

Visually impaired children and adolescents are a mixed group with an extensive need for health care. Only a country-wide register of eye care quality can provide us with an overview of their numbers, and ensure that they all get the help they need.

A registered need

In this issue of the Journal of the Norwegian Medical Association, we launch an appeal for a quality register for visually impaired children and adolescents, such as those all the other Nordic countries already have (1). There are currently two national registers that cover children who may be visually impaired: the Norwegian Neonatal Network (2), where treatment of neonates that have been hospitalised is recorded, and the Cerebral Palsy Register of Norway (3). Neither of them contains information about the children's visual function, however.

A health register is a structured collection of information linked to individuals and concerning their state of health, organised in such a way that it is easy to combine information. A distinction is made between two types of register: central health registers, and registers of medical quality (4). These national health registers are among our most important tools for evaluating treatment and promoting health initiatives for the Norwegian population. As a rule, we want answers to the same questions: Is everyone receiving help? Which form of help is most effective? Is the quality of the help equally good everywhere?

A great deal of work is required to get a register up and running. A good register calls for close cooperation among different disciplines. Delicate situations may very easily arise when data are to be analysed, for example when differing practices in different disciplinary environments are to be compared, and comparisons are made between different regions.

In an article based on a survey from the Cancer Registry of Norway, published a while back, the results could be interpreted as indicating that education and income determine which treatment is offered to users (5). Reactions were not slow in coming (6). A specialist within the discipline was of the opinion that the picture that was sketched was too simplistic, as important variables had been omitted (7). The researchers' results were challenged and it is difficult to form definite opinions as to what is true (8). We can at any rate agree on the importance of registers containing all relevant variables, and that the variables may perhaps have to be changed over time.

Our neighbouring countries have come a long way in developing and using data from health registers. We can use many of their results in Norway as well, as the populations are fairly similar. When it comes to quality assurance of our own practice, there is no point in sneaking a glance across the border. We need to have our own figures in order to be able make comparisons, and thereby ensure that the health service is of the same quality and predictable throughout Norway.

What about the Norwegian Registry of Blindness, *Blindekartoteket*? *Blindekartoteket* was established in 1968. It was one of the earliest health registers in the country, and included both children and adults with visual impairment. But the registry was discontinued in the mid-1990s because of intensified requirements regarding data security and protection of privacy, as well as incomplete registration. Over the last 20 years, the medical community has repeatedly recommended that a register of children and adolescents with visual impairment be re-established. A combined overview is essential for finding the causes of eye diseases, for correct distribution of resources and for ensuring that visually impaired persons receive the services to which they have a right. A register would help to identify patients with an undetermined diagnosis.

Getting a correct diagnosis has always been important, and will not grow less urgent in the time ahead. In view of the opportunities offered by new treatment methods, such as gene therapy when a genetic disorder is the cause of disease, detailed assessment and diagnosis are absolutely essential. The first gene therapy for hereditary retinal diseases is probably not far off. One of the most common is retinitis pigmentosa, which causes severely impaired vision in children and young adults. Some kind of survey and registration of this patient group would be very useful.

Children and adolescents are not a patient group with a great deal of clout. Children with impaired vision often have other functional disabilities in addition, and need someone to be a spokesperson on their behalf. The Norwegian Association of the Blind and Partially Sighted is very active in this respect and does very important work. Offers of gatherings, courses and camps mean a lot to families with visually impaired children and adolescents.

The point prevalence study conducted under the auspices of the Department of Ophthalmology at Haukeland University Hospital, published in this issue of the Journal of the Norwegian Medical Association (1), is another praiseworthy initiative. The study provides a picture of the children, their needs, and the challenges facing the Norwegian health service. The process by means of which data were procured makes interesting reading. The group has put a tremendous amount of work into surveying the situation here in Norway. Despite their efforts, the authors indicate that they may have found only half of the numbers of visually impaired children one might have expected in light of similar surveys in other Scandinavian countries. In order to locate all children with a visual impairment, and promote an equal, predictable health service, a country-wide health registry is a must. It should be established as soon as possible.

Dordi Austeng
dordi.austeng@ntnu.no

Dordi Austeng (born 1968) Specialist in ophthalmic diseases and researcher specialising in retinal diseases. She is senior consultant at the Department of Ophthalmology of St. Olavs Hospital, and a postdoctoral fellow with the Department of Neuroscience at the Norwegian University of Science and Technology.

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