Annual Report 2018

The Health and Social Services Ombudsmen

Preface

The gap between ambitions and resources presents a challenge in the distribution of welfare benefits, between different service domains and within the health service. Difficult choices must be made openly, not behind closed doors. The priorities must abide by the policies and procedures that have been agreed upon. The goal is predictable criteria to frame each individual assessment; an assessment which must be made jointly with the informed and involved patient and service-user. This is no small task. Service-user involvement must be facilitated, and time must be allocated and health literacy must be improved. The benefits of this will be great. The result will be the patient's and service-user's better understanding of the final decision.

Health professionals must be supported in making difficult choices. Managers must reinforce appropriate priority-setting and support staff in their assessments. Politicians must stand by their policies and decisions at all times, including in the face of the threat of newsmedia sensationalism.

As Health and Social Services Ombudsmen, we meet people who have lost out in the competition for health and care. Our task is not to win cases, but to do our bit for just and fair treatment. As such, we address the process that informs decisions. Because as the Norwegian saying goes: *if you cannot explain it, you cannot defend it*.

We help patients and service-users of all ages every day to obtain those explanations. In 2018, a bill was put forward to extend the scope of the Health and Social Services Ombudsmen's service to senior citizens. However, we, and many service-user organisations and service-providers strongly opposed this. Why? Because many might get the idea that we exclusively serve the older population rather than patients and service users of all ages. Instead, the bill resulted in the creation of a separate national Ombudsman for the Elderly corresponding to the Ombudsman for Children. We remain the Health and Social Services Ombudsmen for all patients and service users.

For 2019, we have been tasked with establishing a National Health and Social Services Ombudsman office to liaise closely with the existing local branches. We support this move. We wish to assist in expansion of the service, and regard this as an opportunity to boost the professionalism and impartiality of our work, and to gain a stronger national voice.

In this report, we share experiences and findings from our service to citizens.

Anne-Lise Kristensen

Chair of the Health and Social Services Ombudsmen's Working Committee and Ombudsman for Oslo and Akershus

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- **Patients who leave a consultation within the specialist health service and who are being treated under a care plan must be informed of when their next consultation will be – they want to have the next appointment in hand.**
- **Young people aged between 16 and 18 should not have to pay a user-fee for consulting their GP.**
- **The objects of the user-controlled personal-assistance service for people with disabilities (BPA) must be fulfilled regardless of their place of residence. The Ombudsmen endorse the bill to raise the age limit to 67 for continued BPA service eligibility.**
- **Patients on multidisciplinary specialist drug and alcohol detoxification and rehabilitation programmes should be entitled to complete any commenced dental work regardless of whether they are still in an institution.**
- **The supervisory authorities must be granted the resources needed for proper investigation of violations of patient and service-user rights.**
- **There is a great need in the national health and care services to improve employee literacy in patients' and service-users' rights.**
- **Measures should be implemented to improve the capacity to provide interpreting services. The health service's responsibility to arrange for interpreting services must be fulfilled.**

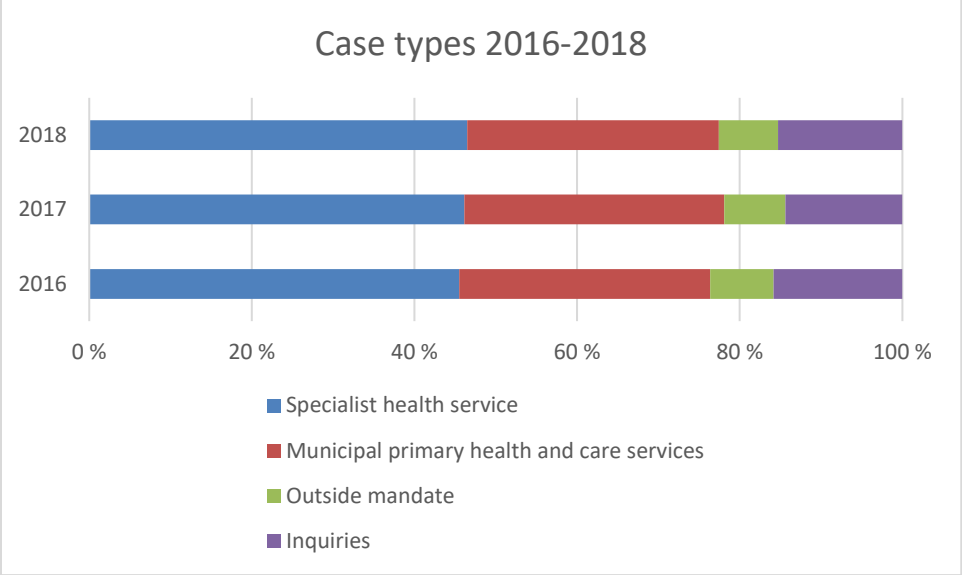
Introduction to the Ombudsmen's services

You will find us all over Norway:

Our office locations:		
Moss	Skien	Kristiansund
Oslo	Arendal	Trondheim
Hamar	Kristiansand	Steinkjer
Gjøvik	Stavanger	Bodø
Drammen	Bergen	Tromsø
Tønsberg	Førde	Hammerfest

The Health and Social Services Ombudsmen are mandated to protect the needs, interests and statutory rights of patients and service-users vis-à-vis the national specialist health service and municipal health and care services, and to improve the quality of those services (Section 8-1 of the Patients' and Service-Users' Rights Act).

In 2018, we received 14,830 new inquiries, representing 17,525 concerns. The majority of the inquiries we receive relate to the specialist health service.



Of the large number of patients who seek or receive treatment, plus the number of citizens who receive social services in Norway, only a relatively small number contact us. However, we believe that our experiences point to areas that should and can be improved. We believe that far more people should take action on their adverse experiences, as we find that it is worth doing so. Because complaints and inquiries can result in improvements. All too often, however, we see the same problems repeated. The service-providers are failing to learn from their mistakes. Individuals with a lifelong need for treatment and assistance have a high threshold for making contact and lodging complaints. The same applies within small communities in which a service-recipient and service-provider may be known to each other. These and other factors result in reluctance to complain out of fear of repercussions.

Individual cases

The Ombudsmen's work is characterised by close and direct contact with patients, service-users, relatives and service-providers. Any citizen can contact their nearest Ombudsman. Contact can be made anonymously, and our service is free.

The Ombudsmen provide an easily accessible service for anyone who has questions, feedback or complaints concerning the national health and care services.

The Ombudsmen attach importance to face-to-face meetings. We listen, ask questions, provide information, help to clarify concerns, provide advice and guidance. We make every effort to assist in such a way that patients and service-users can make their complaints in a constructive manner. If there is a basis for escalating a complaint, we advise on the next steps of the process. If a complaint can be resolved by the patient/service-user and service-provider meeting in person, we can offer to attend dialogue meetings. These provide a relatively informal setting for mutual clarification, explanation, information and apology. Such meetings may also allow complaints to be resolved without a formal procedure on the part of the service-provider or County Governor. Dialogue meetings may provide the parties with greater insight and learnings than a formal written complaint, and may serve to restore trust.

The presence of the Ombudsmen at the local level provides the necessary proximity to, and familiarity with, patients, service-users and service-providers, and is a decisive factor in the Ombudsmen's ability to provide community-level service. We travel to where people live and where the services are provided. With increased reassignment of services from the specialist health service to local authorities, this is becoming even more important.

Quality improvements in the services

The Health and Social Services Ombudsmen work to raise standards in the health and care services, and maintain regular contact with the service-providers. We share with them the evidence from individual cases and contribute an "outside perspective".

The Ombudsmen hold meetings with the boards of the regional health authorities, service-user councils, youth councils and quality and patient-safety committees. We meet with local council officials; both administrators and policy-makers. We conduct regular meetings with the County Governors, the Norwegian Board of Health Supervision, the Norwegian System of Patient Injury Compensation (NPE) and other authorities that contribute to useful and important knowledge exchange.

The Ombudsmen are consulted in drawing up the annual white paper (report to parliament) on patient safety and quality in the health and care services. We also contribute consultation responses within our mandate. Members of Parliament receive information about the Ombudsmen's findings through the Ombudsmen's participation in parliamentary hearings and in direct contact.

Outreach activities

The Ombudsmen work proactively to raise awareness of patients' and service-users' rights and the Ombudsman service, and to share patients' and service-users' experiences of their dealings with the services. We give talks to staff within the specialist health service and in the municipal (primary care) services, political and administrative councils and committees, patients' and service-

users' organisations, and to students, pupils, immigrants on introductory programmes, employees on induction programmes, senior citizens' associations and interest organisations, etc. In our outreach activities, we gain a great deal of insight into experiences and perceptions of the services, and we come into direct contact with patients and service-users who would not otherwise have got in touch with us. The Ombudsmen are also used as speakers at national and regional seminars and conferences.

In 2018, we hosted a breakfast meeting themed "Child and Adolescent Mental Health" at the annual Arendalsuka public democracy festival and political gathering. We also had a stand and participated in a number of other events.

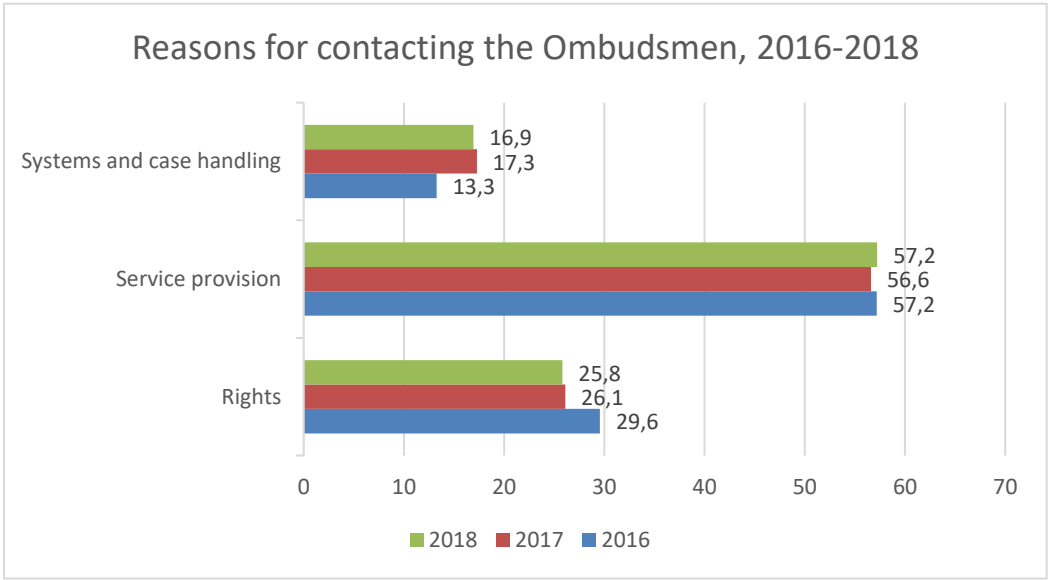
The services of the Health and Social Services Ombudsmen are described on the official Norwegian health portal (helsenorge.no), with contact details for all our local offices in Norway. We maintain a Facebook profile where service-users can get an impression of how we serve citizens and what we are involved in. In spring 2018, we broadcast short infomercials about our services on Facebook and the national TV channel TV2.

Reasons for contacting the Health and Social Services Ombudsmen

More than half of complaints concerned dissatisfaction with the manner in which services were provided. We receive examples of negligent treatment, concerns about mistreatment, patient injuries, defective or delayed referrals, defective information, communication and language problems.

26 percent of the matters brought to our attention concerned rights and entitlements. Typically, such cases concerned alleged breach of patient and service-user rights such as denied applications for services, breach of the waiting list guarantee, failure to grant access to medical records or errors in medical records, or lack of patient/service-user involvement and information.

17 percent of the cases concerned organisation and routines, disorder and inefficiencies such as lack of availability, failures in inter-service coordination, lengthy case-handling times or deficient case-handling.



Selected topics

Do we need fewer and more binding patients' rights?

In order to achieve a patient-centred health service, various schemes have been established to ensure satisfactory care delivery. The established schemes for a contact physician, care plan coordinators, coordinators and individual care plans, and who is responsible for the various schemes are confusing for both patients and staff. We would ask if the time has not come to establish fewer, but more effective and binding schemes.

Patients tell us about a health service run according to schemes and routines that are not always in the best interests of the patient; for example, that a referral to another department in the specialist health service than one currently providing treatment requires a referral from the patient's GP. They also report failures in terms of expectations and planned follow-up between a national and local hospital, and ultimately between those who are to provide local authority care. Discharge notes and medication lists that fail to follow the patient and are not passed on to the next level. Continuity of care and clearly defined responsibilities are important for patients. We hear all too often about tests that were never requisitioned or medical examinations that were not performed, case notes that were not read, and about treatment that had to be postponed for these reasons.

We meet patients who have not been granted an Individual Care Plan, and are also unaware that they have a statutory entitlement to this. We learn of failure to follow up and refer to an established Individual Care Plan, particularly within local authority health and care services. This is a persistent problem in the somewhat larger and complex complaints cases, which have gone unresolved for years, and have placed great strain on relatives. Patients and service-users with complex and comprehensive assistance needs tend also to need more advanced-level expertise and more resources than the local authorities offer. We have received a number of messages of concern from despairing relatives that their son/daughter is not receiving the assistance needed. They tell us that their struggle with the health and care apparatus is the greatest burden. They also report that helpers are unable to keep up with the demands of care-giving, and that the result is repeated emergency admissions. We hear of lack of continuity and predictability for users who have the greatest need for assistance. Holidays and sickness absences result in weeks and months of marginal assistance because it takes time to recruit temporary and new staff.

The Health and Social Services Ombudsmen believe that the service-providers need to show more flexibility and willing to cooperate on and with patients and service-users across all the tiers of service provision in order to make patients' and service-users' needs the focal concern, rather than the organisation of services.

A patient's experience: A patient with several concomitant conditions contacts the Health and Social Services Ombudsmen. He is receiving follow-up from multiple departments at his local hospital, but is also concurrently undergoing investigation and treatment for a serious condition at one of the national hospitals. He finds that he is having to keep track of his care himself and act as his own medical secretary. He is also concerned by the sense that the doctors and other health professionals in the different hospitals only give their attention to and follow up on the specific medical condition they are specialists in. The patient feels that he needs one doctor who looks at the whole picture and whom he could talk to about his overall state of health. When the Ombudsman asks if he has been offered a contact physician, the patient reveals that he has neither been offered this nor even heard about it as a scheme.

Local authorities must take more responsibility for the regular GP scheme

The local authorities must take greater responsibility for ensuring that GPs comply with the General Practice Regulations and other requirements made by the health authorities.

Patients must be given a copy of their referral letter and offered copies of any test results. This will serve to raise standards, improve patient safety and provide peace of mind for patients.

Young people aged between 16 and 18 should be exempt from paying user-fees to remove any barrier to them consulting their GP, including when they do not wish to inform their parents and ask for money for this.

GPs are increasingly in the news talking about their unsustainable caseloads. This is the reality their patients have been reporting for several years to bodies such as the Health and Social Services Ombudsmen. It is now high time to assess the viability of the national regular GP scheme, as advocated by the Ombudsmen back in 2014.

Patients tell us about diagnostic delays, failure to follow up on test results, the short duration of consultations, defective referrals and the unavailability of their GP. Moreover, GP surgeries are failing to reliably arrange for interpreting services for those patients with a need (and right) to this.

GPs in Norway have around 15 million consultations per annum. The Health and Social Services Ombudsmen receive around 2,000 complaints per annum concerning general medical practitioners. This is not many relative to the number of consultations, but as in other health and care areas, we find that the substance of the complaints reveals problems that are known to the GPs themselves, their partners in primary care and in the specialist health service.

Coordination between the specialist health service and primary care providers was also a concern addressed by the Office of the National Auditor of Norway's Document 3:4 (2017-2018) reporting on the findings of an audit of the authorities' efforts to ensure best practices among GPs referring patients from primary to specialist care. This concludes that *"General practitioners and hospital specialists are not sufficiently cooperative on referrals, which often lack essential information. The audit reveals that, in many cases, general practitioners and hospital specialists differ in their understanding of what constitutes essential information in a referral. Half of the hospital specialists in the sample regularly find that referrals fail to state clearly why the patient needs specialist care, and 9 in 10 hospitals find that the quality of referrals is very variable."*

Local authorities must be far more proactive in their supervision of the GPs they contract. This applies to everything from compliance with the General Practice Regulations, universal design, follow-up on complaints and follow-up on GPs who fail to comply with the Directorate of Health's clarifications regarding allowable patient fees.

For the last two years, the Health and Social Services Ombudsmen have advocated amendment of the rules on user-fees payable by young people aged between 16 and 18 to ensure that the legal age of majority in healthcare contexts is changed to age 16 in practice. We would reiterate the need for this. Young people aged between 16 and 18 should not have to pay a user-fee for consulting a doctor.

Lifelong quality of life – in assisted living too

The Health and Social Services Ombudsmen receive complaints daily from elderly people and their relatives. They report problems such as the long waiting list for a place in a nursing home, the insufficient time allocated for home care visits and inadequate staff qualifications in the home care service, the large number of different care workers for care-recipients to cope with, and people with dementia who go unattended for many hours, day and night. We are and must remain, a service for all age groups, including, but not exclusively, elderly patients and service-users, and see this as imperative despite the Government having now passed the bill to establish a national ombudsman service for elderly citizens.

People should be able to stay living in their own homes for as long as possible after they have become care-dependent due to infirmity and frailty. The local authorities should be providing care services of a sufficiently high standard to ensure that all elderly citizens can achieve the best possible quality of everyday life. Instead, however, the relatives of independently residing elderly people with dementia are reporting their concerns to us. They tell us that their elderly relatives are increasingly affected by confusion and anxiety, are unable to keep track of how their days are spent, have not received personal care or meals, and the home care service is provided by a high turnover of care workers. They are worried about what might happen when their elderly relative goes unattended for long periods of the day.

We hear about great disparities between nursing homes in terms of care competence, facilities, professionalism, consideration and respect for residents' individual and basic everyday needs. We hear about persistent high churn among nursing home physicians, and that they are not sufficiently present on site. There is little continuity in the medical care, and the hours spent by physicians at the nursing homes are limited. Many relatives are keen to attend their relative's consultations with the nursing home physician, and assert that this should be possible. We have numerous examples of delayed diagnosis of fall fractures or other medical conditions because it takes too long for nursing home residents to be examined by the general practitioner, and referred to the specialist health service.

The Ombudsmen believe that there is a need to raise the competencies of nursing staff and care assistants. Patients in nursing homes are generally more infirm and prone to illness than in the past, and have a greater need for advanced health and care services. There are also increasing language problems now that both the staff and residents tend to be more multicultural than formerly. This poses a particular challenge in the case of patients with dementia, whose native or first language becomes the only one they are able to understand.

The Ombudsmen often hear that there are insufficient resources for physical rehabilitation in both the specialist health service and in municipal primary care. It is also difficult for patients to understand why some people are granted a full programme of rehabilitation at specialised centres following illness and injury, while others are referred to the local authority rehabilitation service. Great disparities persist in the local authority rehabilitation service, which is often characterised by a long waiting list, a shortage of physiotherapists and occupational therapists, and rehabilitation programmes which appear to be the bare minimum for each individual. We receive complaints from patients who believe that they have lost their potential for maximum recovery because the wait for rehabilitation was too long.

We find that health rights literacy is lacking among health professionals as regards how regulations are to be applied in both the allocation and design of services and specifically concerning matters such as the waiting list for a place and coercion in nursing homes (pursuant to Section 4A of the Patients' and Service-Users' Rights Act). The Ombudsmen recommend raising the level of rights literacy.

A patient's experience: An elderly woman who was wheelchair-bound and affected by multiple medical conditions, moved into local authority sheltered housing with domiciliary nursing care. She developed a pressure sore to the buttocks without the care workers taking any action. The pressure sore worsened and the woman was hospitalised for surgery several times. She then moved into a care home with 24-hour nursing and care. She complained of pain to the ankle/knee, and was eventually found to have a fracture to her ankle. On several occasions, she had scratches and bumps to her forehead, which were presumed to have been caused when she took the lift. None of these incidents were reported as care failures or were recorded in her medical record. The GP decided that the woman needed a higher level of care, and an application was made for a nursing home place. The hospital also applied for short-term nursing home care, but the woman was nevertheless turned down. A complaint was made, and was heeded.

User-controlled personal assistance (BPA) – a service that has come off course?

The Norwegian BPA service for user-controlled personal assistance, whereby people with disabilities are assigned a regular carer whom they then supervise, is subject to undesirable variations from one local authority to the next as regards granting of this service, in terms of both the number of assistance hours granted and how BPA is regarded in the context of other services. The Ombudsmen have been made aware of cases in which service-users have chosen to move to another municipality offering better services. The Norwegian Government has announced an inquiry into the BPA service in 2019. The Health and Social Services Ombudsmen assume that this inquiry will address the extent to which the service is fit for purpose, how adequately it assures the equality and personal freedom of those in need of extensive assistance, and the fact that place of residence must not be a determinant for the standard of the service provided.

The purpose of BPA is to give people with extensive assistance needs greater freedom to personally manage the service provided and their daily lives, and to thereby achieve an active life with maximum independence. Since 2015, BPA has been an individual statutory entitlement for persons with a long-term and extensive need for personal assistance.

The number of complaints to the Ombudsmen concerning BPA increased by 14% from 2017 to 2018. The complaints concern both denied applications for BPA and allocation of fewer BPA hours than the service-user believes are warranted. We see examples of decision letters that are extremely complicated to understand, or so detailed that they count down to the last minute how long an activity is calculated as taking, without taking into account the service-user's variable condition from one day to the next or unforeseeable events. The 2017 Report of the Norwegian Board of Health Supervision states that 207 complaints were filed in that year with the County Governors. In 83 of these, the complaints were fully or partially upheld. The Ombudsmen believe that this indicates that local authorities are far from succeeding in making appropriate and equitable BPA-award decisions, and that the service-users should resort to formal complaints procedure if they are dissatisfied with those decisions.

This begs the question as to whether the legal entitlement to BPA has legitimacy, given that the local authorities are accorded extensive discretionary scope in their assessment of BPA needs and provisions. Given the current content of this service in many municipalities, there is now reason to ask whether local authority cost constraints are taking precedence over the individual service-user's right to lead an independent and equitable life.

The Ombudsmen welcome the Government's forthcoming inquiry into the BPA scheme in 2019. We also support the bill to remove the upper age limit for BPA (currently age 67). The goal of more active years with quality of life for the oldest old should also include individuals with a long-term and extensive need for personal assistance and who are receiving well-established BPA services when they turn 67.

A patient's experience: A young man who needs comprehensive assistance over the course of the day and night applies for an extension in the number of BPA hours allocated because his health has deteriorated and all activities have become more time-consuming. He asserts that the number of hours he has been allocated do not fulfil the intention and purpose of his legal entitlement to be served by the scheme: a fulfilling and dignified existence. The man has full cognitive abilities and is keen to engage in the community and enjoy a social life. His application for extra assistance is rejected on the grounds that the number of hours is sufficient. With the assistance of the Ombudsman, the man appeals the local authority's decision. Several months after his application and subsequent appeal, the man is granted an increase in BPA hours.

The golden rule must be observed.

Mental healthcare is one of the areas the Ombudsmen receive most complaints about. "The Golden Rule", which dictates that mental healthcare and alcohol and drug rehabilitation services should show a higher growth rate than somatic treatment, is still failing to be observed. The Ombudsmen believe that the health authorities should be making stricter demands of the hospitals to realise the proposed change.

Patients and relatives are reporting defective or deficient treatment programmes, and that people are becoming more ill in the long wait for treatment. This applies both to day patients and emergency short-stay patients. Patients are calling for closer, better-quality, better-planned and better-coordinated follow-up. Patients receiving adult mental healthcare describe the intense focus on discharge right from the day of admission. The switch in recent years from short-stay to day-only care is also highlighted by patients who express their lack of confidence in care received from the health service. Many patients who are offered treatment as outpatients state they would rather have the security of an overnight stay as part of the mental healthcare arrangements.

The Health and Social Services Ombudsmen would emphasise that mental healthcare provision also exhibits great variation across different parts of the country and within both the specialist health service and municipal primary care. The Directorate of Health has emphasised that one in ten referrals for adult mental healthcare is rejected (2017). This means that individuals afflicted by a mental health disorder which their GP is unable to treat them for effectively are being referred back to their GP without being seen by a specialist.

The Ombudsmen find that capacity within mental healthcare and multidisciplinary specialist drug and alcohol detoxification and rehabilitation falls short of demand. The outpatient and day clinics are short of specialists.

The restructuring of care provision from short-stay to day-care poses challenges for a number of the patients who contact the Ombudsmen. Some do not wish to be hospitalised, others want to be hospitalised for longer and object to being discharged, while others feel that they are discharged too soon, or wonder why they could not have been admitted to a municipal emergency short-stay clinic. Patients feel that they have been let down by the service all round. The specialist health service may have sound reasons for its decisions, but these are not always properly conveyed to the patients. When patients are informed that no treatment options are currently available, this gives them a sense that they have been given up on, and that their behavioural disorder or mental state are beyond treatment.

The Ombudsmen believe that the mental healthcare options available under local authorities are not generally known to patients and service-users or even to the specialist health service and GPs. There appears to be an arbitrariness in patients or service-users gaining knowledge of or being offered activities and programmes that may be crucial for their quality of life and functioning. The Ombudsmen advocate better coordination of services and increased capacity to enrol patients and service-users on programmes that promote quality of life and self-efficacy.

In 2018, a standardised national mental healthcare pathway was planned and launched for commencement in 2019. The standardised national pathways have been welcomed by many, but also met with scepticism. Some of the concerns are due to the shortage of health professionals within mental healthcare. Some parts of Norway have problems recruiting psychologists, psychiatrists and other specialists, and other trained staff who are essential in assuring both the clinical content and capacity of the services. It will be essential for the administration and documentation of the care pathways not to drain resources and capacity from what matters most in a high standard of patient care. The care pathways can only serve as a framework for effective individual follow-up.

Concern has been expressed about services for children and young people with mental health disorders. Parents, young people and staff are calling for an increase in capacity at outpatient clinics and municipal emergency short-stay clinics, and for cooperation between municipal primary care and specialist care services to be strengthened in order to make better use of their mutual expertise and resources.

Dental care is part of healthcare

In Norway, adults generally have to cover their expenses on dental care, but the Dental Care Act grants exemptions for people with certain conditions. However, problem substance abuse is not an eligible condition. The evidence is that many people with an alcohol or drug problem have poor dental health. Many of them fail to take good care of their teeth. Many of them avoid going to the dentist owing to the cost, and they have severe oral health problems caused by medication and years of substance addiction. We have noted that stays at healthcare institutions are becoming shorter and shorter.

Patients on multidisciplinary specialist drug and alcohol detoxification and rehabilitation programmes barely embark on dental work before they lose entitlement to it. Essential dental treatment should be completed, regardless of whether the patient has finished a stay at a rehabilitation centre.

People with problem alcohol and drug use are entitled to public dental care services while staying in a healthcare institution or for as long as they are receiving municipal home nursing. In this context, the law equates people with problem alcohol and drug use with persons who have long-term/chronic

medical conditions. Institutions and departments offering multidisciplinary specialist drug and alcohol detoxification and rehabilitation are comprised by the institutional concept defined by the Dental Healthcare Act.

Under the Regulations on Fees for Dental Care, patients in healthcare institutions financed directly through annual appropriations have the right to free dental care, provided that their stay in the institution is of at least three months' duration.

In response to the parliamentary resolution in 2005 to ensure that persons receiving treatment on a local authority rehabilitation programme were granted extended county-level dental care, the Ministry of Health and Care Services urged the counties to address the need for local policy resolutions to incorporate this group of persons in the Dental Care Act (Ministry of Health and Care Services' circular I-2/2006 on extended county-level dental care provisions of 2006). Several counties have implemented this.

A patient's experience: A man contacts the Ombudsman because he needs assistance to complete the dental work he started while he was a patient at a detoxification and rehabilitation centre. He had been granted a stay of three months, but as soon as he was discharged, the dental treatment he had started was stopped. He was unable to afford the cost of completing the treatment. He pointed out the problems he now faced, both cosmetic and pain-related, caused by his poor dental health, and that this would make it more difficult for him to get a job and stay sober. The man was referred to NAV - the Norwegian Labour and Welfare Administration for financial assistance to complete his dental work.

New appointment in hand

The Health and Social Services Ombudsmen believe that it should be mandatory for patients who leave a consultation within the specialist health service and are being treated under a care plan to be informed of when their next appointment will be. This will give patients and relatives greater peace of mind and predictability. It will also make it easier for them to object in the event of a breach of the treatment guarantee.

The statutory rights granted to patients and service-users vis-à-vis the health and care services are intended to ensure citizens of equal access to a high standard of care. This requires that service-providers are fully aware of those rights, fulfil them and ensure that their patients and service-users are familiar with them. It also requires the existence of an appeal body to ensure that services are provided in line with laws and regulations. The Health and Social Services Ombudsmen hear daily that this is not the case.

The majority of patients find that they are given a first hospital appointment within reasonable time of being referred by their GP. But from then on, the waiting times may be long, and information about what treatment will be provided and when is altogether lacking. This results in a lack of predictability and ability to plan, erodes confidence and in some cases results in treatment delays and needlessly poorer patient outcomes.

One of the purposes of introducing standardised national care pathways was precisely to prevent this and to ensure better flow in patient care plans. Those with positive experiences of a standardised care pathway emphasise that this is precisely achieved from the smooth flow in the pathway, a pathway coordinator with whom it is possible to make contact, and continuous information about the next step in the programme. But also that they have an appointment in hand when they go home after a stay in hospital or an outpatient consultation.

The Health and Social Services Ombudsmen believe that the experiences of these patients point to an area in which the specialist health services have improvement potential. A requirement for a "new appointment in hand" will enforce patients' rights and contribute to improved patient safety.

The Ombudsmen's appeal for common courtesy

Many complaints to the Ombudsmen concern a lack of consideration and common courtesy. Bad behaviour on the part of health professionals causes added distress for patients, service-users and relatives who are already facing demanding situations. In addition to providing clinically sound care, the health services should also engage proactively in the quality of interpersonal conduct. Negative experiences cause lack of patient confidence in the service, clinical staff and the systems. Comprehensive, appropriate and timely information, the provision of interpreting services when required, recognition of relatives as a resource, and setting aside time for discussion are imperative for sound care that respects human dignity.

Information for patients and service-users

Deficient or defective information is an element in the majority of complaints lodged with the Ombudsmen. These failings occur in dealings with both the specialist health service and the municipal health and care service. In addition, a shortage of sound and appropriate information is reported between the patient/service-user and treatment provider/health professional, but also at a more general level in which patients and service-users lack knowledge and information about the services that actually exist and what they should expect from those services. Many local authorities send out brochures by post to citizens to describe the standards they can expect from their local

authority when it comes to technical services such as snow clearing, water supply and sewage. Local authorities should aim to inform citizens about health and care services standards in the same way.

User involvement

Patients and service-users bring their stories to us that they feel neither seen nor heard by health professionals, and some describe that they are met with arrogance. Patients and service-users have a statutory right to involvement in the provision of health and care services. Knowledge of and the skills required to practice involvement could be improved among health professionals, within both the specialist health service and the municipal health and care services.

The patient or service-user has the right to be involved in making choices between available and appropriate types of services and diagnostic and treatment modalities. The mode of involvement should be adapted to the individual's ability to provide and receive information. It is the responsibility of health professionals to provide information in a format comprehensible to the patient, and the same applies to providing a realistic picture of what the health services can offer.

Relatives

The Health and Social Services Ombudsmen receive complaints from the relatives of patients and service-users. The majority contact an Ombudsman on behalf of someone else, but they may also have concerns about their own role and their own rights as relatives. The local authorities are responsible for offering training and counselling, respite and care-giving assistance to individuals with an especially heavy care burden. (cf. Section 3-6 Municipal responsibility towards relatives in the Health and Care Services Act). The Ombudsmen find that relatives tend to be unaware of this. The Ombudsmen talk to relatives with a heavy care burden who are under great strain, who have limited contact with the local authority and who are unaware of their options for being granted assistance. The Directorate of Health has published a national guideline on relatives in the health and care services. Efforts should be made to familiarise health professionals with this guideline and ensure compliance with it.

Interpreting services

Language and language comprehension are focal in sound and responsible patient care. Some patients have no or only limited Norwegian language proficiency and need an interpreter for communication. The Health and Social Services Ombudsmen are aware that budgetary constraints are used to justify non-provision of interpreting services. Other reasons might be a lack of procedure for booking an interpreter, the lack of availability of local interpreting services and negative experiences of using them. This is cause for great concern and poses a threat to the safety of patients.

Children and other relatives continue to be used informally as interpreters for family members. We are also aware that random individuals familiar with the language in question and who just happen to be available are enlisted as interpreters without he or she having either the skills or authorisation to provide interpreting services. This practice not only threatens the safety of patients, but also patient confidentiality and the patient's integrity and dignity.

Lengthy case handling times threaten legal rights and the safety of patients

Case handling times under the majority of County Governors and the Norwegian Board of Health Supervision are currently very lengthy. This erodes confidence in the final decision and reduces the learning value for the service-providers in cases concerning quality of care.

The Health and Social Services Ombudsmen advocate greater political involvement in order to ensure that health supervision bodies have sufficient resources to investigate violation of the rights enshrined in national health and care legislation.

In the experience of the Health and Social Services Ombudsmen, it is worth making a complaint. Many complaints are upheld by the service-provider, a typical example being within mental healthcare, where the place of treatment will in many cases reverse a decision and offer the service that was originally denied to the patient without the case being escalated to the county governor as an appeal case.

The rate of decision reversal among the County Governors is also high in many domains.

It is a political goal for every citizen to stay living in their own home for as long as possible. We find that this places increased demands on relatives. Relatives contact the Ombudsmen to tell us that they are under immense strain, but are not being offered the respite care they need by their local authority. In such cases, we urge them to make a complaint. Statistics from the Norwegian Board of Health Supervision reveal that 50% of denied applications for respite care are reversed by the County Governors.

However, the case handling time varies and is consistently lengthy. The goal is currently for rights cases, meaning complaints concerning a place in a nursing home, respite care, healthcare from the specialist health service and so forth, to be considered within three months. Based on individual cases, the actual case handling time is now verging on eight months for such cases. This poses a threat to the safety of patients.

Many citizens apply to an Ombudsman for assistance in making a complaint concerning aspects of the health service which they find unacceptable. It is not uncommon for the Ombudsmen's assistance to result in the settling of complaints and fulfilment of rights without escalation to a formal complaint procedure.

This is the best solution for all parties. The main aim is for complaints to result in lessons learned from the mistakes that have been made, to prevent other patients and service-users from being subjected to the same, and, in many cases, for the complainant to receive an apology.

Norwegian System of Patient Injury Compensation (NPE)

Patients who suffer injury as a result of a treatment failure must be informed that they can apply to the Norwegian System of Patient Injury Compensation (NPE) for assessment of their entitlement to compensation. The majority of patients file their compensation claim independently, but the Ombudsmen are able to provide advice and guidance throughout the claims process.

It is important for the patients to receive accurate information and to have realistic expectations of this system. This is because there is no automatic entitlement to compensation if treatment outcomes are not as expected. If the patient has suffered short-term injury or an adverse experience, but no financial loss, then he or she is not entitled to compensation. The NPE does not grant compensation as recompense for distress caused, which some patients can find hard to accept.

Health professionals have variable knowledge of the compensation system, and are not always familiar with the criteria that have to be met for eligibility. This can cause unrealistic expectations

among patients. It is very unfortunate if a doctor tells someone that they have the right to compensation if this has no validity.

Not all prospective claimants are sufficiently proficient in Norwegian to file a claim with the NPE. It is important for the NPE to offer such claimants interpreting services and to cover their costs of any legal representation they need in order to be fully apprised of their eligibility. To that end the NPE should be more proactive in offering to make such arrangements.

The case handling time is far too lengthy both within the NPE itself and within the National Office for Health Service Appeals, which causes added distress to patients.

Summary of the Health and Social Services Ombudsmen's Annual Report for 2018

The Ombudsmen are mandated to safeguard the needs, interests and rights of patients and service-users vis-à-vis the national specialist health service and the municipal health and care service. The Ombudsmen shall contribute to improving the quality of these services.

The Ombudsmen's work is characterised by close and direct contact with patients, service-users, relatives and service-providers. The Ombudsmen also work actively to raise citizens' awareness of patients' and service-users' rights and the Ombudsman service. Norway is served by 15 Health and Social Services Ombudsmen offices staffed by a total of approximately 80 employees.

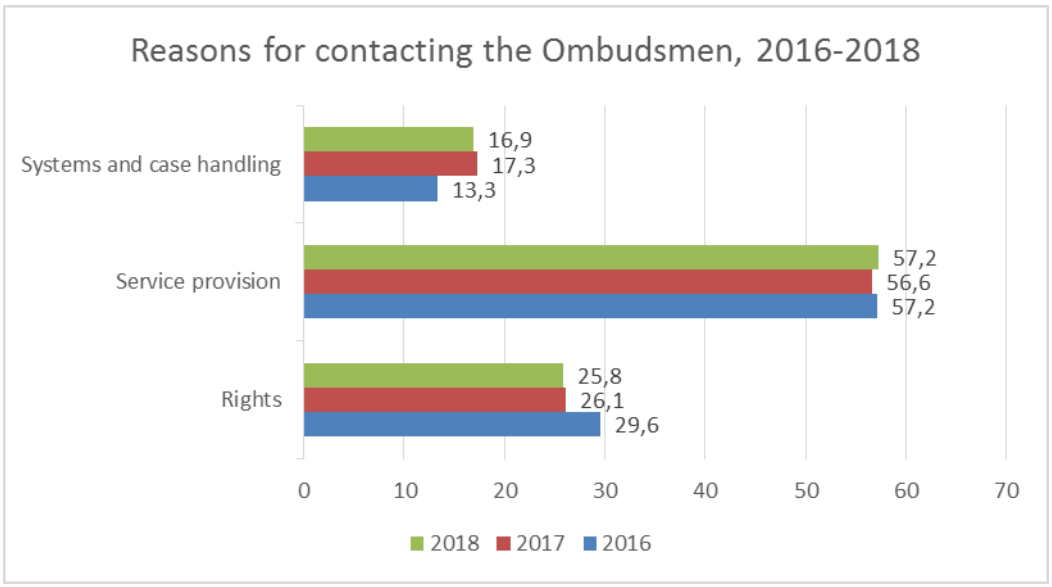
The Ombudsmen attend to a stable volume of cases, with around 15,000 inquiries received in 2018. In 2018, 47% of the cases were related to service-provider locations within the specialist health service, and 31% to service-provider locations in the municipal health and care services. 15% of cases did not relate to a specific service-provider location in that they concerned matters such as general inquiries concerning patient rights. 7% were inquiries outside of the Ombudsmen's mandate.

Reasons for contacting the Health and Social Services Ombudsmen

More than half of complaints concerned dissatisfaction with the manner in which services were provided. We receive examples of negligent treatment, concerns about mistreatment, patient injuries, defective or delayed referrals, defective information, communication and language problems.

26 percent of the matters brought to our attention concerned rights and entitlements. Typically, such cases concerned alleged breach of patient and service-user rights such as denied applications for services, breach of the waiting list guarantee, failure to grant access to medical records or errors in medical records, or lack of patient/service-user involvement and information.

17 percent of the cases concerned organisation and routines, disorder and inefficiencies such as lack of availability, failures in inter-service coordination, lengthy case-handling times or deficient case-handling.



Key topics addressed in this annual report

Do we need fewer and more binding patients' rights?

In order to achieve a patient-centred health service, various schemes have been established to ensure satisfactory care delivery. The established schemes for a contact physician, care plan coordinators, coordinators and individual care plans, and who is responsible for the various schemes are confusing for both patients and staff. The Health and Social Services Ombudsmen are consequently asking if the time has not come to establish fewer, but more effective and binding schemes.

Local authorities must take more responsibility for the regular GP scheme.

The Ombudsmen believe that the local authorities must take greater responsibility for ensuring that general practitioners comply with the general practice regulations and other requirements made by the health authorities. Patients must be given a copy of their referral letter and offered copies of any test results. This will serve to raise standards, improve patient safety and provide peace of mind for patients. Young people aged between 16 and 18 should be exempt from paying user-fees to remove any barrier to them consulting their GP, including when they do not wish to inform their parents and ask for money for this.

Lifelong quality of life – in assisted living too.

The Health and Social Services Ombudsmen receive complaints daily from elderly people and their relatives. They report problems such as the long waiting list for a place in a nursing home, the insufficient time allocated for home care visits and inadequate staff qualifications in the home care service, the large number of different care workers for care-recipients to cope with, and people with dementia who go unattended for many hours, day and night. The Health and Social Services Ombudsmen emphasise that they are, and must remain, a service for all age groups, including, but not exclusively, elderly patients and service-users, and see this as imperative despite the Government having now passed the bill to establish a national ombudsman service dedicated to senior citizens. Employees in the health and care services should build their literacy in patients' and service-users' rights. Measures should be taken to improve awareness and fulfilment of the health service's responsibility for arranging for interpreting services as needed.

User-controlled personal assistance (BPA) – a service that has come off course?

The Norwegian BPA service for user-controlled personal assistance, whereby people with disabilities are assigned a regular carer whom they then supervise, is subject to undesirable variations from one local authority to the next as regards granting of this service, in terms of both the number of assistance hours granted and how BPA is regarded in the context of other services. The Ombudsmen have been made aware of cases in which service-users have chosen to move to another municipality offering better services. The Norwegian Government has announced an inquiry into the BPA service in 2019. The Health and Social Services Ombudsmen assume that this inquiry will address the extent to which the service is fit for purpose, how adequately it assures the equality and personal freedom of those in need of extensive assistance, and the fact that place of residence must not be a determinant for the standard of the service provided. The objects of the user-controlled personal-assistance service for people with disabilities (BPA) must be fulfilled regardless of their place of residence. The Ombudsmen endorse the bill to raise the age limit to 67 for continued BPA service eligibility.

The golden rule must be observed.

Mental healthcare is one of the areas the Ombudsmen receive most complaints about. “The Golden Rule”, which dictates that mental healthcare and alcohol and drug rehabilitation services should show a higher growth rate than somatic treatment, is still failing to be observed. The Ombudsmen believe that the health authorities must impose more stringent requirements on Norwegian hospitals in order to achieve the goal for mental healthcare and substance abuse treatment to show higher growth than somatic healthcare.

Patients and relatives are reporting defective or deficient treatment programmes, and that people are becoming more ill in the long wait for treatment. This applies both to day patients and emergency short-stay patients. Patients are calling for closer, better-quality, better-planned and better-coordinated follow-up. Patients receiving adult mental healthcare describe the intense focus on discharge right from the day of admission. The switch in recent years from short-stay to day-only care is also highlighted by patients who express their lack of confidence in care received from the health service. Many patients who are offered treatment as outpatients state they would rather have the security of an overnight stay as part of the mental healthcare arrangements.

Dental care is part of healthcare.

In Norway, adults generally have to cover their expenses on dental care, but the Dental Care Act grants exemptions for people with certain conditions. However, problem substance abuse is not an eligible condition. The evidence is that many people with an alcohol or drug problem have poor dental health. Many of them fail to take good care of their teeth. Many of them avoid going to the dentist owing to the cost, and they have severe oral health problems caused by medication and years of substance addiction. We have noted that stays at healthcare institutions are becoming shorter and shorter. Patients on multidisciplinary specialist drug and alcohol detoxification and rehabilitation programmes barely embark on dental work before they lose entitlement to it. Essential dental treatment should be completed, regardless of whether the patient has finished a stay at a rehabilitation centre.

New appointment in hand.

The Health and Social Services Ombudsmen believe that it should be mandatory for patients who leave a consultation within the specialist health service and are being treated under a care plan to be informed of when their next appointment will be. This will give patients and relatives greater peace of mind and predictability. It will also make it easier for them to object in the event of a breach of the treatment guarantee.

The Ombudsmen’s appeal for common courtesy.

Many complaints concern a lack of consideration and common courtesy. Bad behaviour on the part of health professionals causes added distress for patients, service-users and relatives who are already facing demanding situations. In addition to providing clinically sound care, the health services should also engage proactively in the quality of interpersonal conduct. Negative experiences cause lack of patient confidence in the service, clinical staff and the systems. Comprehensive, appropriate and timely information, the provision of interpreting services when required, recognition of relatives as a resource, and setting aside time for discussion are imperative for sound care that respects human dignity.

Lengthy case handling times threaten legal rights and the safety of patients.

Case handling times under the majority of County Governors and the Norwegian Board of Health Supervision are currently very lengthy. This erodes confidence in the final decision and reduces the learning value for the service-providers in cases concerning quality of care. The Health and Social Services Ombudsmen advocate greater political involvement in order to ensure that health supervision bodies have sufficient resources to investigate complaints and violation of the rights enshrined in national health and care legislation.