Human Rights of Older Persons in Long-term Care:
German National Report

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1. Introduction

1.1 Research rationale and main question

About 20% of the German population is now over 65 years old. This demographic development means new challenges to the national system of professional nursing care or, in German, *Pflege* (care). In the last twenty years the proportion of older persons in need of care has increased by 30% and constitutes about 2.6 million people (as of 2013, https://www.destatis.de/DE/ZahlenFakten/GesellschaftStaat/Gesundheit/Pflege/Pflege.html) Residents of care homes make up about a third of this population (700 000 – 800 000 people); a majority of them belong to the older old age cohort (over 80 years old) and have significant difficulties with the activities of daily life. Politicians, economists, gerontologists and other experts argue that the current system of German care provision needs to be reformed profoundly in order to respond adequately to this rapidly increasing demand. In particular, care critics suggest that a stronger human rights approach needs to be implemented in the long-term care (LTC) setting. Although the national care watchdog, the Medical Advisory Service of Social Health Insurance (MDS) reports a steady increase in the quality of services provided in residential care, cases of elder abuse are still a tangible problem in many institutions.

At the moment, there is still no exhaustive legal, political or educational framework for facilitation of human rights in residential care. Hence, the first goal of our study is to establish how various actors involved in the care sector – from managers to care recipients – conceptualise human rights in their own terms. What do people understand by human rights in care? What aspects of human rights are addressed as particularly relevant for life in nursing homes? The second goal is to find out how this existing knowledge is being implemented into daily practice. What instruments are being used to secure the dignity and human rights of LTC residents? What kind of organisational empowerments and constraints may affect the implementation of human rights perspectives in nursing homes? And last but not least, what can be done in order to facilitate human rights in the long-term care setting?

The empirical findings presented in Sections 4 to 6 will be preceded by an overview of German domestic legal and public debate on human rights in the LTC setting (Section 2). This discussion will serve as a context for analysing the material we have gathered, and as a basis for recommendations we draw up in Section 7.

1.2 German Institute for Human Rights (GIHR) Mandate in Germany

The GIHR is Germany's independent A-accredited national human rights institution, founded in 2001. It contributes to protecting and promoting human rights. The Institute promotes the integration of human rights into domestic and foreign policy decisions and monitors the implementation of international and European human rights treaties in Germany. Its tasks include providing policy advice, applied research on human rights issues, human rights education, dialogue and co-operation with national and international organisations, documentation and information. Since 2009, the Institute has also been in charge of monitoring the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD). Since 2015, the Institute has received the mandate of monitoring the implementation of the UN

Convention of Children (CRC). Nevertheless, the GIHR is not an ombudsman institution and has no mandate to deal with individual complaints on human rights violations.
The GIHR has acquired a reputation for independent, critical and objective research and advice as well as being a unique and comprehensive service point for fundamental and human rights information on Germany. Through expert meetings and public conferences as well as joint research projects, it has established good working relationships with a wide range of both state and civil society actors as well as academia in its areas of activity and beyond, upon which it can draw for further or advanced information and external supplementary expertise. In 2006 the Institute started its work in the field of care. In addition, the GIHR has always integrated a European perspective and its impacts upon German legislation, jurisprudence and policy. Nonetheless, the GIHR has no mandate and has no powers to access places to investigate cases of reported human rights violations and the mandate excludes access to accommodation and documentation. Therefore we could only access care homes that invited us to come.

2. Developments in Implementation of Human Rights Perspective in German Long-Term Care: Overview

2.1 Foundations of a human rights approach to care

For a human rights approach the policies and laws must be in accordance with the existing human rights obligations of the state. Actions and strategies must take human rights into consideration. The human rights-based requirements are also a yardstick for providing good long-term care. In addition to human rights – such as the right to health, water and sanitation, to food or the prohibition of ill-treatment and deprivation of liberty – the state should also take into account human rights principles such as equality and non-discrimination, participation and inclusion. The foundation of human rights is human dignity. All human beings are born "equal in dignity" (Article 1 of the Universal Declaration of Human Rights). Human dignity must not be earned; it is not linked to a performance concept and is entirely independent of the individual performance of a person - regardless of their need for support or potentially having dementia disease.

Germany has committed itself to implementing human rights through ratification of various human rights treaties. Hence, the state has to fulfill its duty to respect, protect and guarantee human rights for all persons living in its jurisdiction. This means the state must act to respect the human rights of persons in need of care and protect these persons against injuries by third parties (for example, support staff and private nursing homes). All in all, the state is obliged to provide a framework for dignified care. Because human dignity forms the mandatory legal and political basis for integrating a human rights approach into care, human rights and principles must be considered at all stages. For individuals to exercise their rights in full, the state is required to maintain a legal framework and complaints bodies or trials to give its citizens full access to justice. Consultation with civil society also plays a role in ensuring a human rights approach to care. The implementation of all reforms, the review and evaluation of care policies must be measured against human rights and their principles.

The legal character of human rights is based on individual approach; it fosters a paradigm shift through empowering vulnerable groups (such as old people) to become right owners, and not mere beneficiaries. Applied to nursing care, the human rights approach encompasses not only the rights of those needing care, but also the rights of care workers, in particular, their right to just, safe and healthy working conditions. It enables individuals to actively engage and participate in the shaping of policies and rights that sustainably affect their lives and work skills in care.

2.1.1 The human rights framework

Anchored in the concept of dignity, human rights set out to protect every human being. Internationally recognised human rights standards and principles, as contained in core international human rights treaties, encompass and protect older persons. Despite this tacit protection, it has increasingly been argued that there is a gap in the international human rights system because there is currently no specific universal human rights instrument on the rights of older persons and there is no specific right included which covers the right to care. Whereas provisions for some categories of vulnerable persons such as women, children, persons with

disabilities and migrant workers have been made, older people have not yet been considered as a specific group. Protection of older persons with disabilities, to a great extent, occurs within the framework of the UN Disability Convention (UN CRPD) which has fostered new requirements for the removal of barriers and support for self-determination. For older people in care, accessibility is an essential aspect of their lives. The requirement for accessibility is increasingly brought up in discussions with regard to living in familiar surroundings and is seen as a basis for a life in society. Hence, the assistance to live a self-determined, independent and inclusive life is becoming increasingly important. The concept of autonomy –- as outlined already in the UN CRPD with the principle of assisted self-determination – is central to the full guarantee of human rights of older people.

Several international developments have taken place which specified the human rights framework for people in care in recent years. They expanded and have consolidated the paradigm shift towards the rights-holder approach. These developments have also sent a clear signal that these issues require greater attention from policy makers.

While up until now no universal human treaty for older persons as a vulnerable group has been developed, some regional treaties have been adopted recently. In 2010, a working group to discuss the furtherance and promotion of the rights of older persons was established in the UN, with the possible goal of developing a convention on the rights of older persons. Also, in 2014 the first Independent Expert on the human rights of older persons (Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte from Chile) was appointed, for a three-year mandate, by the President of the Human Rights Council. The work of this Independent Expert is also vital to strengthening the human rights of older persons in care.

2.1.2 The legal status of human rights treaties in Germany

Germany has ratified various core human rights documents at universal and at regional level[1]. All human rights treaties are incorporated into Germany's national law. Most of the rights are directly enforceable in domestic courts, given that they are sufficiently determined.

If the human rights which are enshrined in international human rights treaties cannot be applied directly, they do impose legal obligations on the states. The international human rights treaties which Germany has ratified contain obligations which are binding on government as a matter of international law.

The International Covenant on Civil and Political Rights (ICCPR) contains a number of provisions which are particularly significant for persons in LTC, e.g. the right to life (Article 6) the right not to be subjected to cruel, inhuman or degrading treatment (Article 7) and the right to private and family life (Article 17).

[1] At universal level: International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the UN Convention on the Rights of Persons with Disabilities (CRPD), UN Convention on the Elimination of All Forms of Discrimination against Women (CEDAW); at regional level: European Convention on Human Rights (ECHR), European Social Charter (ESC), The Convention on the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT).

The Committee which monitors the implementation of the ICCPR expressed its concerns on the human rights situation of older persons in care homes as follows:

> *".. the vulnerable situation of elderly persons placed in long-term care homes, which in some instances has resulted in degrading treatment and violated their right to human dignity."*[2]

The protections of economic, social and cultural rights for older persons in care homes are particularly important. Due to their various health problems, LTC residents are dependent on care givers for help with nutritional and hygienic needs and for sustaining a dignified quality of life. The ICESCR guarantees in Article 12 "the highest attainable standard of physical and mental health" while Article 11 guarantees "the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing."

In its examination of the German LTC system, the Committee which monitors the implementation of the ICESCR (itself known as the CESCR) has paid particular attention to the rights of older persons in nursing homes and expressed their concerns "(...) that the state party has not taken sufficient measures to improve the situation of older persons in nursing homes who reportedly live in inhuman conditions and continue to receive inappropriate care due to a shortage of qualified personnel and inadequate application of standards of care (Article 12)."[3] Both committees expressed their concerns on the vulnerable situation of older persons in nursing homes and the violation of their human rights. Furthermore, the Committee on ESC expressed its view that Germany has to strengthen its efforts to restructure the care sector and to include more qualified personnel to provide a better standard of care.

2.2 Legal and policy developments on the implementation of a human rights approach in care

The German long-term care insurance was introduced as Social Code XI in 1995. It is an independent part of the social security system and makes financial provision for the risk of requiring care. The statutory care insurance covers a portion of the home and residential care costs should an increased need for nursing or household assistance for a period of at least six months occur. Thus, an individual is assisted to lead an independent and self-determined life – an approach congruent with the principle of protecting human dignity. With the introduction of the care insurance, the risk of becoming a subject of nursing care (*Pflegefall*) had been recognised as a general life risk. The amount of the fee is based on the contribution rate and the assessable income of the members.[4] Family members are in a non-contributory insurance if the

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[2] UN Human Rights Committee (2004) Concluding Observations: Germany 4 May 2004 UN Doc_ CCPR/CO/80/DEU, para 17.

[3] UN Committee on Economic, Social and Cultural Rights (2011), Concluding Observations: Germany 12 July 2011 UN Doc E/C.12/DEU/CO/5, para 27.

[4] Since July 2008 the contribution rate has been a uniform 1.95% of income subject to contributions. Additionally, members aged 23 and older without children have to pay a surcharge of 0.25% (since January 2005). Before July 2008 the contribution rate was 1.7%. Dependent children and spouses, whose monthly income does not exceed the contribution threshold, are insured without contributions as part of family insurance. The higher care premiums was set until 2014, following which, maintenance care rates are adjusted for price increases every 3 years.

family coverage is eligible for the health insurance. However, the receipt of benefits for long-term care does not absolve from payment of contributions.

Another milestone in addressing crucial gaps in the implementation of human rights in LTC was the statement[5] by the Committee on Economic, Social and Cultural Rights on inhumane conditions in nursing homes, released in 2001. It was based on reports about malnutrition, dehydration and administering wrong medication or non-prescribed tranquilizers. Motivated by, among other things, the statement of the Human Rights Body, the German Federal Government has started taking various measures to improve quality of care services and facilitate implementation of human rights into the care system.

2.2.1 Charter of Rights for People in Need of Long-term Care and Assistance

The debate aiming to improve the situation of persons in need of assistance and care took off with the launch of the "Round Table for Long-Term Care" in 2003. Experts from various fields of responsibility with regard to care in old age were involved. As a result of the Round Table consultation, the "Charter of Rights for People in Need of Long-term Care and Assistance", (*Charta der Rechte hilfe- und pflegebedürftiger Menschen*) was drawn up.[6] This Charter contains a preamble and eight articles that include key issues and areas of life. (Article 1: Self-determination and support for self-help, Article 2: Physical and mental integrity, freedom and security, Article 3: Privacy, Article 4: Care, support and treatment, Article 5: Information, counselling, informed consent, Article 6: Communication, esteem and participation in society, Article 7: Religion, culture and beliefs, Article 8: Palliative support, death and dying).[7] In 2007, the Ministry of Health aligned with the Ministry of Family Affairs, Senior Citizens, Women and Youth in order to make a joint effort to raise awareness about the Charter. A special Charter Office was established, to spread the message of the Charter, to coordinate workshops and to monitor further implementation of the Charter. The Charter created a human rights framework for the services of long-term care insurance funds and regulators that works on a voluntary basis. Essentially, the purpose of all Charter-related activities was to provide a guide for healthcare providers, to raise awareness about human rights legislation and to educate them about implementing this into care services for older people. Additionally, free training materials were distributed among various stakeholders in the LTC sector. The active promotion of the Charter ceased in 2012 with termination of financing from the ministries involved and dissolution of the Charter Office. All in all, the implementation of the Charter was too sporadic to result in any tangible nationwide improvements, even though good results were achieved in some pilot projects. At the time of writing, the Charter remains a non-binding, optional instrument, and its implementation is neither monitored nor evaluated by any external quality control bodies.

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[5] *UN - Committee on Economic, Social and Cultural Rights* (2001): Concluding Observations of the Committee on Economic, Social and Cultural Rights - Germany, UN doc. E/C.12/1/Add. 68 from 31 August 2001. Available at: http://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/PDF-Dateien/Pakte_Konventionen/ICESCR/icescr_state_report_germany_4_2000_cobs_2001_en.pdf [Last accessed 13 March 2013], paras 24, 42.

[6] https://www.pflege-charta.de/en/home.html

[7] https://www.pflege-charta.de/fileadmin/charta/pdf/Die_Charta_in_Englisch.pdf

2.2.2 The Long-term Care Enhancement Act

The Long-term Care Enhancement Act (*Pflegeweiterentwicklungsgesetz*) of 2008 aimed to strengthen home-based care, making additional support services available to family caregivers in the course of this reform. This Act introduced the facilitation of employees' home care by close relatives and thus improved the reconciliation of work and family care. Specifically, the law grants workers in a situation of acute care the right to up to ten days off work. This reform anchored the legal right to individual care advice. With this law, the target group of people with limited life skills, especially people with dementia, was taken into consideration. In an evaluation of the Act, it was found that the law had brought improvements for home care by increasing the benefits and addressing increased demand. One of the shortcomings, which became visible through the evaluation, was that the advice for the care was largely underutilised. In relation to the care providers, it was concluded that the financial compensation was too low and their bureaucracy too high. For the inpatient area, it has been reported that the quality of care has improved. Based on the staffing situation, the newly introduced service supports were highlighted as a relief for the care of people with limited everyday skills. However, forecasts of the future availability of qualified personnel suggest that the financial sustainability of the caring infrastructure, is still unresolved. The evaluation shows that improvements have been achieved by the Act, but there are still some shortcomings which have not been addressed from a human rights perspective. Specifically, the information about the rights of care must be improved, as it seems to seriously undermine staff requirements for the future and adequate remuneration.

One part of the reform was on measures which would enhance the quality of the care services performed by care homes and care service providers. The monitoring of out- and in-patient care facilities was further developed with a view to improving the quality of services and increasing the transparency of results. Since 2011, all licensed care facilities are monitored once per year. The results of the evaluation reports are published online and in other suitable places. Based on these MDK (Medical Services of Compulsory Health Insurance Funds) reports, the Medical Advisory Service of Social Health Insurance (MDS) has to draw up a general report on developments in the quality of care in Germany every three years.

2.2.3 Demography strategy of the Ministry of the Interior

The demographic strategy launched in 2011 in the Ministry of Interior in collaboration with other ministries and with extensive participation of civil society set out to address demographic change. Among objectives and strategic measures, the federal government has dealt with nursing for the elderly in its demography strategy. One measure is to develop a long-term strategic approach to self-determined ageing with the development of key points. It includes, for instance, independent living in familiar surroundings, as many older persons like to remain in their homes even with mobility impairments – which was mentioned as a responsibility of all citizens. Also mentioned were the commitment of municipalities, including good municipal structures to facilitate active ageing; the assurance of integrated contact points, multigenerational homes; and testing time bank-based models to enable new ways to help provide care. As a final point, the strategy called for the reorientation of care including the renewal of the care concept and a National Alliance for people with dementia. The cornerstone of the conclusion is to further the nursing profession and to design regulations for the nursing profession. The strategy is constantly being revised; the latest update was in 2015.

2.2.4 Next steps in the reform of the care concept

During the last legislature (2009-2013), after long discussions on the development of a new concept of care, especially a new definition of long-term care needs, all parties finally agreed to set up an expert group to work on the issue. The expert advisory committee was instructed to draw up a new care concept with a new definition which should also focus on persons with dementia. The report was submitted in 2013, but the necessary steps to implement the recommendations have not yet occurred. Key points of the recommendations include a clear definition of who is covered by the new nursing degrees and a new review process for long-term care.

2.2.5 De-bureaucratisation in care

In 2011, the Ombudsman of care introduced a strategy to reduce bureaucracy. Through this process, the Ombudsman has dealt with, among other things, the simplification of nursing documentation. For many years, the bureaucracy has been considered too burdensome and therefore nurses do not have time to actively care. With this in mind, the Ombudsman presented a concept for the simplification of nursing documentation based on scientific research. Its final report was presented in April 2014, the findings of which will also feed into the care reform. The simplification of the documentation can lead to insufficient protection of the nursing staff. It must be ensured that the documentation creates sufficient transparency to review all treatment.

2.2.6 Care Realignment Law (Pflegeneuausrichtungsgesetz)

In 2012, the care realignment law was introduced. It helped to strengthen home care. One innovation was to allow the introduction of the care level 0 to integrate people with dementia into the care system.

In 2014, the office of a new Federal Government Commissioner for the concerns of patients and a care representative for the Federal Ministry of Health were introduced.

The latest report by the MDS shows that the measures taken by the Federal Government of Germany led to some positive results regarding the quality of care, especially in the areas of malnutrition and water deficiency. However, there are still aspects of care, which the policy has not addressed yet or in regard to which the steps taken did not bring any success, such as the number of avoidable restraints (MDS 2012).

2.2.7 First Act and the Second Bill to Strengthen Long-term Care (1. und 2. Pflegestärkungsgesetz)

In 2015, the First Act to Strengthen Long-term Care was introduced to increase revenues for patients and installed a new long-term care fund to secure the financial support. Through this reform, caregiving relatives obtained greater relief, because additional support and relief services were introduced. To support these developments, the increase in support funding was announced. The increased number of supervisory staff from the current 25,000 to up to 45,000 in nursing homes was enshrined in the law. Due to this development being relatively recent, there is no data available on whether the everyday life of nurses and the quality of care has been improved through the reform. By 1 January 2015, the contributions for nursing care will be raised by 0.3 percentage points and during the election period by a further 0.2 percentage points to finance the improved performance. With the second Bill, the new definition of long-term care and a new assessment procedure was introduced, which came into force 2016. The new assessment procedure and the changes in the benefit amounts available to persons in long-term

care which came into force at the beginning of 2017. The distinction made between persons in need of long-term care with physical limitations and persons with dementia (or other mental illnesses) will no longer exist. The new focus will be on each person's individual need for assistance. Since the real need for support will be recorded more effectively this reform benefits persons in care, relatives and professional nursing staff.

2.2.8 New law to make professional training for all care professionals uniform

The recent (2015) launch of uniform professional training for all care professionals, regardless of specialisation (hospital, pediatric or geriatric care) in some German federal Länder may have a variety of consequences that are relevant to a human rights approach. First, uniform education – rather than scattered training and courses whose costs to individual students may or may not be covered by LTC providers – guarantees vocational training open to all people without being discriminated against on different grounds. Second, completion of uniform education should serve as a basic requirement for the introduction of uniform wages. And finally, this educational reform should contribute to training the least skilled personnel (the care and supervision assistants).

2.3 Right to accessible and available care

International human rights treaties do not explicitly provide older people with the right to long-term care. However, articles in various conventions do contain provisions on the right to equal access to healthcare services (as well as an assurance that they are affordable) and on the right to a choice of long-term care setting.

The right to autonomy and freedom are seen as the starting point to one's free choice of a type of long-term care service. Nonetheless, there had been jurisdictions which interpreted the placement of older person in a care home against their will as no violation of their human rights.[8] Article 19 of the CRPD imposes a general obligation on states parties to enable persons with disabilities to live independently in the community, with the choice of where and with whom to live. Furthermore, the government has to ensure that persons with disabilities get all the necessary support to allow them to live independently. The question of whether to give older persons in need of care a choice of which service they would prefer has changed recently to recognise that they should have a choice.

The enjoyment of the rights and freedoms set forth in the different human rights conventions should be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status. This means that a person cannot be discriminated against in respect of his or her rights. This is relevant to make sure that older persons are not denied services, facilities or treatment. State parties have to ensure that older persons can live in the care home of their choice e.g. non-German speakers get the same access to care home as German-speaking older persons.

[8] 8 A/66/173

2.4 Human rights principles in care management and provision

At the moment, most German LTC institutions organise their work on the basis of the so-called Supportive Processual Care (*Fördernde Prozesspflege*) developed by the German nurse and gerontologist Monika Krohwinkel (Müller 2015; Krohwinkel 2013). The most fundamental principle of Supportive Processual Care is respect to personal dignity, achieved through recognition of each person's unique needs and by empowerment of their capacities to meet these needs as autonomous individuals. Only when a person is no longer able to do so should a care professional take over. In that respect, Krohwinkel's care system is fully congruent with the assisted autonomy of the Convention on the Rights of Persons with Disabilities.

The distinct feature of Supportive Processual Care lies in re-defining LTC residents from being mere beneficiaries of care into sovereign individuals and rights owners. In that respect, this care model converges with the human rights perspective, implicitly recognising and fostering LTC residents' right to autonomy, right to social inclusion, right to Highest Attainable Standard of Health and other rights meant to protect personal freedom. It must be noted that Supportive Processual Care serves not only as an essential professional training framework, but also a basis for LTC-relevant policy-making, such as, for example, 'general benchmarks and principles for controlling and developing quality of care' outlined in the German Social Code XI. The ongoing national care evaluation programmes carried out by the federal Medical Advisory Service of Social Health Insurance (MDS) are also rooted in Supportive Processual Care. Such deep incorporation of Supportive Processual Care into organisational processes is a first step towards adoption of a human rights approach in LTC; a step that already results in care workers' growing awareness about older people's dignity, as we will discuss in Sections 4 and 5 of this Report. And although there are still too many misadventures taking place in German care homes, with restrictions of mobility and disrespectful treatment being far from eradicated, national care quality reports show slow, but steady progress for the better.

The guiding orientation of Supportive Processual Care is towards giving LTC residents a basis for living a life as normal as possible. Experts at the Ministry of Family Affairs, Senior Citizens, Women and Youth observed as early as 2006 that to meet this goal, a systematic and wholesome development of all aspects of residential care provision is necessary (BMSFJ 2006, 129-130), with particular focus on the following aspects:

- Sustainable improvement of housing and accommodation structures;
- Activation, rehabilitation and social participation;
- Adjustment of care processes to needs of specific target groups, such as residents with dementia, immigrants or persons in agrypnocoma.

Achieving these aspects in concrete, everyday forms takes place through minute delegation of tasks within the LTC institutions. Most German Homes have at least three sub-departments, and a Home advisory board.

- Care Services Department (*Pflegedienst*) lead by the Head of Care (PDL)

The primary responsibility of the Care Services Department is activation and rehabilitation through providing assistance with all body functions, such as:

- Administration of medication and direct medical care, such as prevention of bed sores, maintenance of excretion bags, etc.;

- Assisting residents with using toilet facilities, washing and bathing;

- Supervising residents' nutrition and water intake.

The Head of Care is in charge of dividing responsibilities between nurses and their assistants; they file all care documentation and also act as primary complaints officers to residents.

The Care Services Department collaborates with physicians, psychiatrists and other medical specialists. Palliative care is also the responsibility of Care Management. To that end, the work of the Care Services Department is essential for implementation of a whole variety of human rights: right to the highest attainable standard of health, right to mobility, right to privacy (with respect to medical and hygienic procedures), right to nutrition, etc.

- Social Services Department (*Sozialer Dienst*)

The Social Services Department serves to empower residents in their social contacts, in particular, through organising day-to-day events and seasonal feasts. In co-operation with the Care Department, the Social Services Department plans and carries out low-threshold activities, ideally ensuring participation of bed-ridden residents and residents with dementia. One of the most important tasks of the Social Services Department lies in connecting the Home with other communal actors, such as, for example, schools, kindergartens, religious organisations, etc. As we will demonstrate in Section 5 of this Report, the work of the Social Services Department is essential for implementation of residents' right to social inclusion and other human rights such as the right to mobility. In addition, the social service provides the required assistance for many tasks.

- Home Management (*Heimdirektor*) represented by the Head of Management

Home Management is responsible for providing all departments with the necessary structural conditions for carrying out their work. The Management is in charge of finances and expenses; it makes final decisions about the material environment of the Home and configures organisational processes in the Home, such as:

- Systematic documentation of care procedures;

- Circulation of information in the Home;

- Complaint and case management;

- Human resources management, for example, team building and personnel training;

- External communication and public relations.

- Home advisory board (*Heimbeirat*)

The Home advisory board is a consultative body consisting of Home residents and third persons, such as community volunteers or relatives. Home advisory boards act as the main self-government instrument, and their main purpose is to ensure participation of Home residents in decision-making processes. Home advisory boards do not have a complaint management mechanism. Although established for a good cause – 'to improve social participation of older people' – the actual effectiveness of Home advisory boards is questionable, as we will discuss at a later stage in Section 6 of this Report.

Although essential human principles are already implicitly incorporated into requirements to organisation of LTC services, there is still space for improvement when it comes to actual implementation of these principles. Reports by various experts and ombudsmen (e.g. Fussek 2015, ZQP 2015, MDS 2012, 2014, Graber-Dünow 2015, Moritz 2013) suggest that violence, neglect and degrading behavior – whether in direct or indirect form – still regularly occur in German care homes, even though some aspects of elder abuse, such as mechanical restrictions of mobility, are gradually becoming less prominent (MDS 2014). Experts suggest that most infringements of human rights in an LTC setting occur due to poor working conditions and lack of skilled personnel in care homes (Brucker 2015, MILCEA 2013): over-worked and poorly qualified nurses may vent their frustration on LTC residents, sometimes deliberately, but very often out of sheer neglect and exhaustion. Hence, as we will discuss further in this Report, to prevent violations of human rights in LTC settings and to facilitate the implementation of principles of dignified care underpinning the care model already adopted in Germany, serious changes need to be made to organisation of care workers' labour and to organisational processes in Homes and Providers.

3. Methodology

3.1 Selection criteria: type of provider, region

At the moment, there are some 11 000 LTC residential establishments functioning in Germany. LTC provision is a field characterised by extreme heterogeneity with respect to providership, approaches to care, size of establishments and so on. The only source of sustainable representative data on living and working conditions in LTC are reports by the MDS, published every three years. In this analysis, we will be drawing regularly on these documents.

Given the very small size of sample in our study, we did not aspire to collect representative data. Instead, our task was identifying and discussing themes that care providers and persons in care considered of particular importance with respect to human rights.

3.1.1 Criteria 1: Types of nursing care providers in Germany

In Germany organisation and delivery of nursing care services is carried out by three types of providers: not-for-profit charitable organisations (religious and secular), municipal bodies and private businesses. The proportion of provider types is shown on the diagram below:

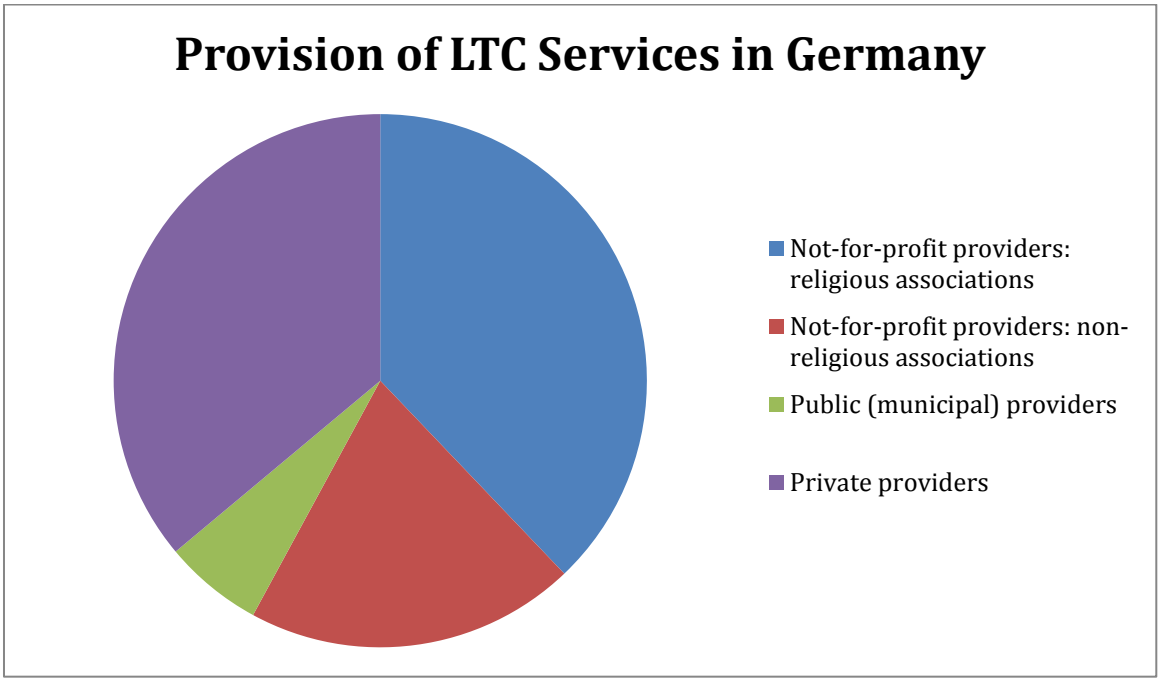

Image 1: Proportional distribution of LTC providership in Germany. Sources: Augurzky and Mennicken 2011, Caritas 2012

The quality of care provided by all providers is centrally monitored and evaluated by the federal Medical Services of Compulsory Health Insurance Funds (MDK). That is, Long-term Care Institutions (LTCI) run by not-for-profit providers are checked on the basis of the same criteria as LTCI run by communal or private providers. On the basis of MDK evaluations, quality grades from 1 (best) to 5 (worst) are assigned to individual homes. Existing data indicates no difference in quality of care across types of providers: the 'care grades' distribute themselves evenly across all types of care providers. Nevertheless, drawing up the sample, we assumed that internal

differences between various providers' organisational structures and ethical principles are likely to be relevant to the ways in which human rights are understood and implemented in individual care homes.

First, working conditions and wages for care professionals vary significantly across types of providers. Private care homes tend to have a higher personnel/resident ratio than the not-for-profit and municipal ones, while their care and assistance expenses are often significantly lower. Some experts suggest that more workers at a lower price is the result of salary dumping: an assumption that private home owners refute, suggesting that they finance their extra personnel through other means, for example, by taking residents with severe mental and physical disabilities whose care is subsidised by the state (Care konkret 2015). Wage differences are also highly pronounced in the not-for-profit sector: a study conducted in 2015 identified that the annual incomes of care workers with the same level qualifications may have up to 38% variation, depending on their employer (*Das Infoportal für den öffentlichen Dienst*: 2015). Aside from wage variations, there are significant discrepancies in labour rights across different types of providers, with religious associations having their own employment regulations which in some respects divert strongly from the national labour code. For example, Christian providers forbid strikes as incompatible with the ethos of faith. All in all, their employees are expected to conform to the Church's moral principles. Certain behaviors, such as divorce, conversion into a different religion or living in a homosexual relationship may become a source of a conflict between the employer and the employee (Wohnen-Im-Alter.de 2015).

The second major difference between care providers is the typical size of an individual care home in their management. Most care homes run by not-for-profit providers have 60 to 150 places, while private homes are significantly smaller, with 10 to 50 places (*Statistisches Bundesamt* 2011: 18). At the same time, larger (over 60 places) private homes have fewer single rooms than comparable homes managed by not-for-profit organisations: 50% against 63% (Augurzky and Mennicken 2011: 42).

Organisational differences across provider types are relevant to human rights research because they have very concrete effects on care workers' daily practices and on older people's living conditions. With these considerations in mind, we recruited at least one home within each category of providers (see table below).

All Homes we have visited may be categorised as care homes, with qualified personnel being available around the clock, according to the German Social Code.

3.1.2 Criteria 2: Regional differences

A recent study conducted by the German Centre of Gerontology (DZA 2010) demonstrates that in spite of the general trend towards population ageing and increase in mean age across Germany, there are strong regional discrepancies in population structure, with particularly strong differences between urban and rural regions, as well as East and West.

The rural German East is ageing particularly rapidly, which, to a large extent, is the result of the high rate of outward migration by younger people. The population there is not only ageing, it is also receding – in contrast to the Western parts of the Federal Republic which, in spite of general population ageing, are characterised by influx or, at least, by stability in its population. These differences have serious implications on delivery and organisation of care services, including residential care.

West German rural and urban communities are shrinking to a much lesser extent than communities in the East. When services are shut down, other service providers take over their functions. Not so in the East, where the closing of a bakery or of a bank branch becomes an irreparable loss factoring into further decrease in quality of life. These infrastructural inequalities may have direct effects on the implementation of human rights of older persons, for example, the right to the highest attainable standard of health and right to access to care. The shrinkage of communal structures may also result in a lack of qualified care personnel, poorer housing quality, lack of facilities, etc.

Further research also points to regional differences in types of care provision. In urban settings, not-for-profit providers are significantly more common than private and municipal ones, whereas in the rural setting the proportion of not-for-profit and private providers is almost the same. Significant regional differences can also be observed in annual incomes of care workers with comparable qualifications, with the annual salary in the West being about 19% higher than that in the East (Bispinck et al. 2013).

3.1.3 Recruitment strategies and sample composition

Keeping in mind the two selection criteria, we aspired to design a sample that would include the most contrasting cases; that is, we were seeking out homes run by all three different kinds of providers and across different regional settings. We have successfully managed to fulfill this intention albeit with one exception: in spite of various attempts and multiple negotiations, we were unable to recruit a single home in East Germany. Although provisional confirmations of participation were secured from a nursing home in Saxony and in East Berlin, both homes have refused last minute on the premise of personnel overload. Both homes belonged to not-for-profit providers.

To ensure the greatest variety of possible results, we have employed several recruitment strategies simultaneously:

1. Direct contact to managers of homes selected through various public access databases, including a database run by the largest German insurance fund, the AOK (http://www.aok-pflegeheimnavigator.de). Over thirty homes were contacted this way, and none of them replied.
2. Contacts to providers and individual managers who have previously participated in various activities and projects directly and indirectly promoting human rights, such as development of the Care Charter or organisation of the German Care Day. It must be noted that we have intentionally abstained from recruiting the same Homes that have participated in Charter Projects. Given the explorative nature of our study, we have decided to exclude establishments that were already working with an unbinding human rights instrument. On the contrary, we believe that a comparison between homes involved in the Charter project and homes participating in this study may provide important insights into how human rights are operationalised and implemented in day-to-day practice. By contacting care providers and managers who were involved in human rights initiatives, we sought access to other establishments in their networks. This approach generated the most results: of five homes we visited, three were recruited in this manner.
3. Networking and snowballing through existing networks. We have received significant support from colleagues in various NGOs, research and state organisations who agreed

to put us in touch with individual homes and providers. Two homes were recruited on this premise.

As a result of our various recruitment strategies, we were able to conduct five site visits (to five different homes). Altogether, 32 interviews were carried out, of which:

- 9 individual interviews with Home Managers
- 11 individual interviews with home residents
- 3 individual interviews with relatives of residents
- 3 group interviews with care workers
- 4 group interviews with home advisory boards
- 1 interview with a home spokeswoman
- 1 interview with a chaplain of a Christian home

For details on each individual home and on sample composition, please check Appendix 1 to this Report.

In this Report, there is a prevalence of direct citations from interviews with care workers than with older persons in care. This, however, does not mean that LTC residents' point of view was not taken into consideration: instead, this is due to a kind of empirical material we have collected. Interviews with older persons were highly informative inasmuch as they offered insights into people's everyday lives and allowed us to observe home residents in their daily habitat. However, these conversations were often not articulate enough to be cited directly. We suggest that to improve the data collection process for further reports, two methodological extensions need to be made:

- Persons with dementia need to be interviewed by means of specially devised instruments (e.g. Hubbard et al 2003), and researchers must to be coached in the use of these instruments;
- Participant observation needs to be included as a research method in addition to interviews.

Along with regular interviews on sites, we have also conducted several expert interviews and consultations with various stakeholders in the nursing care sector:

- two meetings with the CEO of a municipal care provider;
- consultation with a representative of the MDK, which performs as statuary quality control body;
- expert interview with a representative of Care Chamber Initiative.

Sample Disclaimer:

The GIHR does not have a mandate to access care homes and their documentation in order to investigate the implementation of human rights in different setting. Hence, given that we were only able to access homes which explicitly agreed to participate in the research, our sample is doubtlessly biased towards best practice examples: Homes that were willingly co-operating had excellent quality grades and were, altogether, confident about exposing themselves to an external organisation. Results presented in this Report should by no means be considered representative; moreover, various aspects of human rights implementation that we have observed in homes we visited contradict the data collected in quality reports drawn up by the

MDS. Nevertheless, we suggest that the material we have obtained may provide important insights into difficulties the German LTC sphere is experiencing – while also offering best practice solutions.

3.2 Data collection and analysis

In accordance with ENNHRI Monitoring Methodologies, data collection in all homes was carried out by means of semi-structured individual and group interviews. Site visits lasted one or two working days, depending on the amount of interviews, and included a tour of the facility. In Home 2 and Home 5, meals were also taken together with the personnel. In all homes, additional information about services and routines they offer was collected: leaflets, brochures, advertisement, press materials etc. Where possible, photographs were taken.

Interview guides were developed with consideration of the sample guide suggested by ENNHRI and consisted of three groups of questions:

(a) Questions concerning organisation and delivery of care work: care staff workload and income; training requirements for care staff; quality standards applied in the home and methods of their monitoring.

(b) Questions on pre-existing knowledge about human rights and on their interpretation by interview participants.

(c) Questions on actual everyday practices of care: hygiene, nutrition, social participation, health, complaint management and death.

Whereas the first group of questions was addressed to home directors and, partially, to care workers, the last two groups were addressed to all respondents. An average, an interview lasted 60 to 90 minutes.

All interviews were recorded (upon signed agreement of the respondent) and were transcribed by an independent agency. Data analysis was performed with the help of MAXQDA software. Interview experts presented in this Report were translated from German into English in accordance with the 'creative translation' methodology used in qualitative analysis of multilingual material (Overing 1987).

3.3 Ethical considerations

All interviews were conducted with the informed consent of participants. Where necessary, care workers assisted elderly residents with reading and signing of the consent forms (which were printed in extra-large font).

To protect our interview partners' identities, all personal names and toponyms in this Report are fictional, unless the interviewee requested otherwise (see p.27). The LTC facilities are referred to as Home 1,2,3,4 and 5.

Throughout fieldwork, the code of conduct set by the UN for its monitoring work was observed (UN 2001). All site visits were negotiated in advance, so that the researcher remained visible and credible to all study participants. Given the themes of our interviews, we aspired to show sensitivity to people we spoke to, being empathetic with older people for their health problems and with care workers for the difficult conditions under which they carry out their work. It must

also be noted that given the anonymity and confidentiality of this study, cases of neglect or poor treatment reported in the interviews could not be considered as complaints. All information provided by the interview partners was used strictly for research purposes.

4. Paradigm Change in Requirements to Nursing Care: From Neglectful Paternalism to Engaged Empowerment

In sociological and gerontological literature, nursing homes are often referred to as 'total institutions', that is, 'places of work and residence where a great number of similarly situated people, cut off from the wider community for a considerable time, together lead an enclosed, formally administered round of life' (Frank 2002: 44). Existing research on German LTC suggests that there are important structural changes occurring to nursing homes, opening them up to greater social inclusion. As Kirsten Hämel suggests, "in conjunction with the de-institutionalisation movement in Germany, there have been also attempts to re-design the nursing homes themselves" (Hämel 2014: 3). A decade ago, experts at the Ministry of Family Affairs, Senior Citizens, Women and Youth argued that 'high quality care is a care that activates residents and is carried out in accordance with their desires and competencies' (BMSFJ 2006), while various aspects of care delivery must be adjusted to meeting residents' personal needs, from Homes' spatial organisation to the scheduling of daily routines. The legal reification of this approach has manifested itself in Social Code and Care Acts reforms, with the rights of individual LTC residents becoming increasingly important for law-makers, as outlined in § 1.2 of this Report. An important contribution to these developments is the updated definition of 'need for assistance' formulated in the Second *Pflegstärkungsgesetz* (bill to strengthen long-term care), with need for care provision no longer determined through clinical picture, but rather through each individual's capacities to live an independent life. Focus on social inclusion can be seen as another step to implementing a human rights approach into long-term care, in accordance with UN-CRPD. All in all, from being considered as beneficiaries of care, LTC residents are gradually becoming active rights holders.

Legal, educational and organisational developments towards granting LTC residents with greater autonomy may be conceptualised as a *paradigmatic shift in the requirements of care*, implying a progress from paternalistic to democratic structures of care organisation and delivery. This shift does not mean that all German LTC establishments have already fully adopted the human rights approach to care, and that violence, abuse and neglect are eradicated. Sadly, infringements of rights, such as restrictions of mobility or violation of privacy, still remain pressing problems as various expert evaluations demonstrate (ZQP 2015). The paradigmatic shift lies in development of human rights-compliant requirements to quality of care - but whether these requirements are being met, is a different matter. Some positive developments are already manifesting themselves in MDS reports (MDS 2012, 2015): better control over distribution of medication, stricter requirements for immobilisation, stronger requirements for rehabilitation, greater social inclusion of patients with dementia. As discussed in the Methodology Section of this Report, the homes we have visited cannot be regarded as representative cases – instead, they can provide best practice insights into ways the paradigmatic change towards using human rights as a yardstick for good care is being implemented.

4.1 Existing knowledge about and interpretation of human rights: various stakeholders' perspectives

As outlined in the Introduction to this Report, one of the goals of this study is to find out how various actors involved in LTC conceptualise human rights, and what sources of knowledge about them they have. Hence, we have started our interviews with an open question about what

they understood of human rights, and how they thought human rights were applicable to the residential care setting.

Offering their interpretation of what human rights are, most care workers we have spoken to invariably referred to the concept of dignity. The Head of Care Home 1 says:

> *First and foremost, it [human rights - GIHR] means respecting others´ dignity and giving them autonomy. It is crucial that one is allowed to do things on their own without someone else interrupting them or imposing themselves.*

Dignity, thus, is understood as respect for individual autonomy: a conceptualisation underpinning the human rights perspective, too. It must be noted that 'dignity' (Würde) is a central concept of the Supportive Processual Care model practiced and the guiding principle of the German *Grund Gesetz* (Constitution) and taught in Germany, as discussed in Section 2.3 of this Report: by drawing attention to the dignity of older persons, this model places the focus of organisational work on documenting and addressing residents' preferences, and on elaborating a sustainable everyday structure to which residents can contribute by performing small, feasible chores. As a spokeswoman for Care Chamber Initiative, an expert on care education and work conditions, said:

> *By now, the concept of dignity is so firmly incorporated into education that it is impossible to by-pass, it does not matter what level of qualifications one aspires to.*

Examples (given by interviewees) of upholding residents´ dignity and human rights in the LTC context ranged from very general, such as enjoying freedom of movement without restrictions (all homes), and having a free choice of activities during the day (all Homes) to very specific ones, like, 'having breakfast in pajamas' (Home 1), and 'keeping pets, smoking or having a glass of wine before going to bed' (Home 3).

Although all care workers have demonstrated implicit knowledge about the basic principles of human rights, there are some differences in the ways that 'protecting dignity' is operationalised by care professionals of different ranks.

Care managers spoke of human rights in the context of existing legislation and gave concrete examples of their realisation. For example, the Head of Social Services at Home 2 refers to the Constitution as an instrument of human rights protection:

> *Every person has rights. And they need to be upheld. I also think that every person needs at least some protection. Particularly when a person cannot protect their rights cognitively, then some protective function needs to be in place. Also, of course, I have to think of freedom. It's not much different to the constitution, to constitutional guarantees of human rights, I think, is it? Freedom, religious freedom, those are things that come to mind. I think those are the most important ones.*

In some instances, very concrete, pro-active and positive definitions of rights were suggested. For example, the Head of Management at Home 2 gives a straightforward example of how certain administrative decisions in her institutions are meant to promote the right to vote:

> *(Prior to elections) we always need to file an application for a mobile polling station to come here, and we normally base our request on the Human Rights Declaration. Because*

according to the Declaration, everyone should have a right to vote. Our Residents want to vote, too, they just need barrier-free access.

In other instances, however, the definition of human rights offered by care managers was formulated *ex negativo*: that is, in the context of rights violations and infringements.

Not only managers, but also qualified nurses, were able to offer an articulate explanation of what respecting one's human rights meant:

N2 (Home 1): Doesn't matter what skin color or religion, a person has to be respected for who they are. Does not matter where they come from and what their faith is. You have got to treat them like you treat yourself. Unfortunately, that does not happen all the time.

The difference between care workers and managers' knowledge about human rights concerns not the content of the concepts (their understanding of dignity is the same), but mechanisms of their implementation. For lower rank care workers, realisation of human rights means adherence to a set of rules, such as addressing home residents with the polite form '*Sie*' (you) instead of the colloquial '*Du*'. Others mentioned always knocking on residents' doors before stepping into the room, or giving every person enough time to finish their meal. An expert interview with a care educator confirmed that these rules are by now part of the standard care education programme. For managers, instead, implementation of human rights was a matter of structure and organisation of services, while rights of care workers were discussed as intrinsically related to the rights of LTC residents. To them, human rights could not be reduced to a set of rules and sanctions necessary for directing the daily work of personnel – instead, they were a systemic requirement of good care, which became apparent as managers reflected upon their experience in the branch. The Head of Care in Home 1 speaks of the transformation she had observed throughout her thirty years of work experience:

When I just started, the general attitude among colleagues was like this: It is our house, and the resident does what I tell him. Thank God, this has changed. (…) I am really glad that nursing care has finally acknowledged that the elderly person has to be the focus of all activities and that <u>he</u> has the right to decide for himself. <u>He</u> decides how he wants to live and what <u>he</u> wants to do, it is <u>his</u> home, and we are only guests there. I find this development crucial, because it is also something that we pass on to our younger colleagues.

Recalling her professional shift from hospital to gerontological care, the Head of Care at Home 4 conceptualises her experience in very similar terms:

Now that we are talking about human rights, back then [in the Eighties - GIHR] I saw situations that left me speechless. Bed sores were left unhealed. People were addressed with 'Du' [colloquial 'you' considered impolite for the elderly - DIMR]. Some residents were washed in public showers and then let to walk back into their rooms wrapped in a towel and with no clothes on. If someone happened to be in the bathroom when food was served, then they would get their meal while sitting on the toilet. (…) There were almost no qualified care workers back then. No one cared about educating nurses; there were only so-called 'assistants'. (…) I think, this experience had affected me greatly, to the point that I decided I want to aspire to a managerial position where I can change things myself, be in charge, and make a difference.

Most experienced care professionals we have interviewed agree: long-term care in Germany has improved significantly in the last two decades, with older people gaining more and more rights. However, it has become apparent throughout interviews that residents themselves are often not aware of their role as rights holders. In contrast to care workers, elderly residents of care homes and their relatives had no articulated concept of human rights. A 67-year-old daughter of a male resident in Home 1 replies to a question about what she understands by human rights:

> *I: Oh, that's difficult… Hard to say. Well, in relation to care homes, all I can say is that here things are fine. When I watch TV sometimes and see how poorly people are treated elsewhere, I can't imagine how such an atrocity can be possible.*

Residents and their relatives have an *intuitive ex negativo* understanding of human rights: they realise that adversities in care may be qualified as violations of human rights, however, they lack a positive definition rights and have a deficit of knowledge about instruments that can be used to promote these rights. This lack of positive definition may prevent people from speaking for themselves and making complaints, as we will discuss in Section 5.6 of this Report.

4.2 Empowering autonomy: A shift from 'entertainment' to 'engagement'

One of the most fundamental strategies to empower residents´ autonomy is to provide them with stable day-to-day structures in which they can function with the greatest degree of independence. The Head of Management in Home 1 says:

> *There is, of course, always something imposing in care, as if the caregiver knows what´s right. Elderly care is often organised as an event-machine with far too little focus on the normal day-to-day life. I keep asking my colleagues here, all the time: Do people here really need another feast here? Have you spoken to them? Have you sat down with the residents and have you asked them, what they want to have on a daily basis? These are the most important instruments, I think: talking to people, finding out what they consider a 'normal' daily life. To that end, we also carry out reflection conversations shortly after someone new arrives.*

Activating people to take part in daily life is based on the principle of assisted autonomy and participation outlined in the CRPD. This principle may come to pass in different forms and activities, as the Head of Care in Home 1 suggests:

> *Everything that a resident can do themselves, they should do themselves. (…) 'I can do it myself' is an enormously important statement. 'I can make my own bed', for example, or 'I can peel potatoes myself' has to do with one's self-esteem.*

In Home 1, Home 2 and Home 4 residents are, indeed, activated to participate in simple daily chores, such as, for example, peeling potatoes for common meals (an activity literally all persons interviewed in these Homes mentioned), chopping salad or taking care of plants in the home's kitchen garden. From time to time, residents are also assisted with baking in one of the Home's several common kitchens. Where possible, the residents are encouraged to fold their own clothes in their wardrobes, sort out the laundry and to keep their rooms in order. One of the residents at Home 1 also mentioned being in charge of the home's aquarium and feeding the fish on a daily basis. In three of the five Homes we have visited, several common rooms were also furnished with residents' participation. It is worth mentioning that this low-threshold activation

approach was implemented and worked well in Homes with very different organisational structures, number of residents and providership: whereas Homes 1 and 4 are relatively small establishments, Home 2 has about 200 residents some of whom suffer from severe mental illness.

All in all, our visits have convinced us that requirements to LTC are steadily moving towards placing residents in charge of their lives, while creating the necessary care conditions for them. There is, however, always space for improvement – and one of our interview participants, the Head of Management in Home 2, believes that this improvement may come from gerontological care adopting the same fundamental principles that inform psychiatric care.

> *There are some very positive things that one can learn by working with mental illnesses. In normal elderly care everything is very standardised and the old people, they just sort of go along with it. And mentally ill people, they don´t go along. That is, we are perpetually challenged to accept their autonomy and adjust to their needs and their desires because that's what they require. (…) For example, there is a major debate about increasing the personnel ratio for night shifts in care homes now. And we have had better staffed night shifts for thirteen years already because we have a high proportion of patients who are, due to their clinical picture, active at night. So, we have nightly meals and nightly meeting hubs with food and drink. (…) I think that with respect to human rights, one should take a closer look at homes like ours. Here we live the principles that are often missing from elderly care: the readiness to let people take their meals whenever they need or fulfill their other desires.*

Focus on daily routine and involvement in small chores fosters implementation of residents' right to autonomy, making them into rights holders and empowering their sovereignty. Instead of being subjects of 'entertainment', older people are empowered to determine their day-to-day lives. As we will demonstrate further in this Report, this empowerment encompasses various aspects, from improvement of housing to facilities to health rehabilitation programmes. The most immediate level of granting autonomy, however, lies in careful documentation of individual needs and prompt implementation of the relevant decisions.

4.3 Adjusting care to individual needs: Documenting residents' preferences and making them known

In Homes we have visited, various instruments are used to document residents' needs, interests and desires.

At the beginning of the residency, the so-called 'biographical narrative' is drawn up in conversations with the resident or their relatives. The purpose of this narrative is to establish people's wishes, and to implement them into organisation of the care process. The 'biographical narrative', however, cannot serve as the only source of knowledge about the resident: our interview partners stressed the necessity to review every person's records through conversation or direct observation, the latter being particularly important for residents with dementia. A nurse at Home 1 says:

> *In the beginning we draw up the biography, talk to relatives, and so on. This way we know their likes and dislikes. And still, the resident is not obliged to eat ham sandwiches every day, just because his biographical record says he likes them. We watch what they pick from the breakfast table, and if we notice that they prefer marmalade, then we'll make sure they*

will get marmalade, whatever the biography says. If they cannot speak, then we have to observe a lot, and talk to the relatives.

An ongoing record of residents' desires and needs is a tool that permits flexible, supportive care – and protects their various rights, from right to health to right to social inclusion. Sometimes protection of these rights causes conflicts with relatives: the elderly may have a view about what is good for them that is completely different from their children's. In such situations, care workers find themselves in a conflict that is sometimes difficult to resolve. In matters of daily routine, residents' desires are normally prioritised above the desires of relatives. Direct observation of residents' habits and documentation of their desires are used as evidence for making specific care choices. The Head of Care at Home 3 says:

The truth is, some relatives have no idea what their parents like and dislike. A son may be convinced that his mother likes fruit tea because that's what he remembers from twenty years ago when they still lived together. And then we find out from observation that she does not like fruit tea anymore at all, she likes, mint tea instead, whatever he says. She has changed her habits over time, and he has no clue.

This interview excerpt suggests recognition of elderly LTC residents as persons who continue to develop and maintain autonomy even in very advanced age. In Home 1, a daughter of a 91-year-old resident was complaining that her mother was not participating in any events and did not join any activities even though they were 'good for her'. With a mixture of surprise and respect, the daughter said that it does not matter how much she tried to convince the Home management to 'encourage' her mother to do anything at all, they refused to push the woman further. In the end, the daughter has given up: 'they cannot force her if she does not want to' she concluded.

Also in the case of patients with dementia, direct observations serve as primary sources of knowledge about desires and needs. A Chief Nurse at Home 1 says:

Even if a person has dementia, they need to be respected for who they are. They are still autonomous persons who decide for themselves, they make a choice and convey it through their facial expression, their body language and so on. We need to consider it.

Documentation and consideration of the wishes of people with dementia are subject to quality control carried out by MDS. A regular check-up is meant to establish ways that desires and needs communicated by residents with dementia are recorded. The following results were obtained in 2015 (MDS 2015: 131):

Quality Criteria	Proportion of investigated LTC establishments meeting the criteria
In case of individuals with dementia, is personal biography recorded and taken into consideration for planning of everyday routines?	94.3
Are the relatives and significant others of people with dementia consulted?	96.5
Is the well-being of residents with dementia evaluated and recorded, and are there relevant improvements made?	90.2

Information collected through direct observation and conversations is disseminated through regular team meetings and briefs. Flat organisational structures and cross-departmental collaboration (between Care Services and Social Services) are crucial for correct distribution of information about residents' desires and needs. Indeed, daily briefs were referred to by care workers as a primary instrument of processing the feedback they get from residents, from which collective decisions could be made. The Head of Management at Home 1 gives a few examples:

> *Yesterday we discussed one of our residents who complained that she does not like her breakfast cheese to be sliced; she wants it in one piece. For us it is difficult to resolve because sliced cheese is what our catering company brings us, and we don't have anything else. I will have to talk to the Social Services now because they organise special breakfasts from time to time, and I could ask one of their assistants to make sure that this lady gets her Gouda in one piece. Or we will make sure that she always gets a piece of Gouda in her personal fridge. These are compromises we are trying to find.*

Care workers have also mentioned shift changes and coffee breaks as important moments to share observations, where every member of a team, including the most junior ones, is expected to share information with his or her colleagues. Chief Nurse at Home 1 says:

> *We all share a bit. If Jimmy, the assistant, sees or hears something, he tells us straight away, too. It cannot function otherwise, it is the only way. We all have to be observant.*

The increased focus on autonomy brings new challenges into LTC organisation. First, it is a challenge to protecting residents' safety: a theme that was particularly pronounced in discussions on empowering residents' mobility, as we will discuss in paragraph 6.2 of this Report. Second, encouraging autonomy also means creating structures for effective social participation and complaint management, issues we will discuss in paragraphs 6.5 and 6.6. And finally, last but not least, the paradigmatic shift requires a significant reform of care workers' professional training and working conditions. The autonomy and respect granted to older people are closely interlinked with the autonomy and respect that geriatric nurses experience at their workplaces.

5. Care Workers: Providing Rights while Having None?! How Best Intentions May Become Ruined by Poor Working Conditions.

"We do caring work because we like it. The question is: can we care as well as we would like to? Do we have the conditions for it?" These questions formulated by Helmut Wallraffen, the CEO of a municipal care provider in the industrial West of Germany[9], summarises what is, perhaps, the most profound conflict of interests in the care system: the conflict between standards of good care – including respect to dignity and autonomy of home residents – and the working conditions of care personnel who are meant to meet these standards.

The organisation of care workers' labour plays a crucial role in the implementation of human rights in the LTC system. Appropriate professional training and good working conditions for nurses are fundamental pre-conditions necessary to guarantee the human rights of those needing care. At the same time, where care workers' rights are compromised or violated through working conditions in care facilities, there may be serious repercussions on LTC residents. This refers to all professionals working in care homes. The right to work is essential to the realisation of other human rights and it forms an inseparable and inherent part of dignity. The right to work contributes to the survival of the individual and to that of his or her family. Specifically, the rights to work (Article 6 and 7 UN CESCR) guarantee that a person is able to earn a sufficient income on a full-time position (Article 7 ICESCR). At the moment, the organisation of the German care system cannot fully guarantee implementation of these rights. The three most pressing problems haunting the German LTC sector are absence of fair wages, poor regulation of work contracts and lack of qualified personnel. These problems lead to work dissatisfaction, high rotation of personnel - and have a direct effect on quality of care. The current organisation of care work is not feasible for further implementation of human principles declared in the care sector. The Homes we have visited may remain good practice examples and not standard, unless working conditions and salaries in LTC are urgently addressed.

5.1 Unfair wages in geriatric care

The wages in the geriatric care sector remain poorly regulated because there is no nationwide legislation on care sector wages and the wages of geriatric nurses are often lower, when compared to other wages in the healthcare sector. Studies by the German Institute for Employment Research (2015) and by Hans Boeckler Foundation (2012) demonstrate that care workers employed in long-term geriatric care make significantly less money than their colleagues in hospitals or outpatient surgeries. Whereas in hospitals the mean monthly income of qualified nursing personnel amounts to about 3000 Euros, in geriatric care it is some 700 Euro less, coming in at about 2300 Euros per month (Hans Boeckler Foundation 2012: 5). These mean numbers conceal further significant inequalities in care work wages across the German state. First, there are substantial regional discrepancies in incomes: in East Germany (the former GDR region) care professionals earn 18% less than their colleagues in the West. Second, major variations in income can be observed across different providers, with some paying grade-wages, and some setting their own wage standards, often paying their workers only slightly more than

[9] The interview partner expressed a will to be cited by his own name.

minimum wage. Those lucky enough to be employed by a provider that pays grade-wages earn some 19% more than all others.
At the moment, the single instrument to regulate incomes in the care sector is the introduction of minimum wage, just above the legal minimum. The minimum wage in the care sector will be raised in 2017. Article 6 CESCR says that the minimum wage has to be sufficient to secure the livelihood of the worker and his or her family. The evaluation of the current minimum wage will show if it conforms to the provisions of the human rights to work (Article 6 and 7 CESCR). Instead, various policy makers, including the Commissioner for Care in the German Government, Karl-Josef Laumann (Christian-Democratic Union), urge the introduction of nationwide grade-wages for all care occupations across branches and providers. The largest and most influential German trade union, Ver.Di, also demands the minimum wage of 3000 Euro per month for qualified care professionals.

5.2 Unregulated working contracts

Attempting to fulfill the general requirements and, at the same time, adjust their staffing to uneven daily rhythms of long-term care, with peak hours in the morning and during meals requiring more personnel than quieter times in the late afternoon, care providers are increasingly relying on part-time and outsourced workers. The majority of nurses in care homes are women. According to the Institute for Employment Research and Ver.Di, the proportion of part-time contracts in geriatric care is noticeably higher than in other professional occupations: a pre-condition that negatively affects not only workers´ immediate incomes, but also their insurance and pension plans. In public and political debates, this occupational structure is sometimes referred to as 'forced part-timing', affecting less qualified staff most and being particularly pronounced in the German East. This seems to be a structural discrimination of women who occupy the majority of part-time jobs because of insufficient children's day care. Sloppy scheduling and permanently rotating teams result in overtime: in the Hans Boeckler Foundation survey, about 52% of care professionals report having to work extra hours, with 86% receiving appropriate compensation and 14% receiving none.

5.3 Lack of necessary qualifications among personnel

Up until recently, training of geriatric nurses was not uniform. A set of basic qualifications is required to enter the profession; however further training is left at the discretion of concrete individuals or concrete LTC providers. Thus, while some Homes that invest in human resources policies, may organise and pay for their employees' education, others are not willing to make such investments. As a result, individual Homes may be staffed very unevenly, and the market value of care professionals in the same positions may vary drastically due to their individual qualifications, which leads to further income inequality in the sector. At the same time, the LTC sector is suffering from a drastic lack of qualified professionals – in particular, professionals able to supervise residents in various stages of dementia.

The requirements for qualified nurse/resident ratio are outlined in the LTC regulations (*Heimgesetz*) of each German federal land, and serve as a blueprint for individual Homes to calculate their personnel/resident ratio on the basis of residents´ degree of disability. Although there are variations between German states, with Homes in the South-West being better staffed then the ones in the North-East, the general tendency is towards drastic lack of personnel. At the moment, during day shifts a single geriatric nurse has about 12 residents to take care of; at night it can be as many as 50, of whom some 20 may be affected by dementia (Schlarmann and

Bienstein 2015). The current attempts of the German care reformers to compensate for this workforce deficit seem to bring little relief when it comes to protection and promotion of human rights. The initiative to staff nursing care with low-qualified 'Everyday' or 'Supervision' assistants (*Alltagsassistenten* or *Betreuungsassistenten*) was introduced in 2015 as part of the PSG I reform and was meant to tackle the low personnel/patient ratio with minimum expenditure and in the shortest possible time. According to the German Ministry of Health 'Everyday assistants' are not certified to carry out any medical care, and, in strict subordination to qualified nurses, are meant to support long-term care residents with the most mundane activities, such as reading, doing handicrafts, going for walks or going to cultural events. The introduction of 'Supervision Assistants' as a low-threshold support tier in long-term care, policy makers intended to empower residents' autonomy and were willing to create an organisational structure that would enable dignified and respectful interaction with the older persons (http://www.bmg.bund.de/themen/pflege/pflegekraefte/zusaetzliche-betreuungskraft.html). In real terms, however, this reform has led to new challenges in maintaining a high quality of care and in some cases has had the opposite effect when it comes to protection of residents' dignity, as we will discuss below.

Lack of respect to older people's dignity is often unintentional, resulting from poor qualifications and bad training. Nevertheless, rude treatment out of ignorance must not be tolerated – a position clearly expressed in interviews with care managers, relatives of residents and volunteers. A daughter of a resident at Home 5 says:

> *They let totally untrained people right into work, and they have no idea what they are doing. They say to my mother 'Du' or address her by the first name, like, 'Greta, get up, would you?' That's appalling, and I have made many complaints about it.*

For the Home Management, such poor professional behavior of one team member means loss of reputation for everyone else – and a long-term violation of residents' dignity and autonomy, in spite of all best intentions. The Head of Management at Home 1 gives a telling example:

> *Sometimes, a poorly educated care assistant destroys with one blow everything that has been achieved through weeks of consultation and effort. Unqualified care workers often have a very limited horizon of what is possible. Sometimes they are simply not ready mentally to implement everything. (…) Not every supervision assistant comprehends that a resident who is strongly homesick should not be reprimanded, shouldn't be told things like 'You live here now, there is no home anymore, just bite the bullet, lady'. We try not to speak like that because it only makes people even sadder. (…) For example, we had a resident who found it very difficult to get used to the Home, because she has already had multiple hospital stays. She was totally confused and tried running away several times. But above all, she refused to unpack her things. So, we decided to go along, and we communicated it to every, but every person working in the Home, that she should only unpack her bags when she says 'all right, I have decided to stay here'. This approach was documented. But no, one of these new assistants decided she knows better, so she went into this woman's room and unpacked everything. The lady almost went mad, and it is understandable: day in, day out we kept telling her, she would only have to unpack her things when she decides to stay herself, and then someone comes and does the opposite. We had a very serious crisis, and it took this resident several days to re-establish trust in us.*

What LTC needs is not simply more people - but more people with skills that would permit them to implement human rights through concrete, transparent practices.

5.4 Effects of poor organisational structure in LTC on implementation of older persons' human rights – working conditions

Given the low wages, poorly regulated working conditions and lack of qualified personnel, it is, perhaps, not surprising that care professionals report less work satisfaction and more work-related stress than people employed in other healthcare occupations. According to the DAK-Health Report of 2012 (Krämer and Nolting 2012), the nursing care sector is marked by prevalence of chronic, occupational-related physical and mental illness, often leading to full occupational disability. Poor health is one of the reasons for high staff turnover in most nursing care professions. These health disadvantages result from work-place human rights infringements (i.e. not in accordance with Article 7 CESCR), which must be addressed by organisational reforms of the LTC sector.

5.4.1 Violence in care

The right to safe working conditions (Article 7 CESCR) also includes protection from violence and sexual assault – issues that several of our female interview partners reported. In Homes we have visited, discrimination and harassment against care workers were handled by Home Managers (as discussed in Section 6.6). However the absence of a sustainable, independent, complaint mechanism is another hindrance to the realisation of care workers' human rights.

Poor regulation of labour and poor working conditions have further negative effects on LTC residents. This has also been spelled out in the case of Heinisch vs. Germany. Frustration and lack of time are the most common pre-conditions for violence and neglect in care. Unreported mechanical and pharmaceutical forms of restraint are a direct result of nurses' inability to cope with the situation. Even the best of LTC facilities experience this problem, even if in a relatively mild form. The Head of Management at Home 1 says:

> *When I am under stress, I, too, can do things which I disapprove of. For example, a resident comes to me to talk, and I put her in front of the TV instead. Me, the Head of this Home! (laughs) I do precisely the thing I find terrible because I have no time for anything else. I try to find a nurse who could take care of the resident, but they, too, have no time. If I have another colleague who knows residents well enough, I would take her by the hand, walk her to that resident and tell her, look, this lady is feeling a bit sad today, can you talk to her? But there is an absolute deficit of workforce here, and this alone is a strong pre-condition for violence and neglect of human rights in nursing care. Everything that we do, we do with our best intentions, but there are limits for everything.*

5.4.2 Documentation

The implementation of another initiative placing older people at the centre of care – a new documentation system introduced with the First Act to Strengthen Care (after long discussions on how to cut red tape in care documentation), focused on precise recording of older people's individual habits, desires and needs – also often runs into difficulties related to personnel's lack of skills. Whereas some care managers stated that the reform was a 'rush job', others believed it to be a positive development. All interview partners agreed on one principle condition of this reform: the new care documentation could only be performed by qualified workers, who were

able to conceptualise and generalise residents' opinions. Otherwise, it caused frustration and eventually took more of the personnel's time than the previous system.

The best intentions and best aspirations of care workers are, thus, not always practicable. Although a significant shift towards respecting care home residents' human rights is undeniably taking place in people's minds, the organisational structures are not sufficiently adjusted to the paradigmatic change that Care is going through. Although some important steps are already being made to address this problem, there is still space for improvement, as we will discuss in the next section.

6. Daily Practice of Care: Human Rights Perspective

6.1 Right to freedom of movement

Restriction of freedom of movement is considered to be one of the most problematic aspects of long-term care. The freedom of movement is enshrined in several human rights treaties e.g. Article 20 CRPD. While in some cases such restrictions are, indeed, essential to protect residents' other rights, first and foremost, right to health, often enough their implementation is not medically necessary and may, thus, be considered as an infringement of the right to mobility (ZQP 2015). The 4th National Report on Quality of Care (MDS 2015) suggests that some positive developments with respect to restriction of freedom have taken place in recent years in Germany. First, the proportion of LTC residents with some form of mobility restriction has reduced from 20% in 2012 to 12.5% in 2015. Second, the proportion of restrictions carried out without legal order has dropped by 3%, with almost 92% of all restrictions documented in 2015 in taking place in accordance with legal procedures. Finally, the data presented by MDS suggests that LTC establishments have started monitoring the necessity and adequacy of restrictions in a more systematic and regular way: 84.9% of Homes in 2015 carried out regular evaluations of restriction necessity, in contrast to 78.4% in 2013 (MDS 2015: 35). It must be noted that in spite of these positive developments documented in MDS reports, many uncertified mobility restrictions are likely to remain undocumented, in particular, restrictions that are not mechanical (such as belts or bed bars) but pharmaceutical (unsolicited administration of sedatives) or spatial (placing a resident behind a barrier they cannot remove, such as a closed door or a table) (Brucker 2015). It is likely that MDS does not have a full picture of mobility restrictions given that its goal as a control mechanism is not to assess elder abuse, but to assess quality of care (MILCEA 2012).

The decrease in mobility restrictions observed by the MDS is likely to result from implementation of the so-called *Werdenfelser Weg* in many LTC establishments across the country: an approach based on introduction of safety-promoting alternatives to restriction of movement, such as, for example, an alarm mat instead of bed railings. These alternatives are actively promoted by various LTC advocates, such as the *Zentrum für Qualität in der Pflege* (Centre for Quality in Care), MDS, and others. The Homes we have visited were operating in accordance with these latest quality standards.

In our interviews, ensuring freedom of movement is conceptualised as one of the most fundamental principles of safeguarding residents' dignity and of protecting their human rights. As the Head of Management at Home 1 has put it:

> *It is easier for anyone to realise their rights when they are mobile.*

Her colleague at Home 2 (Head of Care) suggests that the very concept of 'bed-ridden' must be challenged in order to enable people to access their rights:

> *We are totally against this concept of being 'bed-ridden' because 'bed-ridden' often means not taking part in life. This is why we have always attempted to mobilise everyone who may be at least partially mobilised, one way or another.*

The two major ways to empower residents' mobility that emerge from our interviews are (a) creating a barrier-free and attractive environment and (b) sustaining residents' health, including

implementation of fall prevention programmes. Below we will discuss these approaches in more detail.

6.1.1 Creating a barrier-free and attractive environment

Both ICESCR (Article 11) as well as CRPD (Article 28) recognise the right to an adequate standard of living, including adequate food and housing and the continuous improvement of living conditions. Article 28 of the CRPD focuses on ensuring equal access by persons with disabilities to adequate food, housing, clothing, clean water, retirement benefits, social protection and poverty reduction programmes, particularly designed for older persons with disabilities. This explicit right of equal access to such programmes, while applicable to older persons with disabilities, may be of interest in the wider development of standards for older persons in care.

Article 9 of the CRPD outlines the kinds of measures state parties have to develop, promulgate and monitor to implement the minimum standards and guidelines for the accessibility of facilities and services open or provided to the public. The CRPD furthers the development of barrier-free facilities which support the movement of older persons in care. The national legislation has to meet the minimum standards outlined by the ratified human rights treaties.

Some basic requirements for environmental safety and barrier-freedom for geriatric establishments (for example, providing a certain number of elevators and wheelchair ramps in the building) are outlined in LTC legislation at the level of the German federal Länder (Länder-level *Heimgesetze*). While complying with these regulations, individual care homes may also introduce further ways to enhance residents' mobility inside and outside of the building. For example, in Home 2, most floors were covered with a special anti-slip cork jacketing that prevented falls and enabled easier wheelchair access. None of the residents we have spoken to have mentioned difficulties in moving about their Homes. Where references to spatial restrictions in mobility were made, they concerned closed-off parts of the building reserved for residents with severe mental incapacitations: an issue discussed further in this section.

Aside from making their environment safe, the Homes we have visited also invested in making their environment attractive and thus to stimulate the residents to stay mobile. Home 1, Home 3 and Home 5 have an enclosed garden attached to the building, and in Home 1, whose premises border on the allotment garden society, the management has arranged a safe and convenient path into the green for their residents. At Home 4, the management has recently commissioned a re-setting and expansion of the Home garden. The availability and accessibility of these outdoor facilities is a premise for implementation of residents' various rights, aside from the right to freedom of movement. The garden is a place where residents socialise, walk and perform small everyday chores: activities through which their rights to health, social participation and autonomy are facilitated.

A further aspect of creating a barrier-free environment is ensuring availability of direct assistance. Help provided by other people remains of crucial importance to many residents who want to remain mobile. The 86-year-old Mrs Thiel at Home 3 says:

> *I don't go anywhere alone or don't do anything on my own any longer. Either I have my children to help me, or a nurse, or someone else. In the beginning I used to ride my*

wheelchair everywhere. Now I can't do it any longer, I have become too heavy; I've gained a lot of weight.

In terms of LTC organisational structure, enabling residents' mobility is a separate task on top of other nursing and medical procedures, and as such, it can only be implemented with the help of extra staff. Normally, mobilising residents for everyday chores and activities is performed by supervision assistants in the Social Services Department. The Head of Care at Home 3 says:

There are a few supermarkets in the vicinity of here, and some of our residents go shopping there. They can go there alone or with assistants. They can also take a bus and go anywhere further, that's what assistants are there for.

In fact, the absence of help was the only kind of mobility restriction directly experienced by our interview partners and their relatives. According to the Home 4 Spokeswoman, whose main function is complaint management, 'having to wait for a nurse to pick one up for an event or activity in the Home, or to be brought back' is the most pressing and widespread complaint she has to deal with. These are situations when wheelchair-ridden residents may feel helpless or abandoned - and which LTC managers and ombudsmen consider extremely undesirable. The Head of Care at Home 4 says:

If a nurse says she will be back in five minutes, she must be back in five, not fifteen minutes. Otherwise, we neglect our residents.

However, given the shortage of personnel (as discussed in paragraph 6 of this Report), such situations will inevitably occur even in the best Homes and due to their mundane, low-profile character, such situations are unlikely to be documented in any quality control documentation.

6.1.2 Sustaining individual residents' mobility: right to rehabilitation

Article 26 on the right to habilitation and rehabilitation[10] (CRPD) postulates that the government must take effective steps to enable persons with disabilities, which also includes older persons in care, to maximise their independence, develop their independent living and manage their impairment or health condition. This right ensures that people in care are maximising their skills for independent living. To make use of these rights, the government has to make sure that disabled persons have access to services which are available as soon as people need them and should be offered where people live in the care home or in the vicinity. Furthermore the government is obliged to ensure that everyone is aware of and can use the range of equipment and technology available to support independent living. An additional aspect of the regulation is that professionals and staff working in these services should be properly trained. [11]

In all the Homes we have visited, some of the residents we have spoken to were regularly visited by individual physio- and fitness therapists who helped them to stay mobile and recover after such debilitating events as strokes or falls. Else, 88 years old, a resident at Home 3, says that her health and her capacity to move have improved significantly since the moment she entered LTC.

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[10] Habilitation means learning a new skill that you did not have before, whilst rehabilitation means relearning a skill, for example walking or talking. Another word for rehabilitation is 're-ablement'

[11] http://www.equalityhumanrights.com/private-and-public-sector-guidance/public-sector-providers/human-rights-guidance/a-guide-to-the-un-disability-convention/part-2-know-your-rights/article-26-habilitation-and-rehabilitation

Having been admitted into the Home in a post-stroke state, she was almost fully incapacitated – and felt significantly better at the moment of our interview:

> *Back then I could not even stand on my own, or get up. And now, thanks to physiotherapy I can move a little bit. I have a private physiotherapist and she does quite a bit with me (…). She comes every Tuesday and Friday and we walk a little bit around the pond, maybe 10 minutes or so. She holds my arm and I hold on to the wooden rail. Sometimes, if I am in good shape, she wants me to make two rounds, but it is too much for me.*

In some cases, mobilising residents required a persistent and multifaceted approach to their health that lies beyond supporting their musculoskeletal system. In particular, this concerns residents with dementia who may experience loss of orientation or other difficulties preventing them from moving. The Management of Home 2 sets out to identify, discern and respond to such difficulties in the most efficient way, as the good practice example below demonstrates.

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Individual Mobilisation by Establishing Better Health Routines: Good Practice Example

Case of a resident with dementia, Home 2:

> *We have a resident who was transferred to us from a different Home where for three years she remained immobile. She was lying in bed in a single room, with no stimulation whatsoever. And when we got her here, we could see that although she had advanced dementia, she still had great interest for the world outside. We tried mobilising her but it did not work, she just kept collapsing. So, we decided to look at the reasons for her weakness, and we found out that although she was getting enough nutrition, she did not get enough fluid. We simply couldn't make her drink enough to stabilise her blood circulation. To resolve this problem, we consulted a doctor and got permission to give her liquid though a tube. Mind you, we signed a paper claiming that we would never, under any circumstances feed her through this tube, and that it was only for liquids. We intubated her at night, and during the day she was finally able to move around and take part in all sorts of group activities. She was immensely happy to see people again, to communicate. She would talk to anyone who passed by, she sang them songs and so on. It was an ultimate breakthrough for her.*

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A crucial aspect of sustaining residents' individual mobility is prevention of falls. The 2015 MDS report established that at least 80% of all LTC residents were in need of special provisions for fall prevention. The overwhelming majority of these people were receiving such provisions (86%), whereas in case of some 14% the measures for fall prevention were either not implemented, or were not adequate: the necessary devices were not in place, doctors were not informed or medication was lacking. Given that the Homes we have visited are the best of their kind, we have not documented any deficits with respect to fall prevention, and, instead, observed various creative and adequate approaches to this matter.

All Homes we have visited have exercise courses for their residents conducted by certified specialists and accessible to everyone, including wheelchair users. Such exercise courses are often classified as 'Falls Prevention' and are free of charge to all residents. Home 4 takes part in a

special Berlin-based fall prevention programme designed and implemented by the largest German insurance fund, the AOK.

The individual approach to mobilising LTC residents is beneficial both to implementation of right to freedom of movement and to right to health. To that end, various approaches to prevention of falls is particularly important: it reduces health risks, on the one hand, and ensures that residents stay mobile, on the other.

6.1.3 Restrictions of freedom to move

Another human rights problem for persons in care is the use of custodial measures or restraints. The protection against arbitrary deprivation of liberty is regulated in Article 9 ICCPR and Article 5 ECHR. Furthermore, Article 14 of the CRPD provides that

> *unless identified in one of a range of narrow exceptions, such as preventing harm to yourself or others through lawful arrest or detention, no one should be unnecessarily detained against their will.*

This right is often overlooked in everyday care. Restraints are usually carried out by bed rail or straps on wheelchairs; a deep armchair or table in front of a chair can cause similar effect. Administration of tranquilizers, limitation of access specific wards or departments also lead to the restriction of movement, up to the deprivation of liberty. Restraint is a form of imprisonment (§ 239 Penal Code) and generally prohibited. Nurses and doctors cannot decide on it without consent of the person in care or judicial authorisation by a guardianship court (§1906 para. 4 BGB). The court must examine each individual case. The number of approved restraints was 75,059 in 2013. It is not known conclusively, how many of the approximately 700,000 nursing home residents are restrained regularly in Germany.

In all Homes we have visited, risk of falls or wandering behavior were unequivocally considered as insufficient reasons for restraining residents in their right to mobility. Care managers gave clear priority to freedom and made everything possible to grant residents their autonomy, even in the face of risks. The Head of Care at Home 1 has put it as follows:

> *We are often confronted with this question: 'Why has he or she fallen down?!' Well, because people have their own will to stand up and move when they feel like it. I try protecting them, I can offer them different alternatives, and if they are refused then it is documented. But there is nothing else I can do.*

Rather than restricting residents in their mobility, various creative ways of enhancing individual safety were implemented, such as alarm mats, alarm bracelets, wheeled walkers, protection trousers and other devices – solutions that the Head of Management at Home 2 has called 'freedom-enhancing' in contrast to 'freedom-restraining'. This is how the Head of Management at Home 1 describes implementation of these solutions:

> *Plenty of our residents have sensor mats. These mats send a signal when someone steps on them, so that a nurse can come straight away and remind the person to take their wheeled walker. We aim to couple sovereignty with security. These sensor mats, they are not to infantilise people, but instead, to empower them, to let them walk on their own after someone comes and tells them, hey, don't forget to take your walker, or let's put*

those protector trousers on before you hop off. (…) We are trying to couple livability with modern assistance gadgets of all kind.

In Homes we have visited, implementation of 'assistance gadgets' is carried out in agreement with residents: the consent to wear an alarm bracelet or protection trousers is documented in written form.

The intention to support all residents in their freedom of mobility may, however, also have its limits. Deliberate restraint of mobility (in contrast to mostly unintentional non-provision of help) is a measure that was practiced in all Homes we have visited – albeit in strictly legal and mild forms.

In Homes 1 and 4, cases of individual immobilisation were mentioned, such as restraint trousers meant to keep a person in the sitting position (Home 1, epileptic wheelchair-ridden resident) and wheelchair belts (Homes 1 und 4, wheelchair ridden residents with severe dementia). In all cases, consent of residents or legal representatives, as well as court decisions were in place. Such individual forms of mobility restraint may prevent a resident from hurting themselves, however, when it comes to safety and comfort of other residents they may be of only limited effect. How can the rights of one person be realised without the rights of all others not being infringed? A telling case from Home 4 provides an insight into this difficult dilemma:

We have one resident with severe dementia who has a wheelchair belt (…). He moves around a lot, and he seems to be very happy about it. He spends a lot of time rolling about the common room, and sometimes it can be difficult. Every now and then the flower pot gets broken, or a vase is misplaced, or once he had plucked all the leaves off a really beautiful tree we had here. In principle, when somebody has severe dementia as in this case and may become a safety threat to others, they need to be placed in a special Home. But his son thinks that another move will kill him, and we keep him here. He is a part of the Home, we can´t just throw him out. And now that we need to place a Christmas tree in the common room, we are really not sure how to make it, how to keep an eye on him that he does not hurt himself or others.

To ensure safety and comfort for all residents, three out of five Homes we visited (1, 2 and 5) practice various forms of spatial separation for residents with severe dementia or otherwise mentally ill persons. In Home 1, this separation applies to meals only: residents with dementia have a separate dining area. This decision is necessitated by having to meet the safety and comfort needs of all residents at the same time. The Head of Management says:

Normally, we do not practice a segregated approach here. We believe that people can provide each other with some basic mutual support. There is, however, one exception: for some residents with dementia, even such small groups as ours are too much. For them, it is too loud, and so on. This is why we decided to have two dining areas in all our groups, one for residents who have severe dementia, and one for those who are more able. This is, of course, a very difficult decision to maintain because [pauses to think] sometimes people from the 'able' dining room start feeling bad that they will also 'end up in a dementia kitchen'. But, at the same time, we also get very direct, sometimes even rude requests from able residents, like, 'take him or her away, they disturb us'. (…) We see very positive results from placing residents with dementia into even smaller groups, protecting them from

noise and disturbances. We would like to do more of this, but for that we need personnel; qualified people who know how to work with residents with dementia.

This interview excerpt touches upon themes that are relevant for other Homes where some forms of separation between residents are practiced. Indeed, cognitively fit residents may associate spatial segregation with stigmatisation and loss of social contacts: 'ending up in the dement kitchen' means losing a part of self, further decline. This perception is particularly strong in Homes with permanent or semi-permanent forms of segregation (Homes 2 and 5), with mentally ill or residents with dementia occupying separate parts of the building, insulated by additional doors. Whereas care managers and workers have a clear professional term for such areas – 'protected wards' (*beschützter Bereich*) – residents themselves do not have a term for those parts of their Homes. In Home 5, two female residents spoke of their former corridor or kitchen neighbors moving 'over there' – a vague definition of a place that, out of fear, cannot be named. Clearly, both residents and Home Managers understand that residents with dementia in 'protected wards' or 'over there' are restricted in their right to mobility and right to social participation. At the same time, these restrictions enable protection of other rights essential to all residents, including the ones in separated areas: right to privacy, right to nutrition and, to some extent, right to highest attainable standard of health.

It also must be noted that in Homes we have visited, the management was making great efforts to compensate for infringements of mobility and social contacts resulting from spatial segregation so that residents in 'protected' and 'regular' wards do not live isolated lives. In Home 2, where a significant proportion of residents suffer from mental illnesses other than dementia, people may be transferred back and forth into separated wards, depending on their clinical picture. Two persons interviewed in this project have been through such transfer, one of them at the moment of the interview living in the 'protected' area. Although due to the interviewees' cognitive state these conversations had little direct informative value, the body language and the sense of affection these two men demonstrated in their contact to care personnel was indicative of trust and safety. What is most important, however, is that both in Homes 2 and 5 residents in 'separated' parts remained, to the greatest possible extent, a part of the Home's everyday life. In Home 2, mentally ill residents may take part in all events and activities organised in the Home as they are picked up, supervised and brought back to their wards by care workers. Both in Home 2 and 5 all residents have access to the Home's outdoor facilities.

The aspects of the right to freedom of movement discussed in this paragraph demonstrate indeed that mobility is an essential pre-requisite for autonomy and for implementation of various other rights. The Homes we have visited aspired to enhance their residents' autonomy both by adjusting their settings to residents' needs, and by investing in residents' individual rehabilitation. Restrictions of mobility were generally regarded as undesirable and where they were unavoidable, attempts were made to compensate for them.

6.2 Right to privacy

The right to private and family life is very broad in scope and covers many different situations which relate to the rights of older people in care. It is enshrined in the ICCPR (Article 17), the CRPD (Article 22) and the ECHR (Article 8). Especially Article 8 of the ECHR outlines that privacy

is defined broadly and relates to all aspects of privacy. The right is realised in and outside of a private home. All close personal ties of any kind are included in the term family life. The right to wellbeing is covered through retaining autonomy, choice and dignity. It requires that there is access to information and participation in decisions that affect one's life. The right to home is meant as respecting every individual's home, not only an apartment or house but also a room in a care home.

The right to privacy also addresses the infringement of the individual's moral and physical integrity. The power of an individual to make decisions as to personal risk and protections to safeguard respect for aspects of an individual's personal identity, including matters such as personal choice as to one's mode of dress.

Some aspects of the right to privacy are regularly evaluated in MDS reports, while the following criteria were developed and measured in 2012 in a sample of 12,190 Homes (MDS 2013: 135):

- Residents can furnish their rooms with their items, and can decide upon the room's interior themselves (98.7% of Homes);
- Residents can use their own laundry (99% of Homes);
- Residents have access to lockable drawers (98.5% of Homes).

Relying on our interviews and our observations in homes we visited, we suggest distinguishing between (a) spatial privacy enabled by physical environment of LTC; and (b) normative privacy enabled by daily practices and by social intercourses between all actors involved in LTC (residents, care workers, relatives, volunteers, etc.). All issues related to personal hygiene were discussed by our interview partners in the context of normative privacy.

6.2.1 Spatial privacy: availability of places where one can be alone

In 2011, according to the data collected by the Federal Statistical Office in 2011, about 60% of places in German LTC were in single rooms, the remaining 40% distributed between two-bed rooms (forming the majority of this at 39.2%) and other forms of accommodation. The proportion of single rooms is, however, likely to increase due to significant changes in requirements to living conditions outlined in the different laws on LTC on the Länder-level. Not only are new homes built in accordance with updated legal regulations on the Länder level, which are slightly different, but also older Homes are renovated in order to increase the number of single rooms e.g. in Berlin the new law[12] stipulates that only single and double rooms are legal forms of accommodation and this requires adjustment of hygiene facilities (such as bathrooms) to fit residents' needs.

The overwhelming majority of LTC residents we have spoken to (with one exception, as discussed below), live in single rooms and have their own hygienic facilities. This uniformity of accommodation, perhaps, results from the structure of our research sample. First, as outlined in the methodological section, the Homes we have visited are likely to be of exceptionally high

[12] Wohnteilhabe-Bauverordnung - WTG-BauV, 7 October 2013 (GVBl S. 542)

standard, including living standard. Second, two of the five Homes were run by private providers who generally have a higher proportion of single rooms.

Having a room of their own and being able to furnish it with their own things is of great importance to people we have spoken to. The significance of such private space demonstrated itself in the ways our respondents showed us around their rooms and proudly presented items that were important to them. Throughout our visits to different Homes in various parts of Germany, we saw rooms that were as different as their occupants. In a town with a long-standing soccer tradition, a resident decorated his room with posters and cups his team had won a long time ago; a religious woman in a small village had icons and figurines of saints – while just a floor above her, a former leading engineer of a large factory has equipped his room with a computer, wireless router and a printer.

Only one LTC resident we have spoken to was living in a double room at the time of the interview: the 72-year old Mrs Hessel at Home 2. Having spent some 15 years in this Home, first admitted with a severe case of depression, Mrs Hessel has never had her own room. At the time of the interview she was sharing a room with a woman who was 10 years older and whose physical condition Mrs Hessel considered to be significantly worse than her own. Mrs Hessel spoke with affection about her roommate and emphasised throughout the interview the importance of this relationship. She assisted her roommate with various chores and saw herself as 'indispensable' to her friend. When asked directly, whether she would prefer living in a single room, Mrs Hessel said no and insisted that living in a double room was doing her good and kept her mind off her depression. Nevertheless, there is a darker side to sharing a room: several times, Mrs Hessel was placed in a room with a dying resident. Understandably, she speaks of this experience as 'scary' and 'horrible' throughout the interview.

> *Most of them were no longer speaking. They were just lying in bed and had to be turned regularly. It has really disturbed me when a nurse would come two or three times in a night to change their diaper. I always woke up and it was very unpleasant. One of them, Maria Beck [name changed - DIMR], died in her sleep, and no one noticed. It was me who found out first and had to go and tell the nurses that she was dead.*

Reflecting on Mrs Hessel's case, it becomes apparent that even when some people find shared accommodation preferable, a severe infringement of their rights may occur.

Spatial privacy is an essential but not exhaustive condition for adherence to human rights. There is little use in single rooms if anyone may enter them anytime, imposing their schedules and decisions on residents. Hence, an equally important aspect of implementing the right to privacy is the normative privacy, that is, behavioral practices adopted in each individual Home.

6.2.2 Normative privacy: daily practices and social intercourse. Personal Hygiene.

In all homes we visited, care workers spoke of clear rules meant to protect residents' privacy. These rules encompass various aspects of interaction and daily care practice: How are residents addressed? Who is allowed to enter their rooms and when? What is the way of going about their personal belongings, including documents and money? How are residents looked after during night shifts?

In all Homes we visited, the personnel are trained to never enter the room without knocking on the door first. This is a principle most nurses brought up immediately when asked about when and how they may enter residents' rooms. We have also observed the adherence to this rule in

action when interviewing residents: whenever a nurse entered a room, mostly to enquire whether we needed a cup of coffee or anything else, they knocked and asked whether they were disturbing or not. An exception was made only for emergencies, as one of the nurses at Home 1 said, 'when the alarm bell rings, then you just drop everything and rush in'.

In Home 1, special attention was paid to the organisation of night shifts. Residents, who do not wish to be disturbed at night, sign a special agreement form, and their rooms are not checked upon till a certain hour. However, they may always call for emergency help if they need to.

All care workers and managers we have spoken to have a very distinct understanding that residents' belongings and personal documents are their private property and cannot be touched without explicit permission. It must be noted, however, that at several instances and in different Homes we heard residents talking of care workers helping them to arrange clothes in their closets or sort out their laundry. That is, residents and nurses are mostly able to establish good functional relationships with each other, where respect for privacy in integrated into social intercourse.

6.2.3 Rights and needs of residents with dementia: How much privacy is too much?

The essential importance of privacy and one's ability to have a life behind the closed door were recognised by all actors in the LTC. There is, however, one major exception, and that is: people with severe dementia. Some aspects of care for residents with dementia challenge the established notion of privacy as ultimate good and leave gerontologists, care workers and policy makers with difficult questions: How much privacy is too much? And is it possible that the right to privacy may morph into loneliness?

Protecting the liberty of people with dementia means providing them with care which will enhance their well-being and this is precisely the point where German national LTC legislation may appear too rigid. The requirements to privacy stipulated by the laws may, in fact, be harmful to residents with dementia and infringe upon their liberty and their autonomy.

Various studies into the clinical pictures of dementia suggest that a familiar atmosphere, repetitive daily structure and, above all, reliable presence of people one trusts and knows may have extremely beneficial effects on a patient's well-being. In contrast, isolation and sporadic contacts may cause irritation, aggression and frustration. To meet the needs of individuals with severe dementia, one type of special care accommodation that we want to mention is the so-called Care-Oases (*Pflege-Oasen*), which has been developed by German gerontologists and nurses. The main features of Care Oases are as follows (Rutenkröger et al. 2013):

- Small group: 5-7 residents with an advanced form of dementia share one living space;
- round the clock care by specially qualified personnel;
- Spatial organisation and equipment which stimulates residents' sensory reactions and supports their sense of orientation: care oases may have a special color- or lighting scheme, and may be equipped with special furniture. A Care Oasis normally consists of social area, sleeping area, quiet area, a kitchen and hygienic facilities.

Care workers and relatives of Oases residents also tend to have high subjective satisfaction with this type of living arrangement and supervision, with nurses reporting significantly lower levels of burn-out than in regular care (Rutenkröger et al. 2013). These positive effects result from

permanent direct contact between care workers which enables nurses to adjust supervision activities to every particular individual. Nevertheless, the proportion of German LTC establishments practicing Care Oases remains very small, with the main hurdle being the legal requirements for living arrangements in LTC which normally do not permit multiple-person accommodations with shared hygienic facilities. The Head of Management and Head of Care at Home 2 who have established and are running such an Oasis in her Home, talk of perpetual conflict of rights that underpins the organisational and ethical principles of Oasis work: this type of care model is constantly attacked by various quality control mechanisms and by policy makers.

> *The Head of Management: we are being permanently reproached for being willing to stick six people into one room and make more money by stripping them of their privacy, while no one sees the real needs of these people.*
>
> *The Head of Care: The truth is, someone who is in a very advanced stage of dementia, does not necessarily need a single room. (…)For our patients in the Oasis, the need for uninterrupted communication, for closeness and help is much stronger than other needs, so that all other rights, such as right to privacy, becomes less significant. (…)We change as we grow old, and our rights need to change, too.*

6.3 Right to highest attainable standard of health

The right to the highest attainable standard of health, which is a fundamental human right, is legally enshrined at international, regional and national levels. The enjoyment of the right to health is recognised by numerous international human rights instruments, including those that have been created to protect the human rights of particular groups, such as children, women, persons with disabilities and those who are subject to discrimination on the basis of race (E/CN.4/2003/58, paras. 10-21). The most important formulation of the right to health is contained in Article 12 of the ICESCR, which is the cornerstone of protection of the right to health in international law.[13]

The CESCR's General comment No. 14 elaborates on substantive issues arising from the implementation of the right to health and addresses particular issues related to older persons, including "preventive, curative and rehabilitative health treatment…maintaining the functionality and autonomy of older persons … [and] attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity".[14]

The Committee for monitoring the implementation of the ICESCR has expressed its view that the right to health requires that medical treatment is "timely and appropriate". To guarantee older persons' right to health in care homes, regular review of medication is necessary. This should include reviews of the appropriateness of continuing with medication. Treatment in the absence of informed consent may amount to violation of a person's physical and moral integrity and, therefore, their right to life.

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[13] Anand Grover, Special rapporteur on the right to health.

The national Quality of Care Evaluation Programme implemented measures on the quality of health provision in LTC on the basis of the following criteria (MDS 2014):

- Administration of pharmaceuticals in strict accordance with physicians' directions
- Appropriate administration of medication
- Pain record
- Administration of pain medication
- Appropriate treatment of chronic wounds (decubitus)

According to the MDS report, in the last few years there have been positive improvements in some aspects of medical provisions in LTC, above all, with respect to prevention of chronic wounds. Nevertheless, at national level there is still significant room for improvement with respect to the administration of medication. In 2013, faulty administration of medication was documented in the case of almost 10% of LTC residents, where dosages, timings or prescriptions were not correct. Aside from that, in almost 14% of cases, medications were not appropriately stored. One of our interview partners has directly experienced misuse and faulty administration of pharmaceuticals. Mrs Hessel (72), who has been severely depressed for many years, speaks of an LTC institution she stayed in before being transferred to Home 2 where she lives now:

> *In Neuburg, I was feeling very poorly. I think they were mixing something into our drinks. Besides, there I was not receiving any sustainable medication; instead, I took a new pill every day. I was feeling worse and worse.*

According to MDS, faulty administration of pharmaceuticals is falling gradually every year. However, given the statistics above, it is a problem still present in many German care homes. Given the high risk potential related to misuse of pharmaceuticals this situation is unacceptable: a state of affairs recognised as 'unsatisfactory' by the MDS (MDS 2014: 26).

Given the nature of our sample and our mandate, we did not encounter or document any cases of medication misuse in Homes we have visited. In fact, LTC residents interviewed in our study reported satisfaction with their health, and, in several instances, claimed significant improvements in their health since their transition into their Homes. This concerns persons with mental and physical illnesses alike, including Mrs Hessel at Home 2:

> *Once I came here, I started feeling much better, and I am very happy with the medical treatment here.*

Else, an 88-year-old resident of Home 4, also reports a significant improvement in her health from 'being unable to stand' on her own to 'walking around the pond' with a physiotherapist. Where no improvements to health were noticeable, the interviewees attributed them to the natural process of ageing rather than to absence of good care. A daughter of a resident of Home 5, who expressed several criticisms about organisational aspects of the Home's life, gave a very positive account of medical care in spite of the fact that her mother's health was not improving objectively:

> *Of course, she is not getting healthier. But that's normal, she is very old. It does not have to do with care. In that sense, they control everything regularly, that she has no inflammations anywhere, no wounds, and things like that.*

In all Homes we have visited, residents were regularly visited by medical specialists; in many cases these were doctors who residents had been in contact with prior to moving into LTC. Both regular and emergency access to medical specialists was available in the Homes we have visited. People we have spoken to – home residents and their relatives – were generally satisfied with medical treatment in LTC. Our interviewees spoke of medical supervision in a way that suggested that treatment was transparent, regular, accessible and based on agreement with the patient (the LTC resident themselves) or, where necessary, with their relatives. A daughter of a resident at Home 1 speaks of an episode of medical treatment:

> *Whenever I need to clarify anything, I talk to Jenny, the chief nurse in Papa's ward. There were a couple of weeks recently when Papa suddenly got rather anxious, more than usual. I told Jenny that I was concerned about him, and she called a doctor, the one that comes regularly. The doctor did come to check on him, and she said, indeed, that Papa needed to calm down a bit, because he also couldn't sleep, which was worse. So, she prescribed him half a pill and he took it for a while, and it did wonders. He has become calmer again, and he could, finally, get some sleep, too. He quit this medication after a while because he no longer needed it. All in all, it was no problem at all. The nurses took care of everything straight away. All one needs to do, is to speak.*

The resident himself (87) does not have a direct memory of this incident (he has a slight case of dementia), however, his account of asking for medical help, albeit very brief, confirms that access to medical help in his Home is rather easy. On a regular basis, he is visited by the same doctor that had been seeing him before his transition into Home and for emergency cases, it was '*enough to tell them out there* [nurses – GIHR]*, and they'd call Dr. Hartmann. Dr. Hartmann always comes straight away*'.

Aside from treating acute cases, LTC residents we have spoken to received regular visits from medical specialists: psychiatrists, orthopedic specialists, ophthalmologists, urologists and dentists. For example, several residents we have spoken to received special podiatric treatment for diabetic feet, others had their urine catheters replaced regularly, and some were supervised by a cardiologist. Mrs Hessel (72) at Home 2 was also receiving visits from a pain therapist who prescribed her an ointment for her legs.

One aspect of physical health that remains frequently overlooked in discussions on care quality standards is dental hygiene – even though the MDS report suggests that almost 70% of LTC residents in Germany need support with cleaning their teeth or dental prostheses. While the majority of these people received the help they needed and requested, in the case of some 15% a poor state of dental hygiene was documented (MDS 2014: 34).

Raising awareness of the significance of oral health in old age is an important item on the WHO global agenda (Petersen and Yamamoto 2005) which suggests that "the negative impact of poor oral conditions on the quality of life of older adults is an important public health issue, which must be addressed by policy makers" (Petersen and Yamamoto 2005: 81).

The Management of Home 2 is paying special attention to dental hygiene by implementing a special care programme that has been awarded various prizes as an example of good practice.

This care programme consists of several principles which not only help to foster the residents' right to health, but also have a positive cumulative effect on other rights, such as the right to autonomy, the right to nutrition and the right to social participation. It includes a holistic

approach and suggests that dental hygiene is also a question of therapy and nutrition. Furthermore the nurses are part of the programme and get special training on dental health.

6.4 Right to social inclusion

Article 25 of the ICCPR provides for the right to take part in the conduct of public affairs and to vote. Many of the provisions for social inclusion in international human rights treaties refer to participation in wider society. The obligation of states to take effective and appropriate measures to ensure all persons with disabilities enjoy their right to full inclusion and participation in the community are principles of the UN CRPD.

The CRPD Committee has indicated that states should not prevent persons with disabilities from voting (as already mentioned in an interview on page 21, 22) and taking part in public affairs, including those placed under legal guardianship. The paradigmatic shift to recognising LTC residents as autonomous rights holders, rather than as patients fully reliant on care personnel (as discussed above in Section 4 of this Report), has resulted in various legal and organisational initiatives meant to foster residents' right to social inclusion. In particular, as discussed in Section 2.3 of this Report, LTC establishments are required to run their own Social Services Department. The work of the Social Services Department has two major objectives: 'outside inclusion' by greater community involvement, on the one hand, and 'inside inclusion' through empowering residents' participation in the Home's daily life. In all Homes we have visited both forms of inclusion were realised in one form or another.

6.4.1 Strengthening social inclusion by integrating care homes into local communities

As Kirsten Hämel observes (Hämel 2014), "The growing demands for a change in nursing home social environment and a greater involvement of civil society have resulted in development of varied types of community involvement in nursing homes". Indeed, the Homes we have visited maintain connections and partnerships with various communal structures: from religious organisations to schools to sports clubs. The only exception was Home 2 where almost no volunteers are involved in planning and organising activities, which the Head of Management attributes to the Home's location in a remote, sparsely populated rural area

The other four Homes in our sample were continually collaborating with external organisations, developing and carrying out regular and special activities for their residents: seasonal feasts, field trips, thematic clubs, religious services, etc. Hämel defines this organisational structure as "hybridisation of services", with care homes being continually confronted with a diversity of organisational objectives and demands. Although the involvement of community structures is motivated by strong commitment to the concept of a dignified life for older people in LTC, the effects of opening LTCI to community support may be mixed, given that involvement of family and volunteer support may bring new questions with them.

Most Care Managers we spoke to considered support of volunteer organisations and individual persons to be an indispensable, inherent part of the Home's life, without which respectful and dignified care would not be possible. Involvement of community services opens up the horizon of possible activities and caters to the specific needs of different residents, allowing them to participate in a whole range of events.

The Head of Care at Home 1 says:

We reach our limits at some point, too, and when I have a single person who has one specific wish; it is always very helpful to have a volunteer who could help to fulfill it. It is always something special when a volunteer can take care of a resident and make something happen that we, as an organisation, would not be able to see through.

LTC residents we have spoken to appeared to benefit greatly from their Home's co-operation with external organisations, while various cultural and social activities were mentioned in interviews as a source of joy and communication:

- Seasonal Feasts: Autumn lantern feast (St. Martin's Day), Christmas, Easter, Summer Feast.

- Regular cultural or religious events: weekly or monthly sermons, bingo club, handicraft club, choir.

- Individual forms of companionship: walks and conversations.

It must be mentioned, however, that the main focus of the Social Department lies not in organisation of 'special' events, but rather, in organisation of daily life accessible to all residents, as we will discuss below.

6.4.2 Empowering residents' participation in Home life

Facilitation of self-government in LTCI is a primary form of recognition of older people as rights holders rather than as objects of care. The role of the main LTC self-government instrument is performed by so-called *Heimbeiräte* (*Heimbeirat* in singular – GIHR) or Home advisory boards, whose operation is regulated by a special legal framework.

LTC legislation at *Länder* -level (*Heimgesetz*) guarantees LTC residents that they may participate in matters of home operation. The Home Participation Directive (*Heimmitwirkungsverordnung*) further stipulates that residents may take part in development of quality control measures and in setting agreements with the care insurance and social assistance agencies (§ 1 para. 2 *Heimmitwirkungsverordnung*).

Participation is generally realised through the formation of local advisory boards, whose members represent the interests and concerns of the home residents (§ 10 *HeimG*). The composition of advisory boards may consist of residents and external persons, such as volunteers or relatives. The advisory board is not only meant to make suggestions about organisation of life in each individual Home, it also must be informed about all decisions made by the Home's provider, and the board's suggestions and concerns need to be taken into consideration. Should a provider not address these suggestions and concerns, it must specify the reasons (§ 32 para. 2-4 Home Participation Directive, *Heimmitwirkungsverordnung*).

Out of five Homes we have visited, four had an established advisory board, and group interviews with all of them were carried out. In one Home (Home 4), an alternative form of resident representation, a Home spokeswoman, was established. The spokeswoman was interviewed for this project, too: this case will be discussed in more detail in Section 7 of this Report (Right to Complaint and Redress).

According to § 30 of the Home Participation Directive, Home advisory boards have a legal right to be fully informed about all essential aspects of care, from material, to organisational to medical. However, in reality the advisory boards are only able to include a splinter of these issues on their agenda: a conclusion formulated by previous research and fully confirmed by our

own interview material, as we will discuss below. The Evaluation of Home Participation legislation, commissioned by the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth in 2006/7 (Mingot et al 2007) suggests that Home advisory boards cannot meet the expectations set out for them by policy makers, mostly due to LTC residents' physical and cognitive impairments and structural factors.

Our interviews further confirm these aforementioned obstacles to the work of LTC advisory boards. First, in all three Homes, members of the advisory boards had limited contact with other residents: the scope of their interaction was confined, at best, to their dining groups, at worst, to their immediate table neighbours. Advisory board members' role as home spokespersons seemed to have little relevance to other residents. Even in Home 5, where a poster with photographs of all Board participants is hanging in a most central and visible space, board members claimed they were hardly ever approached in their 'administrative' role.

In fact, the board members did not identify themselves with their 'spokesperson' roles even with respect to their own lives. The issues that the boards we have interviewed were able to address concerned direct, everyday experiences: the quality of food and, to some extent, organisation of free time.

The following excerpts are indicative of topics and problems that arise in advisory board work:

Home 1:

> *Interviewer: What are the topics you deal with most during your meetings?*
>
> *BM1 (80, resident): Food. (…) Food and household stuff. At first, the food was just getting worse and worse, and it was always the same. Now, I'd say, it has become better. At least, there is more variety, whether it is meat or vegetables. So people are saying, ok, now there if something different. It is important that they notice the difference, but it is terribly difficult to find someone who would participate [in the advisory board - GIHR]. I mean, it is hard. I am getting too old for this work, too. I am 80 years old, too.*
>
> *Interviewer: So, you are saying that things have changed. What is the reason behind it, what do you think?*
>
> *BM1 (80, resident): perhaps, a different cook? I don't really know. A cook, I guess.*
>
> *BM2 (72, community volunteer): Or, maybe they have told the kitchen. I suppose, they did.*

Home 5:

> *Interviewer: What were the topics you discussed during the last meeting?*
>
> *BM1 (resident, 77): Well, we have heavy smokers in the Home, and sometimes they roll out with their wheelchairs right towards the entrance and disturb everyone who has to go in and out. Yesterday I had to pass by, and what do you think, did any of them move? Mr Meyer [Head of Management - DIMR] told me he spoke to the people, but it does not seem that anything is changing.*
>
> *BM2 (resident, 92): Yes, some people are like that.*

BM1 (resident, 77): I don't know whether anything can be changed on that front, but this is not how things should be.

These interview excerpts demonstrate that even when advisory boards problematise a specific topic and document the discussion in a protocol, they are unable to ascertain whether any solution may be implemented, and whether their work has any real, tangible effect on the organisation of Home life and services. Board Members cannot say for sure whether 'anything can be changed', and when a change is in place, they are not certain whether it is related to their own participation in the matter.

Hindrances to self-governance in LTC, related to poor state of physical and mental health of most LTC residents, were recognised and addressed by policy makers already in 2001, when an amendment to the Home Participation Directive was made, permitting third persons – volunteers, relatives, members of non-profit organisations and others – to be elected and to participate in advisory boards. This solution, however, appears to have had little effect on the potency of Home advisory boards as instruments of self-governance. Our interviews suggest that there might be several reasons for it.

First, third persons may have even less knowledge about internal organisational processes in the Home, than the residents do. For example, as we discussed the board's position on quality of food in Home 1, the volunteer member had to withdraw from the conversation because, as she explained, 'she was not eating in the Home and could not contribute to the topic'. This example suggests that integration of third persons into advisory boards is a process that requires a lot of self-reflection on the part of volunteers.

Second, there may be conflicts of interest between resident and non-resident board members, as interviews in Home 5 demonstrated. While the resident members were extremely reluctant to consider the advisory board as a complaint management mechanism, the non-resident member insisted that the board had to express and deliver criticism to the Home administration. The 'third person' (daughter of one of the residents) says:

I have a general feeling that the board does not like to hear any criticism. These old ladies who sit there, all they do is nod and say 'yeah, yeah, it will be taken care of'. We are not a team on the board, I rather feel like a dummy there. Mrs Weber, the board head [BM1 – GIHR] is a sort of 'queen' of the Home, and it is just impossible to tell her anything, to make any suggestions. Besides, she has been living in this village for ages, and she thinks she knows everything. And the worst is, everyone else goes along with it. The other ladies on the board are just her entourage. So, in the end I sit there, I listen, but I can't really exchange. (…) Whatever critical remark about the Home I make, Mrs Weber responds immediately, 'no, here everything is great'.

We observed a similar dynamic at a board meeting in Home 3, where a volunteer non-resident member was steering the conversation towards expressing criticism, while the only resident member present was vaguely abnegating her comments.

Lack of motivation to engage with deficits in Home life may be explained by the desire of residents to be seen as 'grateful' and 'compliant'. This desire stems from residents' perception of their dependent position and fear of consequences, even in best cases like the Homes we have

visited, where direct experiences of neglect or violence were extremely unlikely. These themes will be reflected upon in more detail in paragraph 5.6 Right to Complain and Redress.

All in all, the participatory role of the advisory board, with its objectives and limits, remains unclear both to Home residents, and to its members. We suggest that to facilitate advisory boards' consultative function, various forms of assistance need to be provided to its members, such as, for example, coaching, regular dissemination of information and meeting moderation. The Home management also needs to provide Home advisory boards with feedback on actions taken upon their recommendations. On top of that, alternative mechanisms of social participation need to be introduced or better developed. First, as our good practice examples demonstrate, the right to social inclusion receives its utmost realisation through daily low-threshold activities organised by Social Services Departments. Indeed, as discussed in Section 4.2 of this Report, creating a sustainable day-to-day structure that is accessible to all residents, including those with dementia, is the greatest pre-requisite for participation in matters related to the Home's life. Such activities may be called 'guided household chores' and their purpose is to sustain residents' autonomy and their capacities. Second, the complaint management function, insufficiently performed by advisory boards, needs to be delegated to other low-threshold independent mechanisms, as we will discuss below.

6.5 Right to complain and redress

The right to access to justice is upheld in Article 13 of the CRPD. The right to an effective remedy is enshrined in Article 3 of the ICCPR and Article 13 of the ECHR. The concept of access to justice broadly refers to the right to be treated fairly according to the law. Government is obliged to provide individuals whose rights have been violated with a remedy and reparation, as well as equal protection of the law. In practice, the case should be brought to court or the individual has to get access to free legal aid and to a fair trial. The fair trial can also be achieved through mechanisms such as the UN Monitoring Bodies, Equality Bodies as well as the European Ombudsman at EU level. Access to justice in the form of a remedy and reparation is a process and should lead to the underlying inequalities which gave rise to the violation in the first place being addressed. Furthermore, the protection of human rights requires the effective functioning of the justice system and timely remedies for violations. Whichever means are used to provide redress, a remedy must be effective in practice as well as in theory and law.

At the moment, organisation of independent complaint management in German LTC is extremely fragmented and not transparent, which, to a large extent, results from the general federalist approach to LTC regulation. The mandate to serve as formal complaint offices is held by federal LTC quality control institutions: that is, the Medical Services of Compulsory Health Insurance Funds (MDK) and LTC Surveillance Offices (*Heimaufsicht*). Although most quality control procedures performed by these organisations on the premises (that is, during regular unannounced visits to LTC establishments), as well as the criteria for assigning quality grades, are minutely outlined in various documents, the performance of complaint management is addressed very poorly. It is not quite clear, under which conditions and to which extent the consultative and complaint management function is carried out by MDK and Surveillance Offices.

Some initiatives to provide LTC residents with a direct and accessible mechanism for filing complaints have been established by various NGOs across the country, funded by a variety of

non-profit charitable organisations. In most cases, those are telephone hotlines for LTC residents and their relatives. Unlike LTC surveillance bodies which conceptualise complaints as a tool for quality development, such organisations explicitly render protection of human rights as their fundamental and principle goal (http://www.beschwerdestellen-pflege.de/images/stories/BuhlWEAAD2012-k.pdf) Although such initiatives are an important component of civil participation in everything that concerns nursing care, they are too fragmented and have no legal mandate.

This fragmentation of complaint mechanisms is considered by some experts as an infringement of LTC residents' rights to complain and redress and as an insufficient barrier in the prevention of violence against LTC residents. Another possibility which is suggested by human rights lawyer Susanne Moritz, is filing complaints about elder abuse in LTC straight to Constitutional Court (Moritz 2014). One such complaint has been filed by the German Social Union (VDK) on behalf of seven persons from all over Germany, which expect to be placed in the near future in a nursing home because of their life situation. All complainants fear that their human rights will be violated if they have to reside in a nursing home, because neglect, pressure sores, malnutrition, dehydration and custodial measures with restraining belts or drugs occur far too often to be seen as regrettable individual cases. The conditions under which nurses in LTC must operate, lead to these human rights violations of older persons in care. The Federal Constitutional Court has to decide on the admissibility (VdK 2014). The constitutional complaint mechanism can be seen as a political tool to draw awareness to deficiencies in LTC system.

The shortness of existing complaint management arrangements was addressed as early as 2005 in a comprehensive report drawn up by the Ministry of Family Affairs, Senior Citizens, Women and Youth. The experts conclude that 'an evaluation of conditions under which complaint offices perform their work must be undertaken' (BMSFJ 2005) – however, no such systematic evaluation has occurred to date. The complaint and redress functions of surveillance institutions remain outlined only vaguely and, judging from our interviews, appear to be of little relevance to care workers and to LTC residents alike.

Indeed, in our interviews no references to any independent complaint management mechanisms, whether governmental or non-governmental, have been made, either by LTC residents and their relatives, or by care workers. Where complaints and redress were mentioned, only internal Home structures were involved. In the next paragraphs we will discuss several mechanisms available in Homes we were visiting, and will begin by discussing the most fundamental barrier to making a complaint – the fear of 'moaner' stigma.

6.5.1 'I am not a moaner': Legitimising one's right to complain

Most residents and residents' relatives we have spoken to made a point of 'having nothing to complain about personally' at the start of the interview; in several cases it was an opening line. Instead, there were 'others' who 'always had a reason to moan', but the interviewees themselves found everything 'all right'. Such opening statements do not necessarily adequately reflect resident's real satisfaction with their life in LTC; instead, they are indicative of expectations people had of our mission. With care homes being a subject of perpetual check-ups and evaluations meant to document various grievances and drawbacks, residents attributed us with the function of quality control mechanism. The 'moaning others', at the same time, were a construction meant to present the speaker themselves as a person well-adjusted to the LTC structure and holding no unreasonable expectations. Mrs Hessel, 72, at Home 2:

Personally, I am content. I have nothing to complain about. Sure enough, there are always those who moan but I am not like that.

Interviewer: What do they moan about?

Mostly about food, but also about nurses. I don't even want to mention here what kind of words they say about nurses. We have this lady here, when a nurse is washing her, she shrieks for help immediately, and if you don't know what is going on, you may think she is being murdered. And at the same time, no one is hurting her, they just want to wash her or help her to eat.

Throughout further conversations, several of our interview partners made an effort to present themselves as benevolent and well-integrated into the LTC system – in contrast to the 'moaning' others. This benevolence is reasoned through comparative perspective, while two reference points are continuously brought up: one's own home, on the one hand, and the demonised 'other care homes', on the other. Here a daughter of a resident of Home 1 speaks of her mother's disappointment with a long-awaited festive meal being unexpectedly cancelled:

Monday was Helen's shift, so I asked her who I should tell off for such disappointment. 'In the central kitchen', she said, and I was, like, 'Well, I can't call the central kitchen directly, and I don't feel like sneaking in there and making a scene now'. I don't do things like that. Then I thought that I will bring it up next time there is a field trip. Or maybe, I will talk to Mrs Meier (Head of Management). I don't know, really. You see, every time something like that comes up, I think: my goodness, it looks like I am just picking on everything for the sake of it. One has to accept the fact that it is not like at home here, full stop.

Mrs Thiel at Home 3 expresses a similar sentiment:

It is what it is, a care home. The food is not so good. I think that we have two different cooks because one day the food is very good, and the next day, not so. The problem is, one keeps comparing everything to how it was at home. And this, of course, is a very big mistake.

The demonised 'other homes' create a further angle of comparison to one's own experience: homes one saw on TV 'that had to be closed' (interviews with relatives at Home 1), 'terrible homes' one had relatives in (resident, Home 3) and homes where one stayed before and which had low standards of care (residents, Home 5 and Home 2).

Talking about adjusting one's needs to what is conceptualised as 'objective' reality and withholding complaints, is a strategy of self-presentation typical for total institutions, where dissent may – at least theoretically – be penalised, if not by direct discrimination then, at least, by the stigmatisation of 'moaners'. Old people's dependency on help provided to them by nurses and care managers is a primary reason to 'keep quiet' and 'be reasonable', as various studies demonstrate (BMSFJ 2005). This empirically gathered knowledge fully contradicts well-meaning advice by some German quality assurance experts:

In nursing care, direct verbal complaints are preferable. Residents find themselves in direct contact with care workers, and can articulate their complaints in a confidential setting. Barriers to complaint are particularly low in this environment (Stauss and Seidel 1998: 76).

In reality, however, even in the best practice Homes we have visited, fear of possible sanctions remained a powerful motivation to withhold complaints, as an interview with the residents' Spokeswoman at Home 4 demonstrates:

> *When people complain to me, they also insist that no names should be mentioned. (…) They are afraid they will be treated worse afterwards. I can't say where these fears come from, and I have never heard anything concrete. (…)It is enough if somebody is left to wait too long when they call, of if they are not asked whether they are thirsty, and things like that.*

Thus, as the above citation demonstrates, sanctions for complaint may be so subtle that it would be hard for a resident to conceptualise them as abuse – let alone to document them in a complaint. Maltreatment becomes categorised as care workers' 'bad mood', one own 'oversensitivity' or is simply regarded as an undesirable but inherent component of the LTC environment, in contrast to one's own home. Some residents, however, cultivate the courage to speak for themselves, never mind the stigma– like 86 year old Mrs Thiel at Home 3:

> *Everybody says I should stop moaning. But I say, moaning is in my nature. That's why I get into trouble every now and then.*

So, what does Mrs Thiel 'get into trouble' for? And what does trouble look like? She gives the following example:

> *Today I was told off for criticising the nurse, because, ostensibly the nurse was right. So, normally my hygienic pad should be changed between 8am to 1 pm. But yesterday it was not changed. I was told the pad was still dry. But it wasn't true, I told her the pad was moist and that I needed it changed before lunch. Nope, she wouldn't do it. And today I was told that either I have to use the bathroom and then use no pads, or, if I use pads then I shouldn't ask for help with using the bathroom. Anyways, I kept nagging, so she gave me a pad, in the end. But why couldn't she just explain how it goes from the beginning?*

In this incident, Mrs Thiel's right to privacy and her right to autonomy were infringed – and once she stood up for them, she was 'told off'. The resident here is subject to institutional authority. Mrs Thiel believes that she is the only one in the Home who is unhappy with this state of matters and feels like a lone warrior:

> *When I stand up and say something, I feel like I am putting my foot in my mouth for everyone. The food is not very good here. But when they are asked, no one says anything. It is always 'everything is fine'.*

Our younger interview partners – a relative of a resident in Home 5 and the founder of an Initiative for Care Chamber – explain this seeming cohesion among the residents from a generational perspective. Fear of sanctions, they suggest, is something characteristic of people who are now well above 65 – exceptions were referred to as 'courage', not 'moaning'. The Head of Management at Home 1 describes an incident very similar to Mrs Thiel's; however, her appraisal of the resident's role is far from negative:

> *Recently I found out through our daily briefs that one of our Assistants had the audacity to tell a resident whose urine bag was full that he did not see the need to empty it yet. And I*

think that the resident was extremely courageous, I mean, untypical of his generation, that he kept insisting, no, I feel that there is something wrong with it, you must empty it. (…)

Complaining, persisting and informing the senior management is conceptualised in further conversation with this manager as a fight against outright violence – and a fight for human rights. Other interviewees suggest that the next generation socialised in democratic, post-1968 society will have fewer qualms about making complaints.

Daughter of a resident at Home 5:

I do not have a problem stepping in and saying what I think. But that's because I belong to another generation, I think. We are different. We talk about problems, about difficulties. My parents, they never talked about anything. Also, they never talked about a care home being a possibility in old age.

Founder of an Initiative for Care Chamber (abt. 50):

This playing along that the current generation of home residents engages in, it won't go on for much longer. When people of my age start coming into care, and this will happen sooner than one may think, we will want to keep our freedoms. Personally, I will want to have my Facebook and my pizza once a week. Our generation will not mince our words.

These utterances suggest that with growing perception of older people as outspoken individuals and savvy consumers, complaints will become a more regular practice. The Sixth National Report on Ageing drawn up in 2010 by an expert commission on behalf of the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth suggests that societal values and ideas about old age are changing rapidly, with older people increasingly seeing themselves as independent decision-makers (BMSFJ 2010). Although the existing model of LTC provision is gradually adapting a resident-centred approach congruent with this value transformation, there is still a lot of room for improving the complaint management system.

Establishment of a transparent and reliable complaint management system in LTC must become a policy-making priority in the next few years. In the next paragraphs of this section, we will present mechanisms of complaint management that are already in place.

6.5.2 Internal (Home-based mechanisms of complaint management)

From a human rights perspective, care home providers and managers also have positive obligations to promote and protect human rights. This includes providing LTC residents with accessible information about access to justice, about their rights and about complaints procedures. They need to spread the information about existing ways to report complaints about violations of human rights. Furthermore it would be useful to release contact information of lawyers or civil society organisation that could support care home residents or their relatives in their right to complain.

Interpretations of human rights offered by care workers invariably included references to feedback and complaint management. Care professionals of all ranks emphasised the importance of maintaining an open dialogue with home residents and with their relatives through various instruments both formal and informal.

(a) Anonymous complaint forms and information about external independent complaint offices

First, in all Homes contact details about local MDK and LTC Surveillance Offices were presented in an accessible manner, mostly, in the form of flyers, brochures or posters available at designated information boards.

Second, in two Homes (1 and 5) anonymous complaint and suggestion forms were available from the information boards.

Image 2: Complaints and Suggestion Forms at Home 5, available from the Reception and at the information board by the entrance.

In spite of availability of formal instruments, most people we have spoken to – managers, residents, relatives and volunteers alike – relied on informal ways to put their complaints through, that is, by talking directly to chief nurses or home administration. This choice of complaint strategy is likely to result from high levels of trust in Homes we have visited and is likely to be another indication of the 'best practice' nature of the institutions in our sample.

(b) Open-door strategy

All care managers we have spoken to used the 'open door' metaphor when reflecting upon ways complaints are delivered and handled within their institution. That is, managers presented themselves as being always available for feedback – or having a designated representative in case of personal absence. Managers of higher ranks feel responsible for setting human rights standards for the whole team and become directly involved in conflicts where personal dignity of concrete individuals may be wounded. The best example is an episode reported by the Head of Management in Home 1:

> *Recently, a resident had complained that the night nurse was talking rudely to her. The lady was told to eat her yoghurt with the fork because the nurse, ostensibly, did not have time to get her a spoon. This is precisely the kind of thing I consider to be an absolute violation of human rights. I made sure that the nurse got a serious warning from our HR, and I, too, have spoken to her personally. I came here late at night and explained to her that what she did was utterly unacceptable and that we were informed about it through residents. The nurse said she was very surprised that residents had such power. I told her that I found this power excellent, because if there were no residents, then neither she nor I would have our jobs.*

This account accords fully with residents' and relatives' accounts of making complaints: in most cases, problems are reported immediately to nurses or home administration, while Chief Nurses in the wards are usually referred to as primary 'complaint officers'. Where possible, solutions are sought on the spot, in other cases complaints are documented and discussed at regular team meetings.

In other cases, where the complaint is related to outright violation of residents' rights – such as neglect, refusal to provide help or violence – decisions are taken immediately at managerial level. Discussing incidents when nurses refused to assist residents with their requests, the Head of Management at Home 1 says:

> *We act very quickly. The employee is called to the Head of Care's office, and I am informed too. We also inform the HR Office and the CEO in such cases. And if someone is being really violent or neglectful, they will get a house ban. They will be out until we clarify their case legally. But if something relatively mild, I mean, some people just do not notice that they may become rude, we talk to them, and we talk to the resident who complained.*

It was not quite clear to us from our interviews, how the measures taken to address residents' complaints were evaluated later. Whether complaint management means sustainable monitoring, or on-off actions, seems to depend solely on the organisational structure of each Home. At Home 1, residents who made a complaint are approached in the course of three weeks after measures of redress were introduced, and are asked to give their feedback. We did not hear anything comparable in other Homes.

Daily briefs and 'open doors' also serve as the most effective measures of complaint management for care workers. Managers we have spoken to suggest that they stimulate their employees to talk about their experiences as openly as possible. Accepting not only residents' but also care workers' complaints helps to create transparency in the team and avoid frustration. Care Managers we have spoken to stressed that they encouraged their employees, in particular, women (who make up the overwhelming majority) to talk about episodes of rude treatment, violence or sexual assault they experienced from residents. Such open conversation prevents further conflict escalation, managers suggest.

> *Some residents with dementia do not quite realise that their behavior can be very disturbing. And if you tell them 'Mr Meier, you attempted to hit me yesterday', they will be very surprised. You just have to accept it that his dementia is so advanced that he forgets what he does five minutes later. And you have to either suppress your bad mood, your unwillingness to deal with him here and now, or you ask a colleague to take care of him. It's ok to tell a colleague, look, I can´t see this man or care for him, can you take over? That's how we do it. Home Managers feel strong responsibility for protecting their employees' rights and managing their complaints.*

The Head of Management in Home 3 speaks of an episode of extreme violence initiated by a resident against a nurse: *after several weeks of increasingly aggressive behavior, possibly related to his clinical picture, he attacked one of the care workers with a knife. Luckily, no physical harm was caused, however, not only the person who was attacked, but most employees of the Home felt affected. After several consultations with her colleagues, the Head of Management has made a decision to draft an instruction for such cases, where she specified that a care worker who felt*

attacked had to report to her immediately, or, in case she was unavailable (for example, weekends or at night), they could call the police or psychiatric emergency.

> *I made sure that this instruction was distributed across all teams, and once it had been done, I felt great relief. People who work here were also very grateful that I take these problems so seriously.*

All in all, the open door policy is a most effective complaint management mechanism we have observed in our interviews. Nevertheless, we believe that this mechanism alone cannot substitute for a comprehensive and transparent external complaint office, which not only residents but also care workers could address directly and confidentially. One of the possibilities for establishing such a low-threshold complaint office is a Home ombudsman or spokesperson: a practice we have observed in Home 4 and which we consider to be a good practice solution.

(c) External spokeswoman

Unlike all other Homes we have visited, Home 4 does not have an established advisory board. Residents' interests are, instead, represented by a volunteer spokeswoman who visits the Home once or twice a week, participates in most Home seasonal festivities and whose main function is to collect feedback from residents and their relatives. The spokeswoman functions as a fully independent complaint manager; she is affiliated neither with the Home Management, nor with the Provider, not with any other external control mechanism. Her work is absolutely voluntary and she receives no monetary compensation for it. This outsider position, however, has its downsides: the spokeswoman does not have a definite mandate to act in case of extreme conflict situations. In her current role, she cannot file cases or undertake any other legal action. The spokeswoman herself considers her inability to make decisions a limitation directly related to her poorly defined status as a 'volunteer':

> *Interviewer: What is your decision-making function?*
>
> *Spokeswoman: Mine? None! This is the destiny of all volunteers, you see. When you try push something, you are being told, you come only once or twice a week, you are not here all the time. I mean, it is an important argument of course, but sometimes I think that outsiders often have a different view on problems, and it would be worthwhile to take our ideas into consideration. But as I said, no, I can't make any decisions.*

In spite of these limitations, representation and complaint management through external persons has several important advantages.

First, while visiting the Home, the spokeswoman makes sure that she visits all wards and gets to talk to individuals in different states of health. Simply being able to make several visits a day allows her to identify residents' needs and to lay out priorities.

Second, being an independent actor, the spokeswoman can serve as a buffer between the residents, management and relatives. She has no sanctions to fear – and can exercise no sanctions in return. This position warrants confidentiality and trust, so that things that might otherwise be withheld are verbalised and made known.

Most issues that are addressed in complaints collected by a spokeswoman concern minute everyday details of the Home's life: issues which are of extreme importance to Home residents, but too 'minor' to be filed as complaints to an external surveillance organisation. In interview,

the spokeswoman refers to the following topics: misplaced laundry and personal belongings; being left alone or having to wait to be picked up; being addressed with the colloquial 'you' and the quality of nutrition.

Although the incidents the spokeswoman deals with are minor, they are, nevertheless, very important to residents' and their relatives. These 'small things' are precisely the reality of human rights implementation in an LTC setting. The low-threshold complaint management enables identification of these rights infringements and offsets them in a most immediate way.

6.6 Right to palliative care and death

The Advance Health Care Directive (*Patientenverfügung*) is to ensure that a person of age can define his or her will, as well as if or how medical care is to take place. The Advance Health Care Directive will be set out in advance in writing. The Advance Health Care Directive has to agree or reject the use of medical treatment or medical intervention. This is in accordance with § 1901a Abs. 1 BGB. The Advance Health Care Directive ensures that the person's will shows his right to autonomy to decide if he or she does not want to get more medical treatment and therefore has waived his or her right to health. It has to be secured that the person's full informed consent is expressed in the directive which is directed doctors and medical staff. The Directive may also contain safeguarding measures to ensure the accomplishment of the will.

At the moment, there is no sustainable data on the ways in which the right to palliative care and death is observed in German LTC establishments. While the quality control reports document the mere existence of the palliative care concept in each Home (96% of Homes scored positively on this criteria in 2015), it does not investigate the content of these concepts or residents', care workers' and relatives' satisfaction with its implementation.

Like every death, a death in the LTC environment has two aspects: ritual and formal, and the implementation of human rights needs to be studied in both contexts.

6.6.1 The rituals of dying

In most Homes we have visited, the death and dying processes were accompanied by a variety of rituals. Some of these rituals concerned protecting the privacy of a person who is about to pass away, some were meant to create a social context for final departure, and some had a purely emotive purpose. That is, palliative care in these Homes was not only about granting the dying person a right to death, but also securing the relatives' and other residents' right to social inclusion and right to privacy.

Unless residents are transferred into hospitals, they spend their last hours in their own rooms (provided these are single rooms, which was the case in all Homes). In some Homes, special marks - a paper star or candle – are attached on the doors to the rooms, signifying that there is a dying person behind them, who should not be disturbed. Relatives, however, are allowed to enter the room and stay there without restriction (unless other, special provisions were made by the dying). The nature of the care, however, changes in accordance to the person's needs. The Head of Management at Home 1 speaks of the palliative care concept in her Home:

Our greatest concern is freedom from pain and that the person is feeling well, as much as possible. It all depends on what they wished for themselves. We try to find this out as soon as possible, and often the nurses who worked with these residents before, they know very well what their idea of death was. (…) We do aromatherapy as a part of palliative care, and when we know that the person did not have anything against it, we ask an aromatherapist to mix an oil for them. For us, the care in this phase is all about making a person feel as comfortable as possible.

Nurses in the same Home speak of their understanding of what the 'palliative' concept is:

N1: You've got to be even more observant,

N3: More observant and even quieter than normal. Really have your eyes open.

N1: Exactly, much quieter, and maybe, decorate the room a bit more.

Chief Nurse: Nevertheless, talk to the resident, just very quietly. Tell them, they are not alone, that they needn't be afraid. It is really important. And then, maybe light an oil burner, turn some music on, if they liked music.

N1: Some people need us to hold their hand. I mean, you know what you've got to do each moment.

N2: Some people just want to be alone, it´s also ok.

Home-based rituals make it possible for other residents and care workers to say farewell to the dying. The purpose of these rituals is to protect and emphasise the dignity of each individual Home resident by demonstrating that they remain in the community as a memory, even after they go.

For example, every Home we have been to had remembrance books placed in visible locations – in social rooms or dining areas – they are accessible to all residents. In Home 1, small stones or sea shells are inscribed with names of residents who passed away and are placed in a visible place, too. Another form of collective remembrance is regular memorial services conducted by religious communities supervising the Home. It must be noted here, that all rituals we were told of and observed were neutral in terms of religion. The two Christian Homes in our sample suggested that residents are not forced into a religious approach to death:

The Head of Care, Home 3:

We may put a cross in a room if the person wants it, but if it is not their will, if they say, no, no cross, then, of course, we do not do it. Then we just place flowers and candles, to make it beautiful.

Home Managers we have spoken to also feel the responsibility to provide emotional support to the dying and their family. This may happen in a variety of ways.

The ritual side of death, thus, has appeared respectful and rather unproblematic (at least, the way it was represented in interviews). Where serious potential for conflicts and infringements of human rights has emerged, is the formal side of dying.

6.6.2 The formalities of dying

LTC establishments are not obliged to inform residents about the Advance Health Care Directive; collecting information about this document and filling it in is the responsibility of each individual. Among the older persons we have spoken to, awareness about the Directive appears to be almost non-existent, and it was only brought up in interviews with relatives and care workers. Some of our interview partners mentioned that they have found out about the Advance Health Care Directive, only after they have witnessed severe conflicts around someone's death. Filling in the Directive is normally a task that children or legal representatives of residents take on. In our interviews, mention of the Directive always occurred in the context of being kept alive against one's wishes and being unable to protest. In fact, neither relatives of LTC residents, nor care workers expressed anxiety about death due to intentional or neglectful treatment. I Instead, what they feared for their relatives and patients was 'to be tangled in pipes', as the daughter of a resident at Home 1 has put it.

All relatives we have spoken to have signed the Advance Health Care Directive for their parents upon consultation with them. Nevertheless, in our interviews with care workers multiple cases of forced resuscitation were mentioned, with dying elderly persons unable to express their will and decisions being imposed upon them. Care workers reported on feeling absolutely powerless in conflict situations concerning life and death and being completely excluded from the decision-making process. The policy of non-interference, which dictates the position of care workers in issues of life and death, is meant to protect the autonomy of every individual and ensure absence of abuse at the end of life. The Head of Care at Home 1 spoke of a resident whose greatest fear was to be intubated against her will and be unable to decide about when and how to die. Although this woman had expressed her wishes to the Home personnel many times, she had never signed an Advance Health Care Directive – and once she had suffered a stroke and her children decided on artificial respiration, the Home had no instruments to protect the resident's autonomy and her wishes. She died, as the Head of Care says, 'with her face to the wall, refusing eye contact with her daughter'.

7. Summary and Recommendations

- The human rights approach has been introduced and implemented in many parts of the care concept. The paradigm shift from a beneficiary to a rights holder is implemented on many levels e.g. in the development of the care concept, laws, quality criteria.

- We recommend furthering the implementation of human rights into different parts of the care concept to close the remaining gaps and include human rights and human rights principles in all parts of the quality criteria to show the remaining shortcomings. Human rights standards and principles should be incorporated into LTC as a preventive approach.

- The effects of the new legal definition of need for assistance (as outlined in the Second Bill to Strengthen Care) on utilisation of LTC services are yet to be seen. However, it is essential that access to and choice of care facilities will be guaranteed to all older persons, so that no financial, religious, racial or health-related discrimination may occur.

- Good practice examples cited in this Report demonstrate that LTC establishments may function with minimal restriction of residents' mobility. Freedom of movement must be considered as a criterion of care quality, stimulating extensive establishment of barrier-free and inclusive care facilities.

- Increase in mobilisation and rehabilitation activities, as set forth by the CRPD, may have positive effects on the implementation of the right to the highest attainable standard of health, as well as the right to freedom of movement. Hence, we recommend strengthening the financial and structural environment required for extensive implementation of the right to rehabilitation and habilitation.

- LTC residents' right to privacy is protected by Länder-specific LTC legislation and through training of care personnel. We recommend prioritising needs of concrete individuals and focusing on the well-being of the older person, especially those with advanced dementia.

- On the basis of good practice examples in this Report, we recommend that to achieve improvements in LTC residents' health outcomes and subjective well-being, involvement of medical specialists into care and regular rehabilitation activities needs to be carried out.

- Perceiving LTC residents as rights owners and not only as care beneficiaries empowers their participation in the activities of daily living, such as assisting with cooking or cleaning, and enables them to make autonomous decisions about their everyday lives. Care homes needs to be adequately staffed in order to provide necessary assisted autonomy with the daily routine. We

recommend that LTC facilities support their residents' sovereignty with low-threshold activities and events, stimulating older people's own capacities and open the homes up to greater social inclusion.

- The existing structure of social participation, with the Home advisory board as residents' main consultative organ, seems to be insufficient because of the structural barriers such as missing information, insufficient assistance or absence of feedback on their recommendations. The advisory boards need to get assistance and insight into the outcome of their decisions. Alternative structures or mixed boards should be further considered.

- Our study has identified a low level of awareness about external independent complaint management mechanisms. In Homes we have visited, complaints are dealt with internally and on an *ad hoc* basis. While for best practice homes in our sample this strategy might be sufficient, it can lead to significant problems in LTC organisations with lower standards of care and poorer management, as the Heinisch case demonstrates. Therefore, we recommend that a sustainable low-threshold system of complaint management mechanisms should be established and granted a mandate to provide solutions. Otherwise, access to justice may remain elusive to elderly residents and to care workers alike.

- One well-known factor of violence in LTC establishments is related to poor working conditions of care personnel. Therefore, we recommend independent control of workers' situations, coupled with education and coaching aiming to raise personnel's awareness about what may qualify as inhuman or degrading behaviour.

- To strengthen the human rights of dying persons, provision of palliative care in LTC institutions' needs to be strengthened. It is advisable that care homes proactively inform residents and their relatives about the importance of the Advance Health Care Directive in order to be better able to fulfill the will of dying persons.

- Our interviews with care workers confirm that working conditions and organisational structures vary strongly between individual providers and homes. In particular, poor regulation of wages across regions and providers may result in care workers' professional dissatisfaction, high personnel rotation and a deficit of qualified staff. We recommend levelling incomes in geriatric care with incomes in other care occupations, possibly, by a nationwide introduction of a binding pay scale.

- Our interviews suggest strongly that the structural deficit of personnel observed in geriatric care by various experts may only be addressed through adequately compensated qualified personnel. Therefore, we recommend that quality requirements to nurse/resident ratio take into consideration the proportion of skilled personnel to all care workers.

- The results of our study demonstrate that many care workers have an implicit knowledge of human rights principles and that this knowledge is operationalised as 'dignified' treatment of LTC residents. However, rights awareness is not yet sufficient, varying between different professional groups and is not always being expressed in understanding of implementation mechanisms. In order to ensure stronger protection of care residents' and care workers' rights, explicit and articulated inclusion of human rights principles into nurses' professional training needs to be introduced.

ENNHRI recommendations at EU-Level could be as follows:

- Inclusion of human rights approach into care workers' professional training;
- Stronger dissemination of Council of Europe Recommendations on Ageing, in particular, recommendations on nursing care;
- Regular dissemination of good practice examples among Member States;
- Drawing awareness to human rights of older persons in care;
- Strengthening of EU policies on independent living by providing means for active assistance and rehabilitation, including technical means (in accordance with binding requirements enshrined in CRPD);
- Establishment of independent complaint mechanisms in LTC sector, possibly, an EU Ombudsman;
- Incorporation of LTC-relevant rights into the social pillar, with a reference to the Fundamental European Human Rights Charter.

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Appendix 1: Interview Schedule and Sample Overview

	Home 1	**Home 2**	**Home 3**	**Home 4**	**Home 5**
Location					
Urban	x		x	x	
Rural		x			x
Type of provider					
Municipal	x				
Private		x			x
Non-profit: Confessional			x	x	
Size	60 Residents	151 Residents	120 Residents	60 Residents	

Additional remarks		The home specializes in care of mentally ill people and has a separate „high security“ ward. Also, the home features one of the few specialized dementia wards in Germany.			
Interview Partners					
Head of Management	Female, 50	Female, 53	Female, 36	--	
Head of Care	Female, 51	Female, 57	Female, 46	Female, 58	
Care workers (group interviews)	1.Nurse-in-chief, female, 47 2.Care Assistant, female 62 3.Care Assistant, female, 53 4.Civil Service Volunteer, male, 19	1. Social Services and Coaching manager, female, 46 2. Care Nurse in dementia ward, female, 53 3. Medical Nurse, female, 39 4. Quality manager, female, 39 5. Music Therapist, male, 56 6. Head of Social Services, male, 57	_	_	
Residents	1.Female, 93 2.Male, 87	1.Male, 75 2. Female , 73	1.Female, 86 2.Female, 82	_	

		3. Male, 55			
Residents' relatives	1.Female, 66 2.Female, 62	—	x	—	
Advisory Board (group interviews) or Home representative	3 persons 1.Female, 80, Resident 2.Female, 72, Volunteer 3.Female, over 80, Resident	3 persons: 1.Female, 70 2.Male, 71 3.Male, 69	2 persons plus Care and Management Directors: 1. Female, 67, volunteer 2. Female, 97, Resident.	1 Person: Home Representative Female, 63, Volunteer	
Pastor / Chaplain	—	—	—	Female, 72, Protestant	
Number of Interviews	8	7	5	3	
Total number of interviews					