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Extract from Rigsrevisionen's report on

## efforts directed at patients with acquired brain injury

submitted to the Public Accounts Committee



# 1. Introduction and conclusion

#### 1.1. PURPOSE AND CONCLUSION

- 1. This report concerns the Ministry of Health's activities to support cohesion and quality in efforts directed at patients with acquired brain injury (patients with brain injury).
- 2. With the implementation of the municipal reform in 2007, the responsibility for training services offered to patients was transferred from the former counties to the municipalities along with DKK 693 million for post-hospital training of all patients.
- 3. The background for the study is the government's evaluation of the municipal reform in 2013. This evaluation identified a number of challenges in the cohesion between hospital and municipality and the quality of the training offered by the municipalities in particular regarding patients with brain injury. The challenges concerned differences among the municipalities in waiting times for training, transfer of patient data from hospital to municipality and quality and competencies in the municipal training. The study is focused on the Ministry of Health's management of these challenges.
- 4. 22,000 Danes acquired a brain injury in 2015; 19,000 of these were alive at the beginning of 2016. It is estimated that minimum 120,000 Danes are living with the consequences of a brain injury that often seriously affect the daily life, family life and future of both the patients and their relatives.

Patients with permanent disability from brain injury often need training, when the hospital has completed its treatment of their injury. The hospitals refer the patients to training and rehabilitation (in the following referred to as training) in the municipalities. In 2015, the hospitals discharged approximately 114,500 patients to training in the municipalities; approximately 7,100 of these had a brain injury.

- 5. The Ministry of Health has estimated the health-sector expenditure for treatment and training of patients with brain injury to DKK 110,000 per patient in 2008, with municipal costs accounting for DKK 60,000 hereof per patient. Training can help reduce future costs for help at home, sickness benefits, early retirement, etc.
- 6. The Ministry of Health has overall responsibility for policies in the health sector. This means that the ministry defines the framework for the care of patients across hospitals and municipalities, in the form of directives, guidelines etc. The regions and municipalities are responsible for providing treatment to and train the patients.

## ACQUIRED BRAIN INJURY

An acquired brain injury is sudden physical damage to the brain caused by sickness or an accident – as opposed to brain defects that are present at birth.

### EVALUATION OF THE MUNICIPAL REFORM

In February 2012, the government set up a committee to evaluate the municipal reform. The tasks assigned to the committee included assessing the current distribution of tasks in the public sector.

#### TRAINING SERVICES

Through physical exercises, the patients train their body and physical abilities, such as walking, eating or talking.

#### REHABILITATION

In this report, rehabilitation refers to pathways of fixed duration aiming to provide the patients with coordinated services within health care, social services, employment and education.

The purpose of training and rehabilitation is to restore some or all of the patient's physical, sensory, and mental capabilities that were lost due to the injury.

#### **CARE PATHWAYS**

Care pathways provide an outline of the inter-disciplinary and coordinated care that should be provided to a well-defined group of patients.

Care pathways can also contribute to inter-disciplinary and inter-sectoral communication and to ensuring that the care provided is based on evidence and best practice.

The Ministry of Health has revised an executive order on Training Programmes and Patients' Choice of Training Services after Discharge from Hospital (Executive Order no. 1088 of 6 October 2014). The new executive order took effect on 1 January 2015.

- 7. Since 2010, the Ministry of Health has implemented various initiatives directed towards patients with brain injury. In the years 2011 to 2015, the ministry, regions and municipalities, among others, joined forces and developed a Care Pathway for Rehabilitation of Adults with Acquired Brain Injury (in the following referred to as the care pathway). The ministry has also implemented a special Pool for Strengthening Training and Rehabilitation of Persons with Acquired Brain Injury (the training pool). The special funding was meant to contribute to ensuring that patients with brain injury were offered coherent, high-quality training programmes. The ministry has also revised an executive order concerning Training Programmes and Patients' Choice of Training Services after Discharge from Hospital (the executive order on training programmes).
- 8. The purpose of the study is to assess whether the Ministry of Health has supported cohesion and quality in the training services provided to patients with brain injury. Rigsrevisionen took initiative to the study in September 2015.

#### **CONCLUSION**

The initiatives launched by the Ministry of Health have not sufficiently supported cohesion and quality in the training services provided to patients with brain injury.

It is Rigsrevisionen's assessment that training of patients with brain injury is a complex task with many actors in the chain of management that is designed to ensure, throughout the process, that the patients are offered relevant training. However, the Ministry of Health depends on the ability, willingness and possibilities of other actors for this objective to be achieved. This means that the ministry defines the framework for treatment and training of patients with brain injury, whereas the hospitals and municipalities are required to operate within the framework in their day-to-day work. However, the study shows that the ministry has not to the extent required monitored the effectiveness of the implementation of its objective of creating cohesion and quality to the benefit of the patients. Regarding the training pool, the ministry could have specified the requirements further, and followed up on the efforts of the individual municipalities and their collaboration with specialist providers of training services for patients with brain injury. Such a step might have mitigated the risk of despecialisation, which has the consequence that patients are not receiving training at the appropriate level. The ministry has failed to obtain adequate information on how the problems in relation to training of patients with brain injury, that were identified in the evaluation of the municipal reform, have been handled.

#### Cohesion

It is essential for the achievement of cohesion that the patients receive a training programme and are offered training without undue delay. The study indicates that the hospitals do not comply in full with the requirements of the executive order concerning training programmes; some programmes are sent to the municipalities too late, and the number of training programmes developed by the hospitals varies significantly. As a consequence, the patients may not have equal access to training. The Ministry of Health has been aware of this problem, but has not taken steps to obtain knowledge as to the frequency of this problem. The ministry has informed Rigsrevisionen that it will contact the regions to ensure that training programmes are sent on time. Rigsrevisionen welcomes this initiative.

Another option for the hospitals is to refer patients with complex brain injury to rehabilitation at specialist level. However, the number of patients that are referred to specialist rehabilitation services is very low. This seems to indicate that the hospitals are not referring all relevant patients to these services. The Ministry of Health has informed Rigsrevisionen that the registration of referrals is subject to some uncertainty and the actual number may therefore be higher. In future, the ministry will follow the development in the number of referrals.

The examination also indicates that not all patients are offered training without undue delay, and there are huge variations between the shortest and the longest waiting times in the municipalities. Generally, waiting times have only been marginally reduced from 2010 to 2015.

#### The quality of training

The quality of the training offered must meet with the defined requirements and the different types of training offered must match the patients' needs. The study shows that the Ministry of Health's administration of the funds allocated to strengthening the training services offered to patients with brain injury has not been entirely appropriate; for instance, the ministry has failed to ensure that objectives were defined for the projects. It is therefore not clear if the funds allocated to this area and the follow-up have effectively contributed to securing the necessary quality in the training services offered by the municipalities. The study also shows that the ministry does not know if the training services offered by the municipalities meet the requirements, or if the patients' need for specialist training and rehabilitation is covered by the training services currently offered to patients. Seventy-five per cent of all patients with brain injury are to be offered training services within these two categories. Gathering data on the effectiveness of the training services offered across hospitals and municipalities can contribute to enhancing the quality of the training. Yet, the study shows that no such data is being gathered.

The Ministry of Health has informed Rigsrevisionen that it is planning to establish a dialogue with relevant actors in the area in order to identify initiatives that can prospectively support efforts to strengthen the cohesion and quality of the services available to patients with acquired brain injury.

## SPECIALIST REHABILITATION

Specialist rehabilitation services are offered to patients who experience complicated, significant and/or severe loss of functionality affecting several aspects of life: typically patients with complex brain injury.

The number of specialist rehabilitation services to which the municipalities can refer patients, is limited to a few.

#### ADVANCED TRAINING

This form of training is offered to patients with significant loss of functionality.

Services for patients who need advanced training are provided by health professionals with special competencies.

The health professionals may also be required to coordinate training of these patients with other advanced or specialist care programmes.