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## Freedom of choice for whom?

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**For nearly 20 years, Norwegian health budgets have sponsored undocumented and dubious treatment of children with severe brain injury. There are few indications that this practice will cease.**



Photo: Einar Nilsen

An American 'treatment centre' (The Family Hope Center [\(1\)](#)) has a founder and director with no traceable basic medical training. In hour-long commercials on the centre's website he refers, for example, to child epilepsy as a symptom of 'toxification' of the child, and postulates that many of the functional impairments associated with Down's syndrome are caused by the children having crawled too little as infants, and that the treatment of Down's syndrome should therefore include diet and crawling on the floor. Similar treatments are also supposedly effective in cases of cerebral palsy, dyslexia, ADHD, autism, Alzheimer's disease and generally for 'any condition where the brain fails to function in all areas' [\(1\)](#).

Another American centre (The Institutes for the Achievement of Human Potential [\(2\)](#)) bases its activities on medical theories that were abandoned long ago and treats children with severe brain injury with up to 30 intensive daily sessions for years, using methods that the American Academy of Pediatrics has been warning against since 1968 [\(3, 4\)](#).

Both these centres belong to the cabinet of curiosities in the alternative-medicine industry and have an obvious commercial flair for children with serious diseases. Numerous independent reviews, including a comprehensive methodology assessment from the Norwegian Institute of Public Health, find no evidence of the efficacy or safety of this treatment [\(4\)](#). Moreover, all Norwegian paediatric specialist communities warn against such practices.

In spite of this, ever since 2002 Norwegian governments of varying political colours have [\(5\)](#) ensured that millions of Norwegian kroner earmarked for health are spent each year on sending Norwegian children with serious neurological disorders for treatment in these centres. In 2015 alone, altogether 86 Norwegian children travelled to such centres at the government's expense. This year, the 'treatment' incurred a cost of NOK 86 million to the Norwegian health budget [\(4\)](#). Of this, a full NOK 11 million went on travel, accommodation and fees to The Family Hope Center alone.

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The activity in these centres is largely based on principles developed in the 1950s by the physiotherapist Glenn Doman. Their theoretical basis consists of the bizarre and long-abandoned 'recapitulation theory' from the late 19th century, which postulated that in their ontogenesis, individuals 'recapitulate' phylogenesis by following a development trajectory from the fish stage via the reptile and mammal stages to a fully developed human. Injuries to the nervous system can therefore be healed by bringing the individual back to the stage when the injury occurred (for example fish) to heal there, so that a normal development can be resumed [\(6\)](#).

Treatment options for children with serious functional impairment due to brain injury, and need for habilitation, have been few and far between in Norway. Both the concerned parents and the professional communities themselves have pointed this out on many occasions [\(7\)](#). For some desperate parents, the quite

understandable solution will be to contact groups that can offer some hope that a major improvement is possible. It is thus a risk, and not only for Norwegians, that they may fall prey to dubious operators who engage in undocumented, useless or directly harmful practices (8).

For exactly this reason, the key role of the health services should be to offer something different and better: genuine care, time and sufficient resources to provide the best evidence-based treatment and follow-up. This requires the funding authorities to have the backbone to see what is best for the children and channel limited resources in the right direction.

In this respect, things are presently looking poor in this area. In 2017, the Decision Forum concluded that the provision of undocumented treatment abroad to children with habilitation needs ought to cease (9). There are few signs that this has helped. In a written question to Bent Høie, Minister of Health, in February 2019, the questioner was concerned that this decision 'should not mean that the opportunity to choose other options, including those abroad, is removed' (10). In his response, the cabinet minister reassured her that 'no amendments have been made to the options pertaining to habilitation programmes abroad', that the government will 'ensure that parents will continue to have the opportunity to choose between different options', and that 'those who have already established a treatment programme that includes options abroad under this scheme will be able to continue with it if they so wish' (10).

It could hardly be put in clearer terms: freedom of choice for parents is more important than ensuring that children with serious brain injuries receive evidence-based treatment.

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