring, it would be better to phrase it differently: 'people knock as they enter the room'. This is closer to the reality in the facilities examined. For example, during the interviews with residents, there were up to 5 interruptions by members of staff who stormed into the room 'whilst knocking'. There was also often a distinction made between the residents with dementia and the other residents. In some of the facilities people also knocked before entering the rooms of the residents with dementia. At other facilities that were visited, people entered these rooms without knocking.

- ✓ *They knock first and then I call out 'come in' and only then does the door open. That's how it should be, I think. (resident)*

- ✓ *They knock and then immediately walk in. Well why bother knocking? (resident)*

- ✓ *For residents with dementia, we simply walk into the room, for the other residents we knock (staff)*

We could make the same observation based on the Flemish "Indicators project" in which the statement 'I can be alone whenever I like' received a very high score, but the statement 'I decide for myself who comes into my room' received a lower score.[112]

[111] http://www.codex.vlaanderen.be/Zoeken/Document.aspx?DID=1011700&param=inhoud

[112] http://www.zorg-en-gezondheid.be/vlaams-indicatorenproject-voor-woonzorgcentra-vip-rusthuis

Theme: Privacy

(the scores are between 1 (never) and 5 (always)

Item	Average score	% always agree	% mostly agree	% unanswered out of 6949 residents
My privacy is respected during care	4.65	72.6%	21.0%	0.6%
I can be alone whenever I like	4.63	74.9%	17.6%	0.3%

Theme: Autonomy

(the scores are between 1 (never) and 5 (always)

Item	Average score	% always agree	% mostly agree	% unanswered out of 6949 residents
I decide for myself who comes into my room	4.04	51.5%	24.9%	0.9%

The right to family life was expressed in two ways during the ENNHRI monitoring: the right and the opportunity to receive family and visitors in the room, and by extension in the common areas; and the right to a family life within the department, together with the other residents and the staff of the department or facility.

Family and visitors were welcome in each of the facilities visited, whereby the right to privacy with the family in the room was a priority. In a few cases, the residents and family could also use separate private rooms for private time with family or meetings. We would also like to draw attention to the testimonies of residents who no longer received any visitors. According to members of staff, many residents are in this situation. This is either because there are no longer any other family members, or because the family members were no longer visiting due to family disputes or other reasons.

- ✓ *You have residents who never have any visitors. I certainly understand that you cannot come every day, but still. And on the other hand, you have residents who get a whole lot of visitors. You have all possible variations in frequency and intensity. (staff)*

- ✓ *My children often come on the weekend and if possible, all together, with the grandchildren. My whole room gets turned upside down and there's hardly space to move, but it's so much fun, the whole gang together. The staff also enjoys it, it brings some excitement to our floor. (resident)*

The other definition of 'family life' has to do with living together the other residents and the staff in the department. The term 'homelike' is often used in this context: people want to decorate the rooms in the department as much as possible like a home, in order to create a sense of security and safety.[113] The small-scale normalised living (*Kleinschalig*

[113] Sector specific minimum quality standards

genormaliseerd wonen) is designed to fulfil this need. This is a form of living in which residents who receive professional support, guidance and care, live together as a household in a living and care setting that is recognisable for the resident and that is as similar as possible to his or her home situation.[114]

The characteristics of small-scale normalised living are: as normal, ordinary and recognisably homelike as possible, and a familiar living environment; Where customised care is provided; The care effort is focused on promoting the quality of life of the residents; great importance is placed on the quality of the relationships; The care providers stimulate the autonomy of the residents wherever possible and provide them with security and safety as needed; it is small in scale, intended for a specific number of residents.[115]

- ✓ *Small-scale normalised living fully responds to the quest for a more homelike and family style life. (management)*
- ✓ *Our department even has a cat. The cat goes from room to room and jumps on everyone's lap. At home, we always had cats too. (resident)*
- ✓ *I see a member of staff hug a resident here every day, that's a beautiful thing, isn't it? (family)*
- ✓ *What is better: a TV in your room or a TV in a common area? The one will be better for privacy, the other for community. (staff)*

An important aspect in the right to privacy and family life is the right to sexuality. An article in the magazine 'Knack' reveals how much hesitation and how many barriers surround the subject. In the article it is demonstrated that older persons, too, want and need sexual relations, but this is a difficult matter in facilities for older persons. Often, staff also hasn't learned how to handle such situations. The new generation of older persons is no longer prepared to accept this and they are demanding their right to privacy and sexuality. [116] During the ENNHRI monitoring the subject came up sporadically. For example, partners who came to visit residents were allowed to close the door; the door was closed if a resident was watching erotic or pornographic films; or the resident was left alone for a little while if sexual arousal was noticed during the care. Once, a member of staff reported witnessing sexual activity in the hallway of the department: *I was a little surprised, but I brought them both to the room of one of the residents and left them alone beyond that.*

- ✓ *We do think about the residents' sexuality and we do everything to ensure they're balanced. (management)*
- ✓ *Intimacy is something private between two people. (management)*

[114] *Kleinschalig genormaliseerd wonen in Vlaanderen*. Prof dr. Anja De Clercq http://www.kuleuven.be/lucas/pub/publi_upload/2009_5_AD_Grote%20kwaliteit%20op%20kleine%20schaal_KGW%20in%20Vlaanderen.pdf

[115] *Kleinschalig genormaliseerd wonen in Vlaanderen*. Prof dr. Anja De Clercq http://www.kuleuven.be/lucas/pub/publi_upload/2009_5_AD_Grote%20kwaliteit%20op%20kleine%20schaal_KGW%20in%20Vlaanderen.pdf

[116] Seks in het rusthuis, het oudste taboe. (Seks in the residential care facility, the oldest taboo) Knack, no.10, March 2016.

Other responses on Privacy and family life

Resident

- ✓ My children take turns visiting me, and they come often and unannounced. It was like that at home before, as well, so it's basically stayed the same, only the address has changed (laughter).
- ✓ I rarely see my son. Every once in a while he drops in, every other month or so. Even though he lives nearby.
- ✓ I share a room and then you don't have much privacy. They do have a kind of curtain hung up as a partition, but still.
- ✓ I don't know if I can close my door
- ✓ I can lock my door. The staff have a master key, but that's only logical.
- ✓ The walls here are like cardboard. If someone is talking in the room next door, I hear it. You have to learn how to live in a mini-community here and it's not easy. You have to adapt and give up some privacy and freedoms.
- ✓ There are residents with dementia in our department and sometimes they come into your room, and that's always a bit of a shock. Also if they start shouting, that has an impact on you as a fellow resident.
- ✓ If I go to a family party, then after an hour already I get restless. Then I asked the children to take me home, to my home at the residential care centre. Strange how you can feel at home somewhere else.

Family

- ✓ The room is big enough to be on our own together for a while. And if we close the door, then we are very secure. The staff also always knocks if the door is closed.
- ✓ I didn't know that I could lock the door of my partner's room. That's important, I'm certainly going to ask for a key.
- ✓ In the cafeteria you can literally see the ageing of our society. You see four generations of the same family here; In the summer, the cafeteria is full of people in their 60s with their children and grandchildren who come to visit their 90-year-old parents;
- ✓ I no longer have any family living in this residential care centre, but I still like to visit here. There is a nice, family atmosphere.
- ✓ They should install a lounge. Something cosy, a place where you can get together.

Staff

- ✓ The family has to let us know what the resident wants, they need to provide support and take care of the psychological well-being.
- ✓ We ask about the family situation at intake. We also always ask if there are important family disputes that we need to know about. After all, we often have to comfort residents because there is conflict between their children
- ✓ We always try to create a homelike situation in the rooms
- ✓ The resident has a free choice here whether to leave the door open to close it, it doesn't matter.

- ✓ It's normal that you knock before entering, it's the same here as outside of the residential care centre. Besides, just because you can't speak, it doesn't mean that you can't react or that people shouldn't knock when they enter.
- ✓ All our rooms have a 'occupied' light. If you turn on the light, then you can see from the hallway that we are providing care or that there are visitors. That way you can prevent a breach of privacy.
- ✓ In the past, the central focus at a residential care centre was the care, now the living aspect is more important, feeling at home. That's why you also have the 'small-scale normalised living'.
- ✓ There are cameras in almost all of the common areas. That can be important for safety, we have had break-ins in the past, but in terms of privacy that may lead to more problems.

Management

- ✓ Our staff wear nametags. That is also an important aspect in trying to create a pleasant, family style living environment, knowing who is taking care of you, isn't it?
- ✓ We try to imitate household life: doing the dishes together, folding the laundry, reading the newspaper aloud, doing some exercises; in the afternoon we chop up the vegetables for the soup and take care of the houseplants, the kind of things that you would have done at home with your family, etc.
- ✓ The family is free to come to the residential care centre any time, and the more the better.

3.4.8 Freedom of expression, freedom of thought, conscience: beliefs, culture and religion

The freedom of expression is a theme that often leads to debate and polemics. The *free expression of an opinion* is one of our fundamental rights, but no freedom – no matter how fundamental– is ever absolute.[117] The *freedom to have an opinion* is, however. According to the European Court of Human Rights, Freedom of expression is applicable not only to 'information' or 'ideas' that are favourably received or regarded as inoffensive or as a matter of indifference, but also to those that shock, offend or disturb.[118] The limit imposed by society and legislators is at the point of incitement to hatred, violence or discrimination. The intention of the speaker also needs to be taken into account, as well as the context: whether it is an act performed with this intention in a context in which there is a possibility that hatred, violence and discrimination would be (in)directly provoked.

In a facility, people live together who, by definition, do not have the same opinions, thoughts, cultural or religious convictions. The freedom of thought - in the broadest sense- and the right to express this is a right that was confirmed by all of the respondents. The limits associated with this freedom are the legal restrictions referred to above.

[117] The Centre for Equal Opportunities and Opposition to Racism. Press release, 22 May 2012.
[118] The Centre for Equal Opportunities and Opposition to Racism, Annual Report 2011. *Focus on the freedom of speech.*

- ✓ *They have never said that I shouldn't say something or anything like that. And in fact, I tend to have strong opinions about all kinds of things. (resident)*

- ✓ *I have a blog. If I couldn't express my opinion, then they would shut down the blog. Although I actually doubt that they could do that. (resident)*

In the Flemish "Indicators Project", we see the following results:

Theme: Safety (the scores are between 1 (never) and 5 (always)

Item	Average score	% always agree	% mostly agree	% unanswered out of 6949 residents
I can express my opinion without fearing repercussions	4.08	47.9%	25.8%	2.6%

The cultural and religious diversity in the residential care has been long anticipated, but has not yet been frequently observed in the average Belgian residential care centre, with a few exceptions. Certainly on the side of the residents, the profile of the white senior citizens is predominant. In all cases, the residents confirmed that they were free to practice their religion. In a few of the facilities, there was a chapel. And in all of the facilities, there was a room where the religious residents could spend quiet time, if necessary or desired.

- ✓ *The chapel connected with the residential care centre is truly beautiful. I love to go there.*

- ✓ *Some of my residents are Jehovah's Witnesses. We make sure that they can follow the services by means of an Internet telephone.*

- ✓ *If we had any Muslims among our residents, then I'm quite sure that we would have an imam visit. I don't think that would be a problem. But at the moment, I don't know if there already are very many Muslims in residential care centres?*

Among the staff, however, there has been a large influx of care providers with an immigrant background. First and foremost, in Brussels, but also in the rest of the country, the teams are becoming diverse. In most cases, this involves women with an immigrant background who carry out functions that are at the bottom of the hierarchical ladder (housekeepers, and care providers).[119] The fact that the right to freedom of religion also applies for the staff is demonstrated by the negotiated solution that Unia facilitated in a residential care centre: a female employee in the washing room of a residential care centre asked her employer if she could wear a traditional Arabic outfit instead of the relatively formfitting work uniform with

[119] Centre for Equal Opportunities and Opposition to Racism. *Pilootproject Interculturele Communicatie voor de zorgsector. Rapport in opdracht van de Ministers bevoegd voor bijstand aan Personen* (GGC) May 2012. (Pilot Project on Intercultural Communication in the care sector. Report commissioned by the Ministers responsible for assistance for Persons)

logo. A compromise was reached: the same work uniform, but then several sizes larger so that it would meet the requirements of her religion.[120]

Other responses on Freedom of expression, freedom of thought, conscience: beliefs, culture and religion

Resident

- ✓ I can say whatever I like.
- ✓ There is a weekly mass here with a priest. Quite a lot of residents take part.
- ✓ People have the right to be heard about their inner thoughts. In our society and therefore also in the residential care centre, there is too little attention paid to people's beliefs, you have to question and nourish it. For example, the current pastoral care service is an attraction, but it's not a fully-fledged service.

Family

- ✓ I assume that I can say anything, as long it is not offensive, of course. And also when it comes to religion, you can choose here, that was in the information brochure we received.
- ✓ I have never had the impression that I couldn't say something or that my father was kept from speaking his mind.
- ✓ That is 100% true at this residential care centre. My mother loves to talk about all kinds of things and what's more, she has an opinion about everything. I have the impression that the staff stimulates the interaction.
- ✓ I once stormed off to the senior management with a plate of food. I told them exactly what I thought about it. They allowed me to have my say.

Staff

- ✓ Our residents can say what they like.
- ✓ The residents have freedom of expression; I don't think it would work otherwise. People are assertive and they're only getting more so, you have to take that into account.
- ✓ If the residents can no longer express themselves, then it is up to the family to preserve their rights.
- ✓ That is also our job. You have to ensure that everyone at this residential care centre can express his or her opinion.

Management

- ✓ In this residential care centre, you can say what you like. Of course within the legal boundaries that there are, such as shouting racist slogans and such.
- ✓ Our residents are not restricted in their freedom of speech or in their religion.

[120] http://www.unia.be/nl/rechtspraak-alternatieven/onderhandelde-oplossingen/aangepaste-werkkledij-in-a-rusthuis

- ✓ Religious choice or freedom seems to me to be a fundamental right for our residents. At the moment, we do not have much demand for it, except for going to the Catholic mass of course.

3.4.9 Right to highest attainable standard of physical and mental health

'We must ensure that the residents feel better here, better than before. This way you ensure that they regain some prospects for the future,' says a staff member. It is clear that this objective includes an interplay of aspects and factors. Multidisciplinary and transversal work seems to be a necessary condition.

To give residents the best possible care, attuned to their personal needs and wishes, the importance of 'negotiated care' was often emphasised during the monitoring. In this, an individual care process will be outlined in which the residents are involved and have input into their care expectations and care objectives, a 'care dialog' between care recipient and caregiver. Comfort care, in which an attempt is made to make basic care, such as e.g. washing, dressing and mealtimes, pleasant activities, with a respectful approach to every resident and within his/her possibilities, is always central in this. An important instrument for properly carrying out this negotiated care is the 'care plan'. This is a (written/electronic) document on the planned care for a user. It forms the basis of 'negotiated care'. The care plan implies a contract in which the participants undertake to optimally carry out their part of the care and collaborate with the other disciplines on that specific patient. The care plan is modified as a function of the evolution of the care need. It contains an arrangement based on essential administrative, clinical and paraclinical aspects of the person. The care plan consists of five parts, namely an administrative portion, general objectives, a clinical assessment, task agreements and communication. All of this must ensure personal, maximally achieved care that fulfils the right to the 'highest possible standard of physical and mental care'.[121] In some cases staff members have reacted negatively to this right and too many care and service demands have been made by residents and family.

- ✓ *By applying the principle of negotiated care, through early care planning, the life dossier and transversal consultation, we can provide much more customised care. The more you work in a multidisciplinary way, the more you can work individually. You can see the result in your residents. (staff)*

- ✓ *The people who come in here all have a multi-pathology, so you must also work in a multidisciplinary way to meet their personal needs. (staff)*

- ✓ *Engage in dialogue with your residents about their care plan. With negotiated care you have the best chance of providing maximum care. (management)*

- ✓ *The concept of negotiated care goes much too far for me. I sometimes have a 'utopia feeling': you ask, we do. The limit is always pushed further; residents are sometimes too demanding. (staff)*

[121] Het zorgplan in een woonzorgcentrum [*The care plan in a residential care centre*]. Prof Dr J DE Lepeleire, KULeuven BVGG –Crataegus. http://health.belgium.be/internet2Prd/groups/public/@public/@dg1/@acutecare/documents/ie2divers/18052706.pdf

The residents and family questioned are in general satisfied with the care offered. The individually tailored service or care provision leads to quite a lot of positive feedback, as does the range of possibilities that are offered to maximally meet care or assistance requests. Most residents have the feeling that the facility does everything to take care of needs and to make their life as pleasant as possible.

- ✓ *My physical and mental condition has significantly improved since we have been here. With the physical therapy my stiffness has disappeared. I am less anxious here and worry less. (resident)*

- ✓ *I have to be honest about it; the staff does everything to make it as good and pleasant as possible, they really do. (resident)*

Despite this general satisfaction, critical comments were very often made or points for improvement suggested. Practically every resident or family member could quote a feature that would improve the physical or psychological situation. These points for attention are highly diverse, ranging from infrastructure to aspects of care. It was also repeatedly noted that it was usually the same staff members who provided the maximum possible care or service, and that it was often the same staff members who were inadequate in care or service provision. Family members commented a number of times that it was only thanks to the family itself that the best possible care could be provided. Various family members in various facilities confirmed this: '*You have family members who come several times per week and just work here; that is needed too, to ensure a standard of care. I actually come here to do a job'.*

- ✓ *The windows don't open all the way. Nevertheless sometimes I would just like to air out my room, but I can't. My room also faces north. A bit more sun and light in my room would make a lot of difference in how I feel. If you wake up with a bit of sun, it does you good, you know. (resident)*

- ✓ *When I go to sleep and they put me in my bed, it has to be done a little carefully, otherwise I have back pain all night. I say that too: 'Will you be a bit more careful?' Staff member X answers: 'Yes, but I have to think of my back'. Then I answer, you have to think of my back too. (resident)*

- ✓ *Some staff members here do everything 'fast, fast', and you also have staff members who are a little smarter than others. You have to take account of that if you want to be cared for properly. (resident)*

- ✓ *In the summer, when it's really very warm, they should be able to freshen up or wash the residents more often. (family)*

- ✓ *The care is good, but the dots on the 'i' are missing. That is our task as staff, to do that little bit extra. (staff)*

- ✓ *Isn't that what it's about in a residential care centre? To fulfil the care request of every resident as individually and as well as possible. To offer the best possible care, that is our core mission. (management)*

In the Flemish Indicators project the statements 'I can get the healthcare I need' and 'The care and support I get help me to live the way I want' score very high.

Topic: Responsiveness[122]

Average score for this topic: 4.17

For info: the scores lie between 1 (never) and 5 (always)

Item	Average score	% always agree	% usually agree	% no reply out of 6949 residents
I can get the healthcare I need	4.65	71.2%	23.1%	0.4%
The caregivers know what they're doing	4.50	59.6%	31.5%	0.8%
The care and support I get help me to live the way I want	4.39	54.8%	33%	0.9%
Staff react quickly if I ask for help	4.02	32.5%	42.5%	0.9%
The caregivers have enough time for me	3.86	30%	37.6%	1%
Staff consider my suggestions	3.56	20.5%	33.5%	3.9%

Other responses on the right to the highest attainable standard of physical and mental health

Resident

- ✓ We're the war generation. We understand that you can't always have everything; we have learned to be satisfied with the little we have and not complain too much.
- ✓ If you need help they come very quickly here, and they're always asking if everything is all right.
- ✓ I'm beginning to have trouble reading. They immediately provided a 'Daisy reader'.[123]
- ✓ My bed was broken. I reported it a number of times, but there was no solution. Then I got really angry at the head nurse and suddenly there stood a new bed. Why did that have to take so long or be so difficult?

[122] http://www.zorg-en-gezondheid.be/vlaams-indicatorenproject-voor-woonzorgcentra-vip-rusthuis
[123] Reading aid that can play digital audio books

- ✓ The midday meal is often already on the table at 11:30 am. That follows much too soon after breakfast.
- ✓ If you give a cook some small change then it's normal that he can't prepare a feast with it.
- ✓ I think they are rather nonchalant in preparing and administering medication. They forget my eye drops sometimes. That can happen once in a while, but it happens fairly often.
- ✓ I like to go swimming. I enjoy it and it does an unbelievable amount of good for my body. Unfortunately I can only go swimming if a volunteer goes along.

Family

- ✓ The family members help everyone here, we are real volunteers.
- ✓ The staff give you the opportunity to help give care; that is important. We know best after all what our family needs.
- ✓ At certain times there is no one from the staff to be found. But when the head nurse is standing in the hall, then you see them working some.
- ✓ I see a difference. The head nurse is there for the residents, the team are here for themselves.

Staff

- ✓ We have residents who can barely stand when they come in, and some time later they walk 5 km.
- ✓ It's our aim to get the maximum from the residents; this is our mission.
- ✓ I can take a lot of time with the residents. That is a luxury situation that is not possible in every residential care centre, but it is an absolute added value for the residents.
- ✓ Early this morning a resident asked for an egg. We didn't have any available, but we will see that he gets an egg tomorrow morning!
- ✓ The food is high-quality and delicious; I eat here myself too. But the presentation is really awful. You eat with your eyes too; we have to find a solution for that.
- ✓ The meals are the nails in my coffin; there are so many residents, and there is too little time to feed them as it should be done. You can't offer them what you would like.

Management

- ✓ Isn't that the core mission of a residential care centre?
- ✓ Here too you come into contact with the multidisciplinary teams and workgroups. To approach the resident as a whole from various points of view, from various areas of expertise.
- ✓ Of the entire team of doctors I see only a few who are really suited to working in a residential care centre. It is really a different way of working, a different way of giving care. You are in a multidisciplinary team and you need to confer with colleagues and be constructive. It is the care team that must ensure the best possible care for the resident, with a 360° view of the patient. The era of 'the doctor decides and is always right' is over.

3.4.10 Discrimination

In Belgium the antidiscrimination legislation - with federal laws, decrees and ordinances - prohibits discrimination on the grounds of 19 so-called 'protected criteria'. Discrimination on the grounds of any of these criteria is prohibited and punishable: the five 'racial criteria': presumed race, skin colour, nationality, ancestry and national or ethnic origin; disability; religious or philosophical beliefs; sexual orientation; age; wealth (or financial resources); civil status; political beliefs; state of health; a physical characteristic; a genetic characteristic; birth; social background; gender and language.

There is discrimination when you are treated less well in a comparable situation due to your disability, sexual orientation, age, etc. Discrimination is not an issue when a difference in treatment can be declared objective and reasonable; we then speak of an allowed distinction.

The legislation distinguishes various forms of discrimination: direct and indirect discrimination; giving an order to discriminate; discriminatory harassment; incitement to discrimination, hatred or violence and hate crime; lack of reasonable accommodation.[124]

In the care regulations we also see references to an antidiscrimination policy. Thus the Decree on Residential and Home Care[125] provides several working principles for residential care facilities for the elderly: 'to guarantee the accessibility of residential care without discrimination on the grounds of ideological, religious and philosophical belief or membership or any other criterion on the grounds of which there can be discrimination' or also 'to respect the privacy of the user and his caregivers without discrimination on the grounds of ideological, religious and philosophical belief or membership or any other criterion on the grounds of which there can be discrimination. Despite the fact that age discrimination is not cited as such, we do see age aspects that can be important in care. Thus there is an age limit imposed for residential care centres, with several exceptional measures as previously discussed[126]. Age is a 'special' criterion because it can be a protective measure as well as an exclusionary criterion. In social policy, age barriers have long been regarded as a protective measure; today they are being called into question due to their possibly discriminatory nature. General and uniform framework criteria like age seem too strict and impersonal to be able to take account of the unique nature of individuals and the paths they follow.[127] This seems to be confirmed in the policy that is being developed; thus we read in the concept paper for a Flemish wellbeing and care policy for the elderly that '*we are evolving in the long term toward a demand-driven, age-independent wellbeing and residential care policy in which not age, but care and support requirements and the further life goals (life perspective) of the care recipient form the central starting and reference point.*'[128]

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[124] http://unia.be/nl/discriminatiegronden/discriminatie-enkele-verduidelijkingen

[125] Article 4 Decree on Residential and Home Care: http://www.codex.vlaanderen.be/Portals/Codex/documenten/1017896.html

[126] The age condition of 65 can be lifted in a number of cases if the residential care centre provides a report showing that in the area of the applicant - younger than 65 - there are no other appropriate facilities available that can fulfil the care request, and when the number of users younger than 65 per authorised residential care centre is a maximum of 10% of the total number of authorised housing units of that residential care centre. It is important to note that the number of living units with special authorisation as a centre for non-congenital brain damage (e.g. due to an accident, etc.) is not counted in this.

[127] Discrimination – Diversity: focus age. 2012 annual report, p.19.

[128] Concept paper on Flemish wellbeing and care policy for the elderly. *Dichtbij en integraal. Visie en veranderagenda [Nearby and Comprehensive. Vision and Change Agenda]*. Flemish Minister of Welfare, Public Health and Family, 5 February 2016, p. 3

On the basis of the monitoring, we can distinguish two groups of potential discrimination victims within the care sector:

- Care recipients, in access to care provision and during provision of care or services. We also refer here to the section 'Equal access to health services'.
- Caregivers who are discriminated against by employers, colleagues or care recipients.

For care recipients and caregivers we should pay special attention to the vulnerability of those who can experience discrimination through a combination of factors such as age and/or gender and/or ethnic origin and/or disability.[129] **Multiple discrimination** (or added discrimination) is an issue when someone is discriminated against for multiple reasons. For example, a homosexual care recipient who originates from an ethnic minority can in a certain situation be discriminated against on the basis of his sexual orientation and in another situation on the basis of his ethnic origin. **Cross-discrimination** is an issue when a person is discriminated against on the basis of two or more grounds for discrimination at the same time and when one ground for discrimination is reinforced by one or more other grounds for discrimination. For example, a care facility requests employees of a certain age, with a certain level of experience, with perfect language proficiency and a certain nationality. The combination of requirements can sharply reduce the opportunities of certain employees. **Intersectional discrimination** is an issue when various grounds for discrimination interact with one another at the same time and become inseparable. Thus a female caregiver who originates from a certain ethnic minority can encounter a different sort of discrimination on racial grounds than a man from the same ethnic minority.[130]
Unia has received a number of reports of discrimination in residential care centres:

- A residential care centre imposed an age limit of 75 for volunteers. Due to unclear communication confusion arose as to why that condition existed. On the one hand, the residential care centre claimed that the age limit was a condition set by the insurance company. On the other hand, by its own account it had bad experiences with volunteers older than 75. After the intervention of the Centre the residential care centre decided to completely abandon the age limit. Instead it now conducts regular individual guidance discussions with its volunteers.
- An employee from an external firm makes racist remarks about the native country and 'culture' of a kitchen employee of the residential care centre. The residential care centre, the external firm and Unia take steps immediately and reach a negotiated solution with all those involved.
- A female employee in the wash room of a residential care centre asked her employer to be able to wear traditional Arabic clothing instead of the relatively close-fitting work clothes with logo. A compromise was found: the same work uniform, but several sizes larger so that it fulfils the prescriptions of her religion.
- An occupational therapist replaces another staff member in a residential care centre for the elderly for two years. During these two years she has an epileptic seizure three times. When the job opens up her application is rejected. The management

[129] https://fra.europa.eu/sites/default/files/fra-factsheet_inequalititesmultdiscrimination_nl.pdf
[130]Evaluation of the federal antidiscrimination legislation. Unia, 2016, p 61.
law http://unia.be/nl/publicaties-statistieken/publicaties/evaluatie-van-de-federale-antidiscriminatiewetten

accuses her of a lack of openness about her state of health. The occupational physician had declared her fit for the job. The court decides that there is a presumption of discrimination.

- In the cafeteria of a residential care centre a visitor, in the presence of witnesses, makes a remark with regard to a trainee of foreign origin, such that the opinion of the court is that it involves incitement to discrimination or hate. The perpetrator repeats his point of view in the car park of the residential care centre to the mother of the victim. He referred to the Turkish origin of the victims. The fact that they are of Moroccan and not Turkish origin is irrelevant. The national origin ascribed by the perpetrator suffices.

It is noteworthy that there are no reports from residents (as we can also establish from the elder abuse hotline). This conclusion was confirmed by the residents questioned in the ENNRHI monitoring. They had not had the feeling of being the victim of discrimination at any time. It is important to note that discrimination is limited by most residents to discrimination on the basis of origin, skin colour and religious belief. With regard to the staff too, no discriminatory or racist remarks were noted.

- ✓ *I wouldn't know how they could discriminate against me here. I am white, after all? (resident)*

- ✓ *'Belgians' no longer want to work in a residential care centre. Only foreigners work here, with an exception here and there. And then they say in the media 'They're taking our work away.' I'm happy that at least they still want to take care of us, and they do that well, too. (resident)*

Staff members did testify to cases of discrimination or racism during the monitoring. Usually this related to the facilities where they had previously worked, in relation to colleagues and/or management. In the second place racist remarks from residents, who often had a problem with dementia, were involved.

- ✓ *I left the previous residential care centre because I was being harassed. It clearly had to do with my dark skin colour. My husband first contacted the management and then the police, but nothing came of it. I turned in my resignation and started working here. (staff)*

- ✓ *I left the previous residential care centre because as a white person I was treated in a racist way by the care team, which consisted of 99% North African caregivers. (staff)*

- ✓ *We have had it happen that dementia patients with a colonial past call 'boy' to a black caregiver. We then immediately talk to the caregiver and the resident. (management)*

Other responses on Discrimination

Resident

- ✓ All the residents here have the same rights, I think.
- ✓ The staff treat everyone the same way; you really can't say anything about that.

- ✓ A doctor of Moroccan origin who was veiled once walked in here. They had to calm down my wife then; she thought the devil had come in.
- ✓ I don't want to complain too quickly, because otherwise you're a racist fairly quickly, but they did discharge that staff member. She wasn't friendly and there was always something wrong. You have to do your job well, regardless of your skin colour.

Family

- ✓ The nursing staff are good, but those caregivers are often foreigners and their Dutch is not good. Their customs are different too. But apparently they can't find any others.

Staff

- ✓ The care is the same here for everyone.
- ✓ Because some residents have visits and others don't, you do run the risk that certain residents get somewhat more than others (e.g. things from a shop or such); we take account of that and will be very attentive to that. Everyone wants something extra now and then.
- ✓ Aggression and discrimination often go hand in hand. So the skin colour of the caregivers can be important in the reaction pattern of residents.
- ✓ I have never been approached about my accent or my appearance. I attempt to do my job well and my colleagues appreciate that. I try to provide the best care and the residents sense that. The rest is less important.

Management

- ✓ We treat all our residents the same way, without distinction.
- ✓ We teach the residents to deal with diversity. Our staff cook something from their homelands sometimes, and with about 12 different nationalities you do get to try things. Our residents enjoy that.

3.4.11 An adequate standard of living

Bed, bath, food and care. A great many answers and concerns relating to this topic were linked to these terms by those interviewed, often in combination with the previously discussed human rights like the right to choice and autonomy or the right to the highest attainable standard of health.

A point for improvement that was cited by many residents to guarantee an adequate standard of living related to the meals. In approximately half the cases the residents were not satisfied with the meals or the dining experience, although there were also facilities where the meals were very highly rated. That food is important for the residents was confirmed by all the participants in the ENNHRI monitoring. It is important to note that this does not involve only the food as such, but also the dining area, table companions and the way food is served. The facilities where a buffet is served e.g. at breakfast or dinner can count on many

satisfied residents. These conclusions concur entirely with the conclusions of the survey of the Kenniscentrum Woonzorg [*Residential Care Knowledge Centre*].[131]

- ✓ *I sit down at the table at lunch, lift the cover from my plate, taste, and then put the cover back on my plate. It's not really appetising here, I think. (resident)*

- ✓ *The food is delicious here and you can send in your choice a week in advance, what more do you want? (resident)*

- ✓ *We eat as a family in the cafeteria. This is the same food that the residents get, it's always perfectly good. (family)*

Residents, family, staff and management devoted quite a bit of attention to staffing and staff qualifications during the survey. That staffing is under heavy pressure was confirmed by all those involved, and for many forms a hazard to ensuring human rights in care. A study by J. Pacolet and A. De Coninck of KU Leuven on the financial viability of Flemish residential care centres shows a structural underfunding of the sector. The researchers calculated that an average residential care centre has a deficiency of 1.28 fulltime equivalent (FTE) funded care staff per 30 living units, or an underfunding of 15.3%.[132]

- ✓ *The caregivers in our division don't work, they perform slave labour. That they don't realise that in Brussels (government), that there are too few staff, I don't understand it. (resident)*

- ✓ *The staff work very hard but there are just too few of them; that is the reality. They are shorthanded every day. That's why I stay here as a volunteer too, it's just necessary. (family)*

- ✓ *More colleagues, that's all I ask. That's why I'm always so happy when there are trainees; they relieve the work pressure enormously. (staff)*

- ✓ *We work 30% above the standards the government sets for us with regard to staffing. This is a Kafkaesque situation; if you follow the standards with regard to staff and the standards with regard to quality, you note how poorly they are correlated with each other. You must work above the standard with regard to staff to be able to fulfil basic requirements. (management)*

From a policy perspective, there are accreditation standards and rules with regard to education and training of staff. Thus, e.g. in the sector-specific minimum quality requirements for residential care centres[133] there are requirements set with regard to staffing, staff

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[131] Kenniscentrum Woonzorg: *'Zorgnoden en –behoeften: de kijk van de Brusselaar. Analyse van sterktes, zwaktes, kansen en bedreigingen van de Brusselse woonzorg' [Care needs and requirements: the view of the Brussels resident. Analysis of strengths, weaknesses, opportunities and hazards in Brussels residential care].* 2012, pp.120-121.

[132] Pacolet J, Vanormelingen J. and De Coninck A. *Tempus fugit: Een aggiornamento van toekomstverkenningen voor de zorgberoepen in de Vlaamse Gemeenschap. [An 'aggiornamento' of studies of the future for the care professions in the Flemish Community]* HIVA - KU Leuven. 2014. https://lirias.kuleuven.be/handle/123456789/525473

[133] Appendix to the Ministerial Decree of 10/12/2001 on quality care in residential care centres (Belgian Official Gazette 28.III.2002)

qualifications and training: the facility must employ adequate and professional staff to achieve its goals; the employees must have the qualifications needed for the jobs they perform; the facility is to develop a training policy for its staff members.

In general the staff in the ENNHRI monitoring are satisfied with the development opportunities or the offer of education or training. In some cases staff members declared that this opportunity existed 'only on paper' for them. They declared that they got many fewer training opportunities than colleagues, or even no training opportunities. The importance and added value of submergence sessions in care was regularly brought forward. During this submergence session, caregivers from the field are put in the role of care recipient. According to the staff members surveyed this has an enormous influence on respect for human rights of residents.

- ✓ *I can take the training I want, just as long as it is relevant for me or for the residential care centre. They have never yet refused training as far as I know. (staff)*

- ✓ *It seems as if I cannot take any training at all. My colleagues go for training with some regularity; for me it has been three years. Even the free training is refused for me. (staff)*

- ✓ *I am very flexible on this. As head of service I have even approved training in photography, on condition that that knowledge benefits our facility, of course. Now my employee can go with the residents to make photo reports and such. (staff)*

- ✓ *They should enter these submergence sessions in the standard curriculum for caregivers and assistants. When you have hung in a sit-to-stand lift yourself, you are very careful with the operation afterward; or you know how it feels to have to wear incontinence materials.*

The managements surveyed attached great importance to the qualifications of their staff. They state that they follow the standards, but confirm that the training policy in some cases could still be better.

- ✓ *Good care provision is about competence management: what talents are there in our residential care centre, in the different divisions? Can we learn from each other? How can we use those talents as well as possible?*

- ✓ *If you want to change your way of working, you should involve the staff. That is obvious, but unfortunately not always so simple. You have to guide and adjust, educate and train.*

Aside from the accreditation, regulating and standardising guidelines, there is also another instrument that should ensure the right to 'an adequate standard of living': inspection. For the Brussels residential care centre sector the GGC [*Joint Community Commission*] or the Flemish Community (care inspection) respectively is competent. In Wallonia the inspections fall under 'La Direction générale opérationelle des Pouvoirs locaux, de l'Action Sociale et de la Santé, Departement des Ainés et de la Famille – Direction des Ainés', or under the 'Ministerium der Deutschsprachigen Gemeinschaft, Abteilung für kulturelle und

soziale Angelegenheiten'. In Flanders, the Care Inspection of the Welfare, Public Health and Family policy area is competent.

As an example let us focus on Care Inspection in Flanders. To become and remain accredited, residential care facilities undergo inspections. All the information, model reports and inspection procedures can be consulted on the website of the Care Inspection involved.[134] All residential care facilities in Flanders that are accredited by the Agentschap Zorg en Gezondheid [*Agency for Care and Health*] of the Flemish government receive this periodic inspection (the aim is to inspect every facility every three years). The inspection usually takes place unannounced and tries in that way to get a picture of the daily operation in a facility that is as accurate as possible. Management and staff are surveyed. Depending on the reason for the inspection, there is a selection from a limited number of topics such as profile and number of users, infrastructure, facility services, staff, assistance and service provision, and treatment.

The facilities receive a report of this inspection and have two weeks to react. This report then goes to the Agentschap Zorg en Gezondheid. Here it is decided whether action should be taken based on the inspection report (e.g. with regard to accreditation, etc.). [135]

The many inspections and inspection rounds cause frustration in the sector, however. The main comment that was heard during the monitoring was: do the registrations serve to improve care, to enable work with higher quality, or to enable penalties? One manager summed up the inspections that he as a facility can and may expect: a check by the Rijksinstituut voor Ziekte en Invaliditeit [*National Institute for Health and Disability Insurance*], a food safety inspection, a social inspection, an accreditation inspection by care inspection and a topical inspection by care inspection, an inspection of the Legionella management plan, screening of the staff with the occupational physician and prevention adviser, etc.

- ✓ *The many inspections are established too much from a penalising perspective, too little from a guiding and supportive point of view.*
- ✓ *The inspectors check: the files, the registers, the documents that need to be filled in. They check all the technical things; it isn't just administrative. They don't check the satisfaction or happiness of the 'inhabitants'. There are no 'human' questions.*
- ✓ *The pressure for quality and inspection, with regard to human rights too, has made the care sector a registration sector. Is this a better strategy in striving for care based on human rights? You are monitoring and giving feedback all the time. That presents a challenge: what information, what data do you share with your care staff so that the rights of the residents are guaranteed? You can hardly communicate all the data because then their head will explode after the third resident.*

Other responses on an adequate standard of living

[134] http://www4wvg.vlaanderen.be/wvg/zorginspectie/inspecties/Pages/RUSTHUISenRVT.aspx

[135] http://www4wvg.vlaanderen.be/wvg/zorginspectie/inspecties/Pages/RUSTHUISenRVT.aspx

Resident

- ✓ My basic needs are met, no more, no less.
- ✓ You can't ask for more, there are just too few people working here for that.
- ✓ I have everything I need, food and drink, care and a roof over my head.

Family

- ✓ Very honestly, the food is very good here. We stay to eat here regularly and it is always well-prepared.
- ✓ The rooms are large enough, but apparently for the new regulations they must be even larger.

Staff

- ✓ You have to communicate a lot, actively listen to your residents and ask the question if things are as they want them. Actually it's simple.
- ✓ It can always be better. It can be better with the incontinence material; if the material is a little damp, we are supposed to put it back on. I don't agree with this and change it immediately. They let me do it; I don't get any comment on it.
- ✓ Time is too short to comply with all requests. We cannot respond to every request positively. It's not that we don't want to, but we can't. All requests can be made, just to be clear about it.

3.4.12 Education, training and lifelong learning

Our society has transformed in recent years into a knowledge and information society. Education, training and life-long learning are a necessary condition for participation in social interactions and for the active citizenship that is sought. Lifelong learning ensures the personal development and continuing involvement of the elderly. Lifelong learning is generally defined as 'any meaningful educational activity that has an ongoing nature and is intended to increase knowledge, skills and competence.'[136]

Residential care centres too are not exempt from this trend. As previously stated, demographic shifts and the democratisation of education have effects in the participation and input of the elderly in care policy and thus also in the demand for an opportunity for life-long learning in the residential care centre.

These opportunities are not guaranteed in every residential care centre. The activities offered are usually intended as entertainment[137] and are focussed on 'keeping busy', looking for an 'enjoyable daytime occupation' for the residents. Learning experiences are seldom offered. The learning opportunity for residents with dementia is also limited or nonexistent due to the limited effects and possibilities that this pathology entails.

[136] Leren een leven lang in Vlaanderen? *[Lifelong learning in Flanders?*] *M. Vanweddingen*, Studiedienst van de Vlaamse Regering [*Research Centre of the Flemish Government*], 2008, pp.6-7.
[137] The Flemish government is redefining the definition and role of 'facilitators' at this time.

- ✓ *I'm in my 90s now, but I would still like to learn to work with a computer. If they would offer it then I would do it. (resident)*
- ✓ *Teaching residents with dementia new things is difficult; often the issue is maintenance. (staff)*

In some facilities learning experiences are in fact explicitly included in the offer. Two facilitating factors are important in this: the presence of staff members who specifically focus on this is essential, and the presence of a Local Service Centre strengthens the offer. The content of the training sessions or learning experiences is very diverse. A computer class is offered (e.g. Skype so that they can communicate with grandchildren), language lessons or other learning opportunities.

- ✓ *We have several staff members who organise this; our occupational therapist is the driving force behind it. (management)*
- ✓ *The Local Service Centre is also established here and we collaborate intensively with them. They offer lessons and activities where we are also welcome with our residents. The possibilities are really very extensive, from wheelchair dancing to Spanish lessons. Really they provide a broad range of training sessions, lessons or information sessions that we cannot offer.*
- ✓ *You can study all day here if you want. (resident)*

Other responses on Education, training and life-long learning

Resident

- ✓ The older you are, the more you think you know everything. Only now do I realise that I really don't know anything. So I want to keep learning more, but that doesn't really happen here.
- ✓ They organise computer classes, Skype, you can take Spanish and English lessons…

Staff

- ✓ You must always try out new things with the residents, again and again, what works and what doesn't work. You always find an interest or challenge that they enjoy.
- ✓ We always work in small groups of 10 to 12 people and try to work in a rather focused way. That does mean of course that 20 residents don't do an activity at the same time. Then they say rather quickly 'there's nothing happening here'. Playing bingo is easier of course, sitting the whole department down together and calling out numbers. That is a choice you make as a facility.
- ✓ We can still teach our cognitively strong residents something, but not the dementia patients.
- ✓ There is no coordination between the Local Service Centre and our residential care centre. Not so many residents really take part in the activities or classes.

3.4.13 Redress and complaints

Life in a residential care centre doesn't always go smoothly. Somewhat over half of those surveyed in the Test-Aankoop magazine study 'Home sweet home' – mostly family members of residential care centre residents who are no longer independent – have experienced one or more serious problems at some time. In most cases this involved the daily help (e.g. washing the elderly person or helping him/her out of bed). Other frequently arising complaints involve inadequate medical information for the family and the administration of medications. The vast majority of those surveyed who have experienced a problem have discussed it with the care staff or – somewhat less often – with the management of the nursing home.[138] There are various organisations that residents, family, staff, management or others involved can turn to with questions and complaints. These results correspond in broad terms to the annual reports of the hotlines and information points concerned.

Hotlines and information points, in the plural. Many players are active, distributed over the various parts of the country. In Brussels we have Home info/Infor-Homes; the SEPAM (Service d'Ecoute pour Personnes âgées Maltraitées) and the Brussels Meldpunt Oudermis(be)handeling [*Elder Abuse Hotline*]. In Flanders the Vlaamse Woonzorglijn [*Flemish Residential Care Line*] is active, as is the Vlaams Ondersteuningscentrum Ouderenmis(be)handeling [*Flemish Elder Abuse Support Centre]* and other information points or advocates such as the Vlaams Patiëntenplatform [*Flemish Patient Platform*]. In Wallonia we find the Agence Wallonne de lutte contre la maltraitance en Cas Seniors asbl, etc.

In general it is accepted that the **residential care centre residents themselves** are seldom inclined to complain, out of fear that they will be neglected or even sent away and have nowhere else to turn.[139] We see this confirmed in the figures of e.g. the Woonzorglijn.

During our ENNHRI monitoring it was reported that in the event of questions or problems the family or the head of service of the department was first approached and then the management. It is important to note that in each of the facilities visited, information on the complaint organisations or information points was clearly posted.

- ✓ *I would tell my children or I would go to X, she is the head of service and I trust her. (resident)*

- ✓ *You have some information on the 'complaint line' (Woonzorglijn) lying at the secretary's office and there is a telephone there, so you can just ring if you have a complaint. (resident)*

- ✓ *We record our complaints in an electronic file and this provides real added value, we learn from this; what has occurred before, how did we solve it? You improve your organisation from complaints, so we take each complaint seriously. (staff)*

- ✓ *Most complaints we receive relate to the laundry (lost clothing) and the detailed care (shaving, nail care). (management)*

[138] Test aankoop/Budget en Recht [*Budget and Rights*] no. 227. Home Sweet home? Niet altijd! [*Not always!*] March – April 2013, pp. 8-13.
[139] Test aankoop/Budget en Recht [*Budget and Rights*] no. 227. Home Sweet home? Niet altijd! [*Not always!*] March – April 2013, pp. 8-13.

As an example, we take a closer look at the operation and the latest results from two hotlines.

The Brussels Elder Abuse Hotline

As previously indicated, the Brussels Meldpunt Ouderenmis(be)handeling [*Elder Abuse Hotline*] is the contact point for anyone in the Brussels Capital Region who is facing or suspects a situation of elder abuse. The target groups are primarily:[140]

- the elderly, at home or staying in a residential facility, who are the victim of situations of elder abuse, and their personal environment including family members, caregivers, friends, etc.

- professional environment: for a number of the elderly a support network already exists, i.e. home care (all cooperation initiatives relating to home care, health insurance, hospital, the OCMW [*Public Centre for Social Welfare*], service centres, day centres, etc.) or care/nursing staff within a residential facility/hospital. These assistants form the first intermediates for reaching the elderly.

- general public: not all situations of elder abuse take place in a care context. Thus the importance of reaching other parties who come into contact with the elderly, like socio-cultural associations, unions/clubs of retired people, etc.

We mention a few points for attention from the 2014 Annual Report of the hotline. The entire annual report and more information on the operation can be found on the home-info website.[141]

In residential care it is primarily families who contact the hotline when something goes wrong. But it appears that often people are afraid to report problems in a residential care centre out of fear of reprisals. Sometimes it is expressly asked that there be no intervention; people only want to report the problem.[142]

The hotline received 198 calls in 2014[143]. Of these calls, 59% deal with a situation of abuse in a residential facility; 20% deal with abuse in a home situation, 21% of the calls deal with another topic that relates to elder abuse, and 21% deal with various information.

The analysis shows that 30% of the calls come from the family; these are primarily reports about a residential facility. In addition we find that 10% of the reports are by the elderly person him/herself and 38% of the calls come from an external service provider/assistant. In 10% of the calls it is the management itself or a staff member who wants advice on a specific situation in the residential facility. The majority of the calls (21%) concern a complaint, 30% are requests for information, and 14% are repeat calls.

Flanders: residential care line

[140] http://www.home-info.be/v4.0/publicaties/jaarverslagen
[141] http://www.home-info.be/v4.0/brussels-meldpunt-ouderenmisbehandeling/wat-is-ouderenmisbehandeling
[142] Brussels Elder Abuse Hotline. 2014 Annual Report, p.2.
[143] Brussels Elder Abuse Hotline. 2014 Annual Report. pp. 13- 25.

The Woonzorglijn [*Residential Care Line]* gives information and advice and handles complaints on residential elderly care facilities in Flanders. Residents of these facilities, their families, friends or acquaintances, and staff too can turn to the Woonzorglijn with all kinds of questions and complaints about a residential care centre, rest and nursing home, service flat, short-stay centre or day care centre.[144] Below we present the most important features of the 2014 Annual Report of the Woonzorglijn. The full report can be viewed through the Woonzorglijn at www.woonzorglijn.be.

In 2014 the Woonzorglijn received 2152 calls, the majority (93.1%) of which involved information requests. Family members formed the largest group of contact persons (59.7%). In the complaint calls, which comprise 5.2% of the total number of calls, family members also take the lion's share, with a total of 7 out of 10 complaint calls.

Seventy-five percent of the complaints dealt with care, nursing, and service provision in the residential care centre. Most of the complaints reported dealt with the help and assistance that residents receive in the facility, the staffing arrangements, and the meals. After the complaints were investigated by the Woonzorglijn or by means of an onsite inspection, the majority of the complaints, namely 67.3%, appeared to be unfounded. Only 94 of the complaints, or 25 percent, were declared founded in 2014. Moreover, a complete solution was found for only 20 complaints. The remaining complaints were followed up further or partially solved. Thus on an annual basis only 5 percent of the complaints, founded and unfounded, were solved.

The founded complaints concerned primarily the help and assistance, the staffing arrangements, and the rights of the user. The drop in the number of founded complaints in 2014 (5) versus 2013 (13 complaints) with regard to the medication aspect is marked. Twenty-six complaints involved the meals. However, only five of these were considered grounded.

There is also a trend with regard to complaints formulated by staff themselves. We see an increase from 4.8 percent to 7.1 percent versus 2013, an increase of almost 50 percent. Consistent with this trend, we see a rising number of complaints on the staffing arrangements in general, from 36 complaints in 2013 to 49 complaints in 2014.

Other responses on Redress and complaints

Resident

- ✓ If I need a lawyer then I ask the staff. They arrange it.
- ✓ I go to the management and they should assist me legally.
- ✓ I wouldn't dare to do it, because how would I be able to pay for a lawyer? I think many of my fellow residents think of it the same way.

Family

[144] http://www.woonzorglijn.be/

- ✓ As long as there is no financial trickery or they don't abuse, legal assistance is not needed in a residential care centre.
- ✓ In the event of complaints, I would first approach the staff; they are also closest to the residents and they should solve these problems first of all.

Staff

- ✓ If the residents request it, we contact the justice of the peace or an attorney of their choice. It's completely possible.
- ✓ When legal assistance is needed, it often involves family matters or inheritances.
- ✓ The electronic complaint system is not yet fine-tuned; we still have to improve it.
- ✓ Registration of complaints is an added value for us, we learn from it: what recurs, how did we solve it? Complaints help you improve your organisation, so we take every complaint seriously.

Management

- ✓ If needed and desired, the justice of the peace comes to the room itself in the event of problems. They usually even come the same day!
- ✓ It's a question of making it known, and the social service immediately looks at what is possible.
- ✓ If residents need an attorney, they need only ask.
- ✓ Sometimes we have to manage what the residents no longer know how to manage.

3.4.14 Palliative and end-of-life care

- ✓ *I live today, not tomorrow. I have the impression that people now are more occupied with their death than with their life. (resident)*

Palliative care and end-of-life care are strictly controlled by regulations and standardisation.

Palliative care is defined by the World Health Organisation as 'an approach that improves the quality of life of patients (e.g. residential care centre residents) and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.[145]

The care here focuses on the wishes of the patient, where comfort-increasing care that does not delay or accelerate death, but is directed toward pain alleviation; treatment of all sorts of disorders, e.g. incontinence, respiratory difficulties, constipation, etc.; physical relaxation; rehydration and feeding of the patient; and reduction of undesirable side effects of treatments is primarily provided. In addition to medical and paramedical treatment a terminally ill patient also receives psychological support. [146]

- ✓ *Palliative care often involves comfort care. (management)*

[145] World Health Organisation (WHO) definition, 2002.
[146] www.palliatief.be

This means that palliative care:[147]

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling (if indicated);
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies.

Palliative care is possible in various places according to the wishes of the patient and his/her family: at home; in a specialised day centre; in hospital and … in a residential care centre. Residential care centres must therefore have an offer of palliative care, as was confirmed by the facilities surveyed. This could usually also be found in the info brochures and documents of the facilities. It is also possible for family members to take palliative leave or receive financial help to reduce the costs of palliative care.

- ✓ *They already put those papers in among the first documents you get from the residential care centre. I do find that odd and confrontational. (family)*

Euthanasia is the act of intentionally ending life by someone other than the person concerned, at the latter's express request.[148] In Belgium euthanasia is legally possible under well-defined conditions and according to a well-defined procedure. Euthanasia is recognised as the right of every ill person to choose life or death, insofar as he finds himself in the circumstances specified in the law of 28 May 2002. On 13 February 2014 a bill amending the law of 28 May 2002 was approved to make euthanasia for minors possible. The law says nothing about euthanasia for dementia patients.

Conditions[149]

Euthanasia can only be carried out if the following conditions are fulfilled:

- The written request is voluntary, considered, repeated and not a consequence of external pressure.
- The patient is in a medically hopeless situation.
- The physical and/or psychological suffering is persistent and unbearable and cannot be alleviated.
- The condition of the patient is attributable to a serious and incurable disorder caused by accident or illness.
- The patient is an adult of sound mind.

[147] www.palliatief.be
[148] www.gezondheid.be
[149] http://www.belgium.be/nl/gezondheid/gezondheidszorg/levenseinde/euthanasie

- The patient is a minor of sound mind and judgment. The psychologist or child psychiatrist decides on the capacity for judgment of the minor[150].

An important instrument is a 'living will'. In this document one can – as a person of sound mind - express his will with regard to the end of life and possible refusal of medical care, in the event that one is no longer capable of making his will known.

A living will is valid if it is:

- drafted according to a legally prescribed model form
- drafted or confirmed less than five years before the beginning of the legal incapacity of the patient
- drafted in the presence of two adult witnesses, at least one of whom has no material advantage in the event of death.

The living will can also indicate one or more trusted persons who if necessary inform the treating physician of the will of the patient. The trusted persons must also sign the form. The patient can retract or modify his living will at any time. In any event the living will is only put into practice if the patient suffers from a serious and incurable disorder resulting from an accident or illness, if he is not conscious, and if his condition is judged to be irreversible.[151]

Express request for euthanasia[152]

Aside from this living will, euthanasia is only possible at the express request of a patient who is still capable of expressing his will to die. That request must be recorded in writing, and it must be dated and signed. If the patient cannot draft the request himself (for example, because he is paralysed), a third party can do that for him in the presence of a physician.

During the monitoring all the facilities confirmed that they clarified such matters with the residents via early care planning – possibly via a palliative care reference person. We can regard early care planning *as a process of continuous consultation between the (future) patient and caregiver(s), focussed on clarifying someone's values and wishes with regard to his or her (future) palliative care (care at the end of life). These values and wishes are preferably also shared with family members and/or important relatives, with a view in particular to indicating an (appointed) representative.*[153] These data are put in the care file so that all those involved have the needed information. In most cases the early care planning has been discussed in the course of an evaluation discussion that the facilities have with the (new) resident after an average period of 4 to 6 weeks.

- ✓ *Residents often mention that themselves. If not, it is discussed in the 'early care planning'.*
- ✓ *Six weeks after admission there is a follow-up discussion, and everything is then discussed in the presence of the social service, the head of nursing, the palliative*

[150] 13 February 2014, Amendment of the law of 28 May 2002 (the euthanasia law).
[151] http://www.belgium.be/nl/gezondheid/gezondheidszorg/levenseinde/euthanasie
[152] Idem
[153] www.palliatieve.org

care reference person, the family and the resident himself. In 50% of the follow-up discussions the necessary documents are put in order.

In some cases the residents stated that they had not yet discussed this, not with the family and not with the residential care centre. In several cases the residents had already made the necessary arrangements before admission to the residential care centre. Most residents discussed it with the residential care centre via the palliative team, the palliative manager or palliative care reference person, or other channels (head of service, etc.). In some facilities the family was actively involved in this care.

- ✓ *I assume that my children will decide all of that. (resident)*
- ✓ *I went to the city hall, had papers drawn up for euthanasia; they have that file here too (in the residential care centre) and my administrator also has a copy, so all of that is settled. (resident)*
- ✓ *I discussed that with the palliative manager and my wishes have been written down. (resident)*
- ✓ *We teach the family hand massage. This provides a specific activity during the often difficult moments you go through. This way you also make physical contact; that is important. (staff)*
- ✓ *Anything is possible in palliative care; 'the sky is the limit'. (management)*
- ✓ *Questions on euthanasia can be asked and are answered. We start from the welfare of the resident and go along with the story of the resident or the family as long as the medical and ethical boundaries are not exceeded. (management)*

Other responses on palliative and end-of-life care

Resident

- ✓ I haven't thought about it yet. I still feel so good too, all of that seems not necessary to me yet. We will settle that when it's needed.
- ✓ I have settled that with the funeral director. The residential care centre knows about it.
- ✓ Several weeks after my admission I had a discussion with the head nurse and the palliative nurse. They asked all of that then, what I want and what I don't want.
- ✓ In this residential care centre they keep a sort of 'life dossier' per resident; all of that is in it. I also had everything recorded, that's already all decided.
- ✓ I brought that up myself during a consultation with the nurse. She took care of the necessary papers then together with my children and the doctor.

Family

- ✓ In the transition from the service flat to the room that was not discussed, but when he was rather ill and it didn't look good for a while, we did receive a letter about that from the palliative services. Now that is all settled.

- ✓ My partner doesn't want to discuss that. As a result of the discussion we had with the palliative team of the residential care centre, I have arranged papers for myself. My partner doesn't want that, that is clear.
- ✓ That is discussed in a very respectful way. A weight fell from my shoulders when those documents were in order.
- ✓ That has been discussed with the doctor, the head nurse and the social service. Very respectfully and clearly.
- ✓ My father-in-law doesn't want to go to the hospital anymore, he wants to die here. He is aware of what he's doing and what he is going through. He wants to die more quickly. We're happy with his choice.
- ✓ There are no defibrillators in this residential care centre; I do find that bizarre.

Staff

- ✓ Euthanasia is a personal decision, except for dementia patients; as soon as someone is diagnosed with that, it's not possible anymore.
- ✓ Euthanasia is only possible for an irreversible coma. We discuss that with the resident during an evaluation discussion. We put everything on paper; the family is involved, and the general practitioner.
- ✓ You do notice that this is always a major decision for the doctors too.
- ✓ We do as much as possible for comfort care and involve the family in it too – if they want that.
- ✓ Some don't want to talk about it with us, others give us all the information so that we can take care of the end of their life.

Management

- ✓ You have to be very attentive with regard to these requests. There are few residents after all who explicitly say 'I want euthanasia'. What you do hear very often is 'I don't need any of this anymore.' You have to recognise and acknowledge this correctly; perhaps the grandchildren or children didn't come by this week, is this part of it, or something else? You have to be able to assess this well and that is not easy.
- ✓ We have a multidisciplinary steering committee that discusses these questions. Every request is heard.
- ✓ We hold an evaluation discussion and then we discuss this: what are your wishes and expectations; what are your treatment guidelines? Then we split the process in two; the administrative and regulatory aspect on the one hand and the communication and care aspects on the other hand.
- ✓ I do wonder about it quite a bit sometimes. For whom is the right to self-determination? For the resident or for the family?

3.5 Extra: Findings on staff relations and rights

On the basis of the observations during our monitoring we can state that the majority of the care staff in residential care centres work hard every day to provide good care and to fulfil the residents' expectations and quality requirements. The staff members surveyed are also of the opinion that their rights as staff are in general well respected. But due to the rising

workload, the increasing regulation and the increased administrative burden, this often comes under pressure. The care becomes more difficult, but at the same time care workers must provide care with fewer colleagues.

- ✓ *In the care sector you must first of all be able to work quickly, the pace is fast. (family)*
- ✓ *The head of service sits doing the administration in the secretarial office all the time, and the rest of the team are also constantly making notes and recording. Those people can't provide care, they have to write or type all the time. (family)*

We already mentioned this in section 3.4.11 'An adequate standard of living', where a study by the KU Leuven on the financial viability of Flemish residential care centres shows that the average residential care centre has a deficiency of 1.28 fulltime employed equivalents (FTEs) of financed care staff per 30 living units. In care of the elderly in particular a great need will arise; on the one hand there are the staff who retire and must be replaced, on the other hand the number of the elderly needing care is also rising. In five years a new and increasing gap will become apparent between supply and demand. Until 2020 the gap stays closed, but as of 2025 the demand definitely rises faster than the supply.[154] The study recommends working further on the influx in care professions, in combination with an integrated policy that takes account of the future scarcity of manpower in each measure.

In addition, staff diversity in the care sector is high. Not only do job seekers with a migration background enter this sector faster, it is also a sector where four generations of caregivers/assistants provide care to several generations of care/assistance recipients, and where intergenerational cooperation is a necessity. Furthermore we note that primarily women are active as caregivers or assistants; men seem to find their way to care professions in residential facilities less quickly.

- ✓ *The young generation are more occupied with their schedule than with giving care. (staff)*
- ✓ *If you hire older employees, you have a better chance of a success story. They know what it means to work in a care environment, what it requires from you physically and psychologically. (management)*
- ✓ *The system of age-related leave days is advantageous but unfortunately also has drawbacks; for every hour less that an older staff member works, a younger staff member must work an hour more. That demands intergenerational cooperation. (management)*
- ✓ *For me the perfect team consists of various personalities of both genders and of various ages.(management)*

The right to education, formation or training - as also specified by the regulators[155] - seems to be guaranteed for most staff members, although we hear a dissonant voice here and there.

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[154] Pacolet J, Vanormelingen J. and De Coninck A. *Tempus fugit: Een aggiornamento van toekomstverkenningen voor de zorgberoepen in de Vlaamse Gemeenschap [An 'aggiornamento' of studies of the future for the care professions in the Flemish Community].* HIVA - KU Leuven. 2014. https://lirias.kuleuven.be/handle/123456789/525473

[155] Appendix to the Ministerial Decree of 10/12/2001 on quality care in residential care centres (Belgian Official Gazette 28.III.2002)

Thus the facility should develop a formation, training and education policy for the staff. Every staff member, except for the maintenance and kitchen staff, takes at least 20 hours of continuing education over a period of two years maximum. Management must take eight hours of extra continuing education annually.

- ✓ *I think that we can take a lot of training, but that is legally regulated, I think. (staff)*
- ✓ *There are colleagues who have already taken care submergence sessions, but I have never yet had that offer. (staff)*
- ✓ *I am convinced that we would do our job better if we knew more about these human rights. Training would be useful. (staff)*

The personnel policy was often one of the greatest concerns of management, both in looking for suitable staff and in daily management of personnel matters. The social recognition of care professions also leads to discussion and frustration. Despite the fact that most staff members think that they are properly paid (with regard to the financial compensation we note a difference in the answers between the communities: in Wallonia the staff are more dissatisfied with their compensation; in Flanders more satisfied), they express their dissatisfaction with society's appreciation of their work. Staff also often cited the too-great distance between management and the workfloor. Heads of service mitigate this account; they clearly experience less of a gap between the hierarchical levels.

- ✓ *There is little respect for residential care centre employees in our society. We are seen a little bit as failed hospital staff. But that image is wrong. (staff)*
- ✓ *There is a negative atmosphere around a residential care centre; it's not an attractive employer. You notice that already at college; fellow students don't understand that you consciously choose a residential care centre and not the action of the surgical ward in a hospital. (staff)*
- ✓ *As management I am constantly occupied with the wellbeing of the employees. I can't do otherwise; there are so many rules and procedures that I spend a gigantic amount of time on it. It is no longer in proportion; the 'regulitis' takes on absurd proportions. (management)*
- ✓ *In our recruitment and selection discussions that is something that we highlight; we strive for a very good balance between private life and work. After all, we want to generate long-term employability. (management)*

Other responses on staff relations and rights:

Resident

- ✓ You have quite a few staff members here who are clearly working reluctantly, that really stands out.
- ✓ The night team is chronically understaffed; don't the managers see that too?
- ✓ I think that they are entitled to some more colleagues.
- ✓ I haven't yet seen the staff here sitting on a chair often; they don't have the time for that.

Family

- ✓ The staff changes internally rather often here; they switch departments regularly. They don't want people to get stuck in their job or habits. Sometimes this is a shame; after all, you develop a bond with some staff members. Unfortunately I have the impression that the good workers all change and the poor ones stay.
- ✓ I have been coming here for 21 years (!?). At first I came here for my grandparents, but some time after their deaths I had to have my mama admitted here too. The change is very noticeable. Earlier it was all somewhat looser, maybe somewhat more lax, more mistakes did occur. Now it sits on the other end of the spectrum; much more control and rules, but also therefore much more administration and much less time for care provision.
- ✓ There should be a better male/female distribution. There are far too many women and far too few men.

Staff

Recognition

- ✓ I'm proud to work here; I always say that to others too.
- ✓ If you don't like working here, then you don't stay. The job is really too hard for that and your work is not rewarded.
- ✓ There are nurses in my team who earn more than I do as head of service. They get something extra if they do a night shift or work on the weekend. As head of service you get no bonus, but you can be called or consulted every weekend. That's part of the position, they say.
- ✓ As head of service you are entitled to a car in this residential care centre.
- ✓ The doctor listens to us. He checks, uses our info and takes up for us if needed.
- ✓ You notice that the residents appreciate your work, you really feel that.
- ✓ I feel really valued for my work by the managers.

Hierarchy

- ✓ We only see the managers when there is a problem. But it seems to me to be useful and necessary to just walk through here, have a chat with staff and residents.
- ✓ There is quite a lot of distance between the staff and the residents on the one hand and the management on the other hand. There are residents who don't know who the management is.
- ✓ The management should consult us somewhat more on changes.
- ✓ The managers should work a week in every department. They are rather out of touch with the workfloor sometimes.
- ✓ A 'Good morning' costs no money and can mean a lot for staff satisfaction.
- ✓ They can keep their annual fruit basket; a little compliment from time to time would be nicer.
- ✓ They expect you to be flexible, but the organisation is also flexible

Employee relations and working conditions

- ✓ Quite a few experienced staff members have left here for retirement. That offers opportunities to make a fresh start, but you also put an enormous amount of time into guiding and training the new staff. Not all my colleagues are suited to work in a residential care centre, but they do all have ability, and we make use of that.
- ✓ What do I look for in my colleagues? I look for openness, collaboration, having the same commitment, wanting to offer quality.
- ✓ As a nurse you also have many care tasks and administration. The care providers give care, period.
- ✓ I think that the occupational therapists and physical therapists in this residential care centre have a very easy job. Working without stress and earning well, that's how I see it.
- ✓ The work usually follows the same routine. There's not a lot of variation.
- ✓ A shift is not a shift, strictly speaking. It always runs over somewhat; you're working with people and not with machines, after all. You can't just turn them off for a while.
- ✓ The on-call nursing is a terrible shift. You give pills the whole time throughout the various departments, seven hours at a time. In the evening you take a pill yourself for headache.
- ✓ Because of the small-scale normalised living, I will be working as a nurse in the entire residential care centre. I chose this job because of the close contact with the residents. Now I will be a stranger to these people. The job will become more technical and less human.
- ✓ There are a lot of managers here, but few helping hands.
- ✓ Of course they ask me to cook on a budget, but I think that happens in very many families too, at least that's the case at my house.
- ✓ There is a childcare centre connected with the residential care centre; as an employee you appreciate that.
- ✓ Connecting a childcare centre with the residential care centre would solve a lot of practical problems for the staff.

<u>Evaluations and adjustments</u>

- ✓ 360° evaluations would really be something for our sector: your manager(s), your colleagues, doctors, the residents and the family. Then you have a proper picture of your employee, I think.
- ✓ We are very conscientiously occupied with our tasks and are followed up in that. We get feedback from our head nurse or from colleagues during team meetings. That's how it should be, too; after all, you learn from each other
- ✓ The staff rotate within the department here, so you come in contact with other residents, you get to know different techniques, different colleagues. You come out stronger as a caregiver.
- ✓ As a cook you have the final responsibility. The food must be good and it must look good, period. You are judged on that. If you can't provide that, then maybe you haven't chosen the right job.
- ✓ As a staff member you are entitled to clarity. If you want to offer high-quality care, you must coach and support your co-workers non-stop.

<u>Education</u>

- ✓ I learned during the submergence sessions to just go and say that you heard the bell and that you will come and help a bit later when there is a call signal. The resident knows that he will be helped and you can finish your other task without stress.
- ✓ Submergence sessions seem useless to me, I don't have to feel what the other person feels to do my work well. Does every doctor test out every medication he prescribes?

Management

Contact and accessibility

- ✓ My door is always open; they know that.
- ✓ As a manager you must be on the workfloor every day; staff and residents must know you, you must be approachable.
- ✓ I work the whole morning every day somewhere in a department; that way you get a good view of the ins and outs of that department.
- ✓ If I as manager come to a department, that should not be seen as an inspection. If I come to inspect, then I say so; I call it such.
- ✓ Management is always visible, in other residential care centres, they hide in their offices.

Wellbeing and personnel policy

- ✓ We have had psychosocial surveys done; now we work with transversal working groups and we hold performance interviews. That seems important to me.
- ✓ The staff here are a priority; our services are after all provided by people, not machines. So 'absenteeism discussions' are held if we notice that people are frequently ill or always absent at certain times, e.g. in holiday periods. Why are you absent often? What are the reasons? Can we change something in this? The combination of family and work is a frequent reason. As an employer you must seek solutions, appropriate solutions per staff member.
- ✓ The issue of burnout is too often considered purely professional. This happens with us frequently. We have many caregivers on our workfloor who are in a constant care situation, both here (at work) and at home, after all. Combine this with the low wages that characterise the sector, and you have a perfect breeding ground for burnout. For just that reason we focus very much on part-time work.
- ✓ We often have to urge our caregivers to take that little extra step. Naturally we shouldn't generalise too much, but still.
- ✓ I am very flexible with personnel requests and attempt to fulfil them when possible. As compensation I want no union representation, they know that.
- ✓ The job description of our heads of service is too broad, much too broad. I realise this as a manager, but I don't have many alternatives.
- ✓ To guarantee good overall operation of your residential care centre, your heads of service should put a high value on collegiality. They must support each other, take over tasks, and give advice. If this isn't possible, then it is impossible to implement a decent care policy.

- ✓ The challenge is to involve our people in the vision of the residential care centre, in work procedures that can eliminate difficulties, in convincing as to why. Change is difficult; I experience that every day with the staff.
- ✓ Our staff members follow the required training, but can also follow education of their choice. In the care sector you have primarily a horizontal career path after all; you must take account of that if you want to motivate your staff. Therefore nurses and caretakers can advance via training to have final responsibility for certain matters (palliative team, incontinence material).

Intake and recruitment procedures

- ✓ During the first introductory round I give applicants a tour and see how they deal with the residents. You can learn knowledge and expertise, you have or you don't have a good basic attitude. Often people come to apply with a negative attitude; I can't work in a hospital, so I'll just go to the residential care centre.
- ✓ I look for feeling and love for people in applicants. We teach them technical expertise ourselves.
- ✓ In recruiting we look for long-term commitment. Selecting for vision can help in this: why and how do you want to work in a residential care centre? Why do you choose our residential care centre?

Conclusions

Conclusion 1: Key challenges

Implementing a Human-Rights-Based Approach in Residential Care: Key Challenges

The care sector is not in an era of change, but in a change of era. The sector is at a crossroads. On the one hand accessible, affordable, but also high-quality care based on human rights is sought after. On the other hand, an attempt is being made to find an answer to the demographic evolution that can catapult the cost of care to new heights. These budgetary concerns and the developments in care supply and demand point to the importance of intra- and transmural collaborations, of a coordinated approach to high-quality care and assistance provision tailored to the individual (older) care recipient. Some residential care centres have already taken steps toward this; others have yet to start.

To ensure a human-rights-based approach in residential care centres, we detect the following challenges on the basis of the monitoring:

Informing the citizen of his rights as a person in (residential) care

Present and future residents of care facilities should be thoroughly informed of their rights in care. This involves not only the 'cure' aspect, but also the 'care' aspect. An informed care recipient can guarantee his own rights in a negotiated care relation or have his rights enforced by third parties. In this way a citizenship approach to care can be facilitated. This is not just a task for policy, but also for the broader civil society and for the facilities themselves. The single-window principle for all aspects of residential care can be brought forward in this. It is primarily important that the implementation and observance of human rights is continuously monitored and that the public are informed of the results.

Eliminating entry barriers for target groups

On the policy front, all entry barriers should be levelled via a transversal approach to the care offer. At this time there is still a distribution of those who have a free choice and access to the residential care centre and those whose opportunities are limited or cannot make use of it at all. There are still a number of obstacles to equal access to residential care for the elderly, which due to an accumulation of factors is and remains inaccessible for certain target groups (such as e.g. the elderly in poverty, the elderly with a migration background, older LGBs, couples and spouses, etc.). All authorities must include these target groups in their care policy so that freedom of choice and equal access to high-quality care are ensured for everyone and not just for the greatest common denominator.

A vision of human rights in theory; application of human rights in practice?

The many standards and rules specified by government and/or care providers that are supposed to guarantee the quality of care - and the observance of human rights - do not always allow for implementation. Good care is relational care, the experience that people have. Whether or not residents have the feeling that they are treated as a citizen (and so with

respect for their civil and human rights) depends primarily on practice, not on any vision ‘on paper’ of the facility or on the ‘administrative registration’ of the observance of their rights. In striving for a verifiable human rights approach, the ultimate goal often fades: providing older residents with high-quality care based on human rights. It is necessary to acknowledge/recognise the important role of a board of directors of the facility. They should provide the overall framework within which the facility must ensure the human rights approach. The voice of the older resident is also not equally loud everywhere; input and participation should be a priority.

Countering a phased violation of rights

During care provision, the risk of - consciously or unconsciously - sliding into a (negative) spiral where the rights of care recipients are increasingly trampled underfoot can very quickly arise. These are often small ‘undesirable’ steps in care provision that increase the risk of a human rights violation. This involves a (usually) stepped but structural situation of constantly deficient or undesired care provision in which residents run the risk of a violation of human rights. Each separate step or action is not in itself immediately inappropriate or an infringement of rights, but if we assess all these steps in a care process we quickly arrive at elder abuse in place of a human rights approach to care. People slip, as it were, into unacceptable behaviour. It forms a challenge to the entire facility to be attentive to this and to intervene as quickly as possible. A clear and frequently communicated framework is necessary, monitoring of employees essential.

Learning, teaching, training

In our society (human) rights are of more and more importance. Citizens of all ages are beginning to demand their rights, in care relations too. It goes without saying that care and assistance providers must pay attention to these rights and must respect them. Providing high-quality care to the vulnerable elderly is however a profession. Gaining knowledge and learning skills with regard to human rights is therefore a basic condition (and basic right) for caregivers. An inclusive approach to human rights in basic care and assistance provision training is a necessary starting point. Additional education and training for caregivers and care participants who are already active in the sector is essential.

Collaboration inside and outside the facility

A major challenge in ensuring a human rights approach covering the requirements in residential care for the elderly lies in the collaboration between those involved, both intramural and extramural.

A multidisciplinary and transversal collaboration between the various care and assistance providers within the residential care centre ensures a holistic approach to the individual care need. Such a multidisciplinary vision of the demands and wishes of the older resident can to a high degree ensure respect for the stipulated human rights.

Local embedding and involvement is a second point for attention. The residential care centre should not be a ‘care island’ in the local community, but a care hub with tendrils to the local or regional offer of activities, services and care provision, in which residents and staff go outside the residential care centre walls and where the local community is brought inside.

Regional collaboration between various residential care centres can further bring about the spread of expertise and the implementation of good practical examples with regard to human rights. This collaboration can include structural aspects as well as actual collaboration and exchange between staff members or a regional implementation of functions and assignments.

Conclusion 2: Findings and recommendations

Findings and recommendations at the European level

- **All competent authorities and participants should implement and observe in its entirety the European charter for the rights and responsibilities of older people in need of long-term care or assistance.**

- **Set up a body to ensure fundamental rights (of the elderly) are respected or reinforce the capacity of existing organisations in terms of fundamental rights.**

To ensure the fundamental rights of elderly people are respected in all care homes, a body must be set up to establish targeted sanctions if these rights aren't respected. Existing bodies must be reinforced so that they have the capacity to ensure the fundamental rights of elderly people are respected.

- **Highlight the work of nursing homes that set up actions and practices that respect and favour the access of elderly people to fundamental rights**

This reward can come in several forms (financial, label, etc.).

- **Information and awareness campaigns on the human rights of the elderly**

The elderly, both those of today and of tomorrow, must be repeatedly informed of their rights in care via targeted information or awareness campaigns that (also) address a broad public. Voluntary caregivers, family members and by extension the entire environment of the care recipient too should be aware of the basic rights of the elderly. This should also be cited in the documentation and info brochures that the residents or the family receive upon admission.

- **Implement a consistent approach to the citizenship model of care**

A paradigm shift from a medical model of care (the patient) to a citizenship model of care (client and citizen) should be implemented promptly so that every person can design his or her customised care and service provision with respect for human rights. All the care participants involved should make a contribution to a supported approach to ensuring the citizenship model in care for the elderly.

- **Give priority to attention to discrimination on the basis of means and to the affordability of long-term care and residential care**

The affordability of care should be given priority in the offer and in regulations by the respective authorities. The often precarious situation in which older care recipients find

themselves should not be exacerbated by financial barriers. Especially when we take account of target groups that are subject to a combination of care risks, this can be an insurmountable barrier. The risk of discrimination on the basis of means may also be facilitated by all kinds of regulations, standards, habits and customs. Constant attention to this risk, or a so-called 'poverty impact assessment', must be transversally included in the care policy.

- **Attention to age discrimination and multiple discrimination**

Age is often a determining factor in care. In just as many cases it is used as an exclusion criterion. All the authorities involved must base their care policy on the care and assistance request of the applicant, not his or her age. Moreover, both the care recipient and the caregiver can be subject to various discrimination criteria that exclude them from basic rights. Multiple discrimination and cross discrimination therefore require a comprehensive approach, with special attention to the voice of the older notifier, who often does not find his way to official bodies.

- **Emphasis on training and education**

Providing high-quality care to the vulnerable elderly is a profession. A human rights approach in care should therefore be included in the standard curriculum of care education. Education is focussed primarily (thus not always and everywhere) on the technical aspects. A human rights approach in practice requires that this principle be included in training and education. A thorough knowledge of human rights and the necessary skills to implement this are paramount.

Staff who are already working in the field are entitled to and need additional education and training with regard to human rights. During this on-the-job training, specific practices will be shared and tested against theory and experiences with regard to the human rights of residents and care recipients. In doing so, a deeper understanding and application of human rights will be achieved in the respective facilities. 'Tell me and I forget, teach me and I'll remember, involve me and I learn'. It goes without saying that here we have in mind not only the care-giving staff, but also the service staff and management of facilities.

- **Make staff aware of the risk of a shift in care provision**

In general it can be said that in the residential care centres visited a human rights approach is pursued. During the monitoring however we could note that an infringement of rights in care can take place very quickly. This often involves small 'undesirable' steps in care provision that increase the risk of a human rights violation. Each separate step or action is not in itself immediately inappropriate or an infringement of rights, but if we assess all these steps in a care process we quickly arrive at elder abuse in place of a human rights approach to care. Vigilance over and modification of care activities are therefore necessary and should be undertaken by the whole care team. Guidance programmes should be established for this.

- **Increase the inspections and controls regarding the quality of care**

Allow residents to give their opinion on human rights aspects; rather than just a purely technical inspection, check care relations and check whether residents do indeed have

access to rights. It is important moreover that user friendliness and low regulatory burden for staff and management are included in every requested registration of quality and care.

Additional findings and recommendations on the national and/or regional level

- **Establishment of a national human rights mechanism**

Although our country has a number of bodies - at the federal, community, regional and inter-federal level - that are involved in the field of human rights, Unia believes that there is an urgent need to establish a national human rights mechanism. To establish such an institute with an A status, civil society and the various federated entities must first be consulted. The federal government must fulfil its promise and thus put plans on the table as soon as possible to design that long-awaited institute.

- **State of health**

In the Antidiscrimination Law the criterion '*current or future* state of health' is cited. Taking into account the ageing of the population, a reference to the 'current or future state of health' is in the experience of Unia too limiting and takes no account of the state of health in the past. It seems necessary to harmonise and broaden the protected criterion to the 'state of health' (in the past, present and future).

- **Set up local roundtables to develop adapted policies for the elderly**

  - Make people aware of the reality, needs and expectations of elderly people;
  - Encourage the consultation of local players and partners;
  - Provide incentives and encouragement to ensure the success of projects carried out with partners, aimed at improving the quality of life of elderly people;
  - Achieve a common goal, through countrywide mobilisation to work on problems specific to elderly people.

- **Taking into account the specific difficulties of elderly migrants and calling on the authorities concerned to guarantee them equal access to their rights in law and in practice.**

    - Considering demographic change and new migrations, Unia recommends taking into account the heterogeneousness of the "elderly migrant" group, since the realities of every group is unique and strongly conditioned by the circumstances of their immigration. The aim is to gain increased knowledge on the actual needs of these ageing immigrant populations, which are increasingly isolated, especially among women. Unia suggests carrying out more censuses that are more precise, studies that are more focused on their state of health (victims of early ageing, strenuous occupations and subsequently exposed to various conditions and diseases such as diabetes, high blood pressure, depression, etc.). By knowing more about elderly migrants, it would be possible to take into account certain inequalities and traumas linked to exile (shame of not being able

to return to the home country, impression of being useless, feeling empty with no work identity, discrimination, exclusion of certain public and private spaces, etc.).

- Unia recommends developing tools to make information accessible to elderly migrants. This means targeting people who don't have a good command of the language (or none at all) and who don't know their rights.

- Unia recommends encouraging the use of interpreters or intercultural mediation in order to provide quality care in establishments. The access to rights and services for elderly migrants could thus be facilitated. Being able to communicate in one's mother tongue reassures and establishes a certain level of trust. Faced with illness and long-term care, migrants must be able to understand the treatments and care in their own language and be supported in their suffering and questions concerning end-of-life issues.

- For the free movement of elderly migrants, it is important to review the authorised period of stay abroad, currently limited to 29 days, thus eliminating the suspicion of fraud that weighs upon immigrants who travel back and forth.

➢ **Recommendations regarding adapted care for ageing people with a disability**

In an effort to provide an adequate response to the needs of ageing disabled persons[156], the study performed by the 'Observatoire de l'accueil et de l'accompagnement des personnes handicapées' provides a series of recommendations.[157] Unia supports these recommendations.

- On the one hand, the answers must be individualised in order to take into account the person's specific needs, and there must be a diverse offer of places to live: keeping the person at home, keeping the person in residential or care structure, creating places in centres or residential establishments for elderly people with a disability, creating specific projects in care and nursing homes, development of sheltered housing, etc.

- On the other hand, collaborations between the disability sector (specialised services) and the care and nursing home sector must be developed according to different perspectives: training staff in care homes on how to communicate with people with a disability; sharing the care of disabled people between a care home and a specialised day centre, or monitoring by a specialised support service, etc.

- Furthermore, the scales used to assess the level of dependence in order to qualify for aid from the healthcare fund, must imperatively take into account the requirements in terms of support and care specifically needed for the care of a person with a disability.

[156] It is important to remember that a retirement home isn't a place of residence adapted to a young disabled person. The recommendations given below only concern ageing disabled persons or persons with geriatric conditions.

[157] Study by the 'Observatoire de l'accueil et de l'accompagnement des personnes handicapées', Cocof, p. 40 and ff.

- Fourthly, places for ageing people to socialise and engage in leisure activities must be developed in order not to reduce the intensity or the frequency of social relations once the disabled person has been placed in a care home.

- Finally, a system to identify the number of people with a disability in care homes / nursing homes must be set up so that these people are known to administrative and private services specific to the disability sector, and can benefit from the support and aid that these services offer.

XXX

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