

Differences across counties in the registered prevalence of autism, ADHD, epilepsy and cerebral palsy in Norway

BACKGROUND In 2012, we published an overview of the prevalence of developmental disorders and neurological diseases in children in Norway, which was unknown at the time. In this article we will compare diagnostics and treatment across counties and institutions.

MATERIAL AND METHOD The prevalence across counties of autism spectrum disorders, ADHD, epilepsy and cerebral palsy in children aged 0–12 was estimated with the aid of data from the Norwegian Patient Register for the years 2008–11.

RESULTS In the age group 6–12 years, nationwide prevalence amounted to 0.6 % for autism spectrum disorders, 2.0 % for ADHD, 0.9 % for epilepsy and 0.3 % for cerebral palsy. In total, 5.0 % of all twelve-year-olds were registered with one or more of these diagnoses. The prevalence of autism spectrum disorders and ADHD varied between the counties, from 0.3 % to 1.5 % for autism spectrum disorders and from 1.1 % to 3.5 % for ADHD. For epilepsy and cerebral palsy there was little variation between the counties. Diagnostics and treatment of these four conditions are spread over 29 somatic hospitals and 102 units for child and youth psychiatry.

INTERPRETATION The variations across counties in the prevalence of autism spectrum disorders and ADHD are most likely due to variations in diagnostic practices. We ask whether it is appropriate to spread the provision of treatment across such a high number of institutions.

Developmental disorders and neurological afflictions are a significant cause of morbidity and reduced ability for children to function (1) and often require comprehensive follow-up from the healthcare and other assistance services. Despite this fact, until 2012 no overview of the prevalence of such conditions in the child population of Norway was available, and comparisons of diagnostics and treatment across counties and institutions have therefore been impossible. One exception is cerebral palsy, for which a national quality register has been in operation since 2006 (2). The inclusion of personally identifiable information in the Norwegian Patient Register in 2008 permitted systematic study of these conditions on a nationwide basis. The register collects activity data from all Norwegian specialist health services. In June 2012, we published an article on the prevalence of autism spectrum disorders, ADHD, epilepsy and cerebral palsy in Norwegian children (3). The figures were based on data from the Norwegian Patient Register for the years 2008–10. These four conditions were selected because they are the most prevalent developmental disorders and neurological afflictions in children. They also lend themselves well to registry studies, since they will invariably be diagnosed in the specialist health services and thereby recorded by the Norwegian Patient Register.

We demonstrated that the prevalence of these four conditions increases with age, that they are more prevalent among boys than among girls, and that there is a large degree of overlap between them (3). The estimated cumulative incidence at age 11 amounted to 0.8 % for autism spectrum disorders, 3.4 % for ADHD, 1.1 % for epilepsy and 0.3 % for cerebral palsy, and as many as 4.3 % of all eleven-year-olds had been registered with one or more of these diagnoses. In this article we describe the differences in prevalence across counties and how children with these conditions are distributed among various health institutions. These new estimates are based on data from the NPR for the years 2008–11.

Material and method

Data sources

The Norwegian Patient Register collects activity data from Norwegian hospitals and outpatient clinics. Reporting to the register is mandatory and linked to the system for reimbursement of expenses for performance-based funding. Conditions are reported as ICD-10 codes (International Classification of Diseases, 10th revision) (4). The Norwegian Patient Register was established in 1997, but national identity numbers were not reported until 2008, following an amendment to the Personal Health Data Filing Systems Act adopted by the Storting in 2007. Reporting of

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MAIN MESSAGE

At the age of 12, altogether 5% of all children in Norway have been registered with autism spectrum disorder, ADHD, epilepsy and/or cerebral palsy.

The examination and treatment of these conditions are distributed over a large number of units.

There is significant variation across counties in the prevalence of autism spectrum disorders and ADHD.

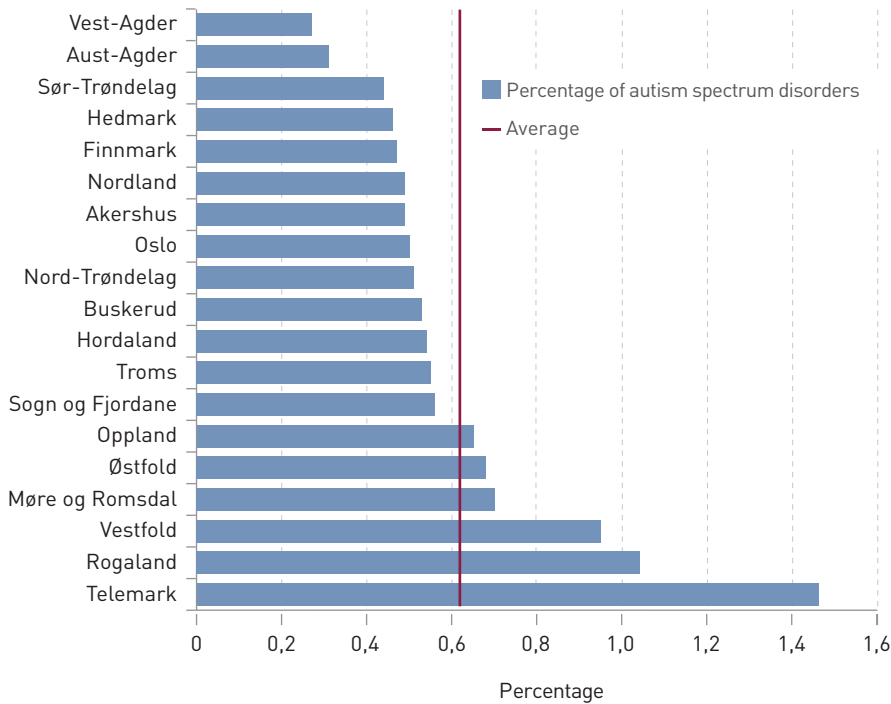


Figure 1 Prevalence of autism spectrum disorders by county in 2008–11 in children aged 6–12 (autism spectrum disorder registered as a main or other condition once or more during the period)

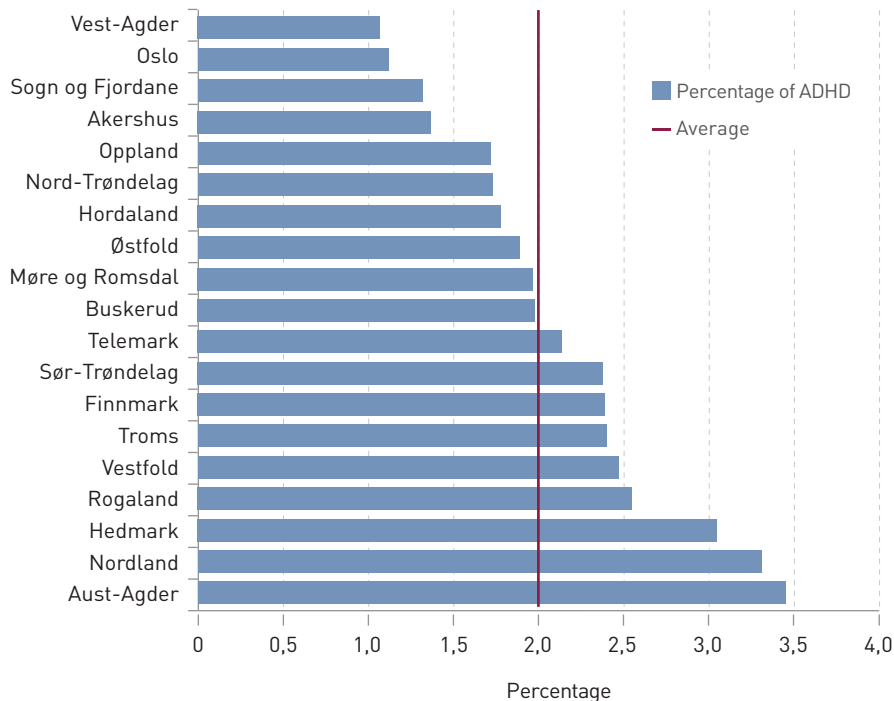


Figure 2 Prevalence of ADHD by county in 2008–11 in children aged 6–12 (ADHD registered as a main or other condition once or more during the period)

national identity numbers is a precondition for being able to count individuals and follow them over time. The register stores national identity numbers in encrypted form.

Specialists in private practice who have a contract with the regional health authorities are also encompassed by this obligation to report. However, their reporting of national identity numbers remains incomplete, and data from private contract specialists are therefore not included in our estimates.

An anonymous data file was prepared by the Norwegian Patient Register, containing data for the years 2008–11, i.e. the first four years after the collection of personally identifiable data had begun. The data set comprised children born in the period 1999–2011, who were thus 0–12 years at the end of the follow-up period. Disease codes from the following ICD-10 chapters were included: F84 Pervasive developmental disorders; F90 Hyperkinetic disorders; G40 Epilepsy; G41 Status epilepticus; G80 Infantile cerebral palsy.

The data file contained information about gender, year of birth, county of residence and the year when the condition was registered. The file did not distinguish between «main condition» and «other conditions», but the Norwegian Patient Register had prepared statistics of all children registered with the relevant disease codes as their main condition in the various institutions in 2011. No quality assurance of the figures from each institution was undertaken, and they are presented with the reservation that errors may have occurred during the reporting.

Disease codes in chapters G40 and G41 are jointly referred to as epilepsy. We excluded the codes F84.2 Rett's syndrome, F84.3 Other childhood disintegrative disorder and F84.4 Overactive disorder associated with mental retardation and stereotyped movements, from the definition of autism spectrum disorders, since these are commonly not subsumed under the autism spectrum in a research context.

Estimates

The prevalence of the various conditions by county was estimated by dividing the NPR figures by the total number of inhabitants with the corresponding year of birth for each county. By «prevalence» we mean the proportion of children who are registered with a given condition in one or more of the years 2008–11. In the comparisons by county we included only the age group 6–12 years (children born in the period 1999–2005), since ADHD and Asperger's syndrome rarely are diagnosed before the age of six. Comparisons across counties and conditions will thus be more informative when the youngest children are left out. To investigate the frequency of

follow-up by the specialist health services, we subdivided the disease codes by year and estimated the proportions of registered cases that were recurring during subsequent years. These estimates included the entire material (age 0–12). The entire material was also included in the overviews of the number of children per institution.

Data on the number of persons in the total population were supplied by Statistics Norway. The complete study population encompassed all those who had been born in the years 1999–2011 and were resident in Norway on 31 December 2011. This population amounted to a total of 797 356 individuals, whereof 408 354 were boys and 389 002 were girls.

Ethics

The data file used for estimation of prevalence did not contain any information that could be linked to specific individuals, i.e. no directly or indirectly personally identifiable data. The use of such de-identified data files does not require approval by the Regional Committee of Medical and Health Research Ethics or The Norwegian Data Protection Authority.

Results

A total overview of the number of children with the different disease codes, by gender and year of birth, is shown in e-Table 1. The prevalence rose consistently with age, and in twelve-year-olds (children born in 1999) it amounted to 0.9% for autism spectrum disorders, 3.4% for ADHD, 1.0% for epilepsy and 0.3% for cerebral palsy. In total, 5.0% of all twelve-year-olds were registered with one or more of these diagnoses. In the age group 6–12 years, the boy/girl ratio was 4.5 for autism spectrum disorders, 2.8 for ADHD, 1.3 for epilepsy and 1.3 for cerebral palsy. These figures concurred well with previous estimates (3).

Among the children suffering from autism spectrum disorders, ADHD and epilepsy, many of the cases could not be retrieved in the specialist health services every year. Among the children registered with autism spectrum disorders, 70–74% were registered with the same condition also in the following year. The percentages declined to 61–62% after two years and to 54% after three years. For ADHD, the proportion with a repeated registration amounted to 66–79% after one year, to 59–62% after two years and 44% after three years. For epilepsy, the proportion was 67–70% after one year, 59–62% after two years and 55% after three years. Cerebral palsy differed from the other conditions in that for the large majority of the registered cases – more than 85% – the condition was registered by a specialist every year.

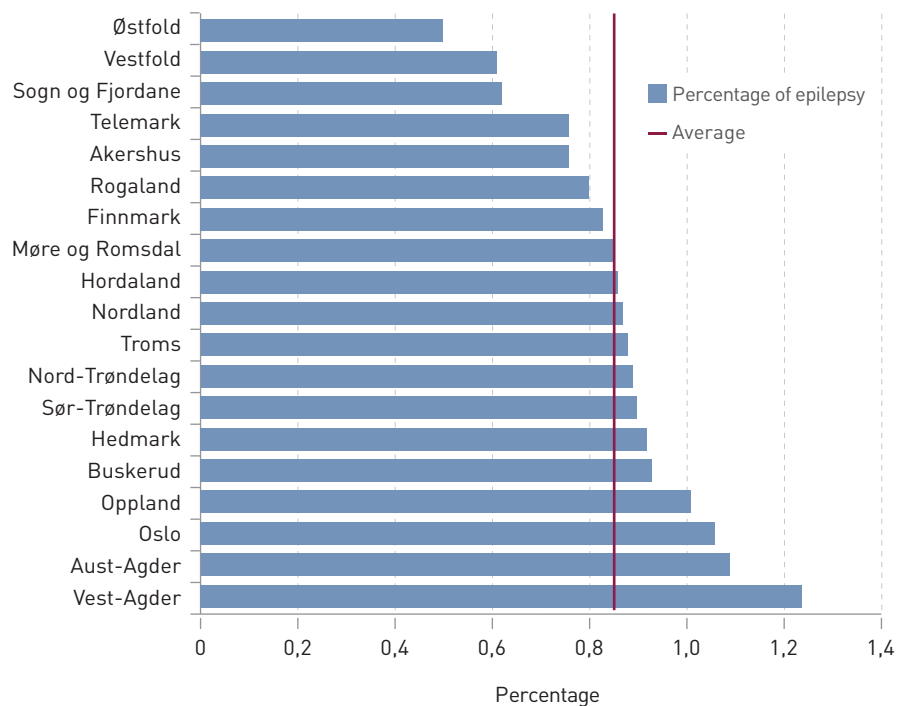


Figure 3 Prevalence of epilepsy by county in 2008–11 in children aged 6–12 (epilepsy registered as a main or other condition once or more during the period)

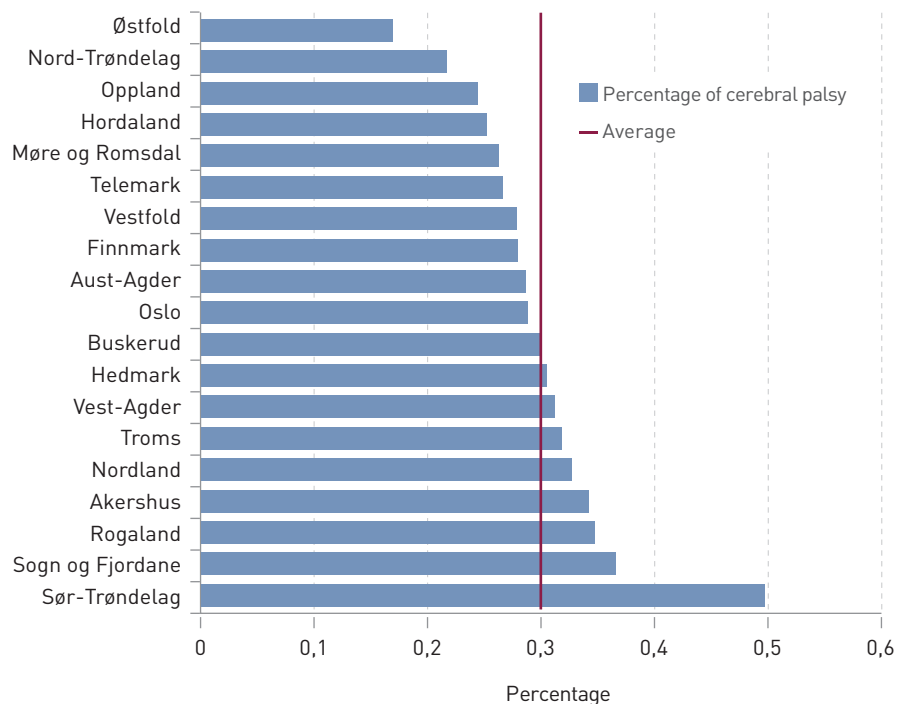


Figure 4 Prevalence of cerebral palsy by county in 2008–11 in children aged 6–12 (cerebral palsy registered as a main or other condition once or more during the period)

Table 2 Somatic hospitals: Number of children aged 0–12 registered with autism spectrum disorders, ADHD, epilepsy or cerebral palsy as their main condition in 2011

| | Autism spectrum disorders | ADHD | Epilepsy | Cerebral palsy |
|---|---------------------------|------|----------|----------------|
| Fredrikstad | 57 | 9 | 94 | 58 |
| Akershus University Hospital | 86 | 26 | 206 | 166 |
| Drammen | 75 | 59 | 227 | 137 |
| Oslo University Hospital (Ullevål, Rikshospitalet, National Center for Epilepsy – SSE) ¹ | 85 | 14 | 799 | 342 |
| Innlandet Hospital (Elverum, Lillehammer) ¹ | 71 | 93 | 187 | 80 |
| Tønsberg | 10 | 16 | 90 | 75 |
| Skien | 10 | 9 | 67 | 42 |
| Sørlandet Hospital (Kristiansand, Arendal) ¹ | 53 | 70 | 187 | 77 |
| Stavanger University Hospital | 36 | 87 | 167 | 136 |
| Haugesund | 38 | 14 | 106 | 25 |
| Haukeland University Hospital | 9 | 25 | 264 | 155 |
| Førde | 18 | 5 | 41 | 36 |
| Ålesund | 31 | < 5 | 83 | 37 |
| Molde | < 5 | < 5 | 21 | < 5 |
| Kristiansund | 18 | 27 | 40 | 20 |
| St. Olavs Hospital | 63 | 36 | 204 | 149 |
| Namsos | 5 | 33 | 29 | 6 |
| Levanger | 35 | < 5 | 56 | 19 |
| Bodø | 9 | 37 | 94 | 54 |
| Sandnessjøen | < 5 | 20 | 6 | < 5 |
| Rana | < 5 | 8 | 5 | 5 |
| Vesterålen (Stokmarknes) | < 5 | < 5 | 18 | < 5 |
| University Hospital of North Norway (Tromsø) | 18 | 39 | 114 | 63 |
| Hammerfest | < 5 | < 5 | 7 | 6 |
| Kirkenes | < 5 | < 5 | 10 | < 5 |

¹ Figures were reported for the enterprise as a whole, not permitting distinctions between individual institutions

Prevalence by counties

Figures 1 to 4 shows the prevalence of the four conditions by counties. For autism spectrum disorders (Figure 1), the national average was 0.6% for the age group 6–12 years, while the prevalence varied at the county level from 0.3% in Aust-Agder and Vest-Agder to 1.5% in Telemark. The two Agder counties were significantly below the national average, while Telemark, Vestfold and Rogaland were significantly above. For ADHD (Figure 2), the national average was 2.0% for the age group 6–12 years. Vest-Agder had the lowest level even here, at

1.1%, while Aust-Agder was at the top with 3.4%. Akershus, Oslo, Vest-Agder and Sogn og Fjordane were significantly below the national average, while Hedmark, Aust-Agder and Nordland were far above.

The differences across counties in the prevalence of epilepsy and cerebral palsy were markedly smaller than for autism spectrum disorders and ADHD. For epilepsy (Figure 3), the national average amounted to 0.9% among children aged 6–12, and most counties were close to this level. Østfold was lowest at 0.5% and Vest-Agder was at the top with 1.2%. For cerebral palsy (Figure 4),

the national average amounted to 0.3%. As for epilepsy, Østfold had the lowest prevalence at 0.2%, while Sør-Trøndelag had the highest at 0.5%.

Number of children per institution

Children with autism spectrum disorders and ADHD are followed up in somatic hospitals and by the psychiatric services for children and youth, while those who suffer from epilepsy and cerebral palsy are followed up only in somatic hospitals. In 2011, children were registered with the four conditions in 29 different somatic institutions. Table 2 shows the

number of children per institution. There was a significant numerical spread between the institutions, and many institutions had fewer than ten cases of each main condition. Nine hospitals had fewer than ten children with autism spectrum disorders, ten had fewer than ten children with ADHD and seven had fewer than ten children with cerebral palsy. As regards epilepsy, there were fewer institutions with small numbers of children, and those at the bottom were mainly hospitals that had no paediatric ward, but most likely had received children with epilepsy for emergency treatment.

In the system of psychiatric services for children and youth there were 98 institutions where autism spectrum disorders and ADHD had been registered as main conditions in children in 2011. Table 3 shows the number of such psychiatric units in each county and the average number of children with autism spectrum disorders and ADHD per unit. The total number of units amount to 102, but the four third-tier institutions under Oslo University Hospital Ullevål had failed to report any disease codes. Even here, there was a large spread in the number of children per year, and many institutions reported small numbers, especially with regard to autism spectrum disorders. Among the 64 psychiatric units that submitted individual reports, altogether 38 (59%) had fewer than ten patients with autism spectrum disorders as their main condition. Among the enterprises that only reported aggregate figures, there were also several where the average number of patients with this condition amounted to fewer than ten.

Discussion

For Norway as a whole, the prevalence of autism spectrum disorders, ADHD, epilepsy and cerebral palsy was in line with our previous estimates (3). There are significant differences across counties with regard to autism spectrum disorders and ADHD – to an extent that can hardly be explained by way of underlying real variations in prevalence. Our findings indicate that considerable regional variations in diagnostic and/or coding practices have developed. If so, this will concur with the differences across counties that have been demonstrated for treatment practice regarding ADHD, with large variations in the proportion of inhabitants provided with anti-ADHD drugs (5). The medical profession will have a large interest in obtaining more knowledge about the causes of these regional variations. In light of current figures, we may question whether children with autism spectrum disorders and ADHD are provided with uniform and equal health services in Norway.

As regards epilepsy and cerebral palsy,

Table 3 Psychiatric services for children and youth: Number of children aged 0–12 registered with autism spectrum disorders or ADHD as their main condition in 2011

| County | Number of psychiatric units | Average per psychiatric unit | |
|------------------------------------|-----------------------------|------------------------------|------|
| | | Autism spectrum disorders | ADHD |
| Østfold | 6 | 12 | 45 |
| Akershus and Buskerud ¹ | 11 | 8 | 39 |
| Oslo ² | 10 | 7 | 29 |
| Hedmark | 5 | 5 | 50 |
| Oppland | 2 | 20 | 77 |
| Vestfold | 4 | 35 | 82 |
| Telemark | 4 | 51 | 43 |
| Aust-Agder | 1 | 0 | 88 |
| Vest-Agder | 4 | 1 | 19 |
| Rogaland | 10 | 29 | 56 |
| Hordaland | 9 | 19 | 46 |
| Sogn og Fjordane | 3 | 13 | 30 |
| Møre og Romsdal | 4 | 14 | 56 |
| Sør-Trøndelag | 7 | 4 | 55 |
| Nord-Trøndelag | 2 | 4 | 46 |
| Nordland | 7 | 3 | 23 |
| Troms | 5 | 3 | 32 |
| Finnmark ¹ | 4 | 3 | 26 |

¹ Vestre Viken Hospital Trust encompasses units in both Akershus and Buskerud counties, and no distinction between the two counties was possible.

² The four third-tier institutions under Ullevål Hospital (Sogn Inpatient Unit, Lille-Sogn Outpatient Unit, the Child Psychiatry Unit and the Neuropsychological Unit) had not reported disease codes to the Norwegian Patient Register and are not included in the table.

the geographical variations in prevalence are relatively minor. Most likely, this is because diagnostics of such conditions leave less room for discretionary judgement, but we would not exclude the potential importance of the fact that the diagnostic responsibility is concentrated in a considerably smaller number of institutions than is the case for diagnostics of autism spectrum disorders and ADHD.

The lack of data from private contract specialists may have caused a certain underestimation of the prevalence of ADHD. Overviews of consultations reported for social security reimbursements show that 5–10% of all ADHD diagnoses are registered by private contract specialists. Many of these patients will be registered in public health institutions as well, but we have no knowledge of the potential degree of overlap. Children with autism spectrum disorders, epilepsy and cere-

bral palsy are almost exclusively diagnosed and followed up in public health institutions, and the dearth of data from private contract specialists will have had only little effect on the prevalence data for these conditions.

Many of the health enterprises, including Oslo University Hospital, report disease codes from the enterprise as a whole, without any specification of institutions. This is a weakness of the reporting practice, since health enterprises mostly consist of several units in various locations and with varying traditions for diagnostics and treatment. The value of this reporting would increase if the individual institutions were specified for each health enterprise.

Norwegian specialist health services for children are strongly decentralised. Our count shows that the four conditions we have studied here were registered in 20 somatic hospitals and 102 psychiatric units in 2011. As a

result of this decentralisation, many institutions treat a very small number of children in each diagnostic group. The quality of the diagnostics and treatment provided for these four conditions has not been investigated, but we believe that there is reason to ask whether the current dispersion of specialist competence over so many institutions really is an advantage with regard to the patients.

The geographical and physical separation of paediatrics from the psychiatric services for children and youth is also a source of wonderment to us. Neurological and psychiatric afflictions in children often result in complex disease pictures, making cooperation across specialities and professions essential. Being aware of the comprehensive overlap that may occur between various conditions and of the neurobiological basis of many of these disorders, this strict separation of paediatrics from the psychiatric services for children and youth appears artificial as well as outdated.

For many children with autism spectrum disorders, ADHD and epilepsy, the conditions cannot be found in the Norwegian Patient Register every year. In some cases this may be due to coding practice, but it remains obvious that a large number of these children are not provided with consistent follow-up by the specialist health services. We assume that they are followed up by GPs and the educational and psychological counselling services at the municipal level. For children with ADHD, this is in line with the guidelines for diagnostics and treatment issued by the Norwegian Directorate of Health (6). We believe that it would be interesting to investigate whether this follow-up is of sufficient quality when undertaken only under the auspices of the educational and psychological counselling services and the municipal healthcare services. These services are even more decentralised than the specialist health services, and the number of children correspondingly smaller. No registry data are currently available from the educational and psychological counselling services or the primary health services to provide the kind of information on the specialist health services collected by the Norwegian Patient Register.

A national register facilitates investigation of the prevalence of diseases with de-identified data files and a minimum of resource use. A national register also permits comparisons of prevalence across counties and institutions. This would be impossible if the reporting had been made voluntary and based on consent.

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References

- Boyle CA, Boulet S, Schieve LA et al. Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics* 2011; 127: 1034–42.
- Cerebral parese-registeret i Norge. Årsrapport 2011. www.siv.no/omoss/avdelinger/cp-register/Sider/enhet.aspx [20.6.2013].
- Surén P, Bakken IJ, Aase H et al. Autism spectrum disorder, ADHD, epilepsy, and cerebral palsy in Norwegian children. *Pediatrics* 2012; 130: e152–8.
- World Health Organization. *International Classification of Diseases*. 10. utg. Genève: WHO, 1990.
- Lillemoen PK, Kjosavik SR, Hunskaar S et al. Føreskriving av legemiddel mot AD/HD 2004–08. *Tidsskr Nor Legeforen* 2012; 132: 1856–60.
- Veileder i diagnostikk og behandling av AD/HD. Oslo: Helsedirektoratet, 2007. www.helsedirektoratet.no/publikasjoner/veileder-for-diagnostisering-og-behandling-av-adhd/ Publikasjoner/veileder-for-diagnostisering-og-behandling-av-adhd.pdf [20.6.2013].

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