

Descriptive study of young disabled children aged 2–6, enrolled in mainstream schools, and benefiting from special needs assistants in the Bouches-du-Rhône in 2014

B. Roth, E. Jouve, A. Daguzan, A. Richardson, R. Sambuc, O. Bernard, M.C.

Lagouanelle-Simeoni

► To cite this version:

B. Roth, E. Jouve, A. Daguzan, A. Richardson, R. Sambuc, et al.. Descriptive study of young disabled children aged 2–6, enrolled in mainstream schools, and benefiting from special needs assistants in the Bouches-du-Rhône in 2014. Archives de Pédiatrie, 2021, 28 (1), pp.39-46. 10.1016/j.arcped.2020.10.005. hal-03964946

HAL Id: hal-03964946 https://amu.hal.science/hal-03964946

Submitted on 22 Mar 2023

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers. L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.



Distributed under a Creative Commons Attribution - NonCommercial 4.0 International License

Version of Record: https://www.sciencedirect.com/science/article/pii/S0929693X20302426 Manuscript_5efcb7564ad0c0a4d60c476f470fa5d2

Descriptive study of young disabled children aged 2–6, enrolled in mainstream schools, and benefiting from special needs assistants in the Bouches-du-Rhône in 2014

Short title: Who are the young disabled children attending mainstream schools in France? B. Roth^{a*}, E. Jouve^a, A. Daguzan^{a,b}, A. Richardson^c, R. Sambuc^d, O. Bernard^e, MC. Lagouanelle-Simeoni^{a,b}

^a APHM, Hôpital Conception, Service d'évaluation médicale, 13005 Marseille, France.

^b Aix Marseille Université, Laboratoire de Psychologie Sociale (LPS), 13100 Aix-en-

Provence, France.

^c MDPH (Maison Départementale des Personnes Handicapées), Conseil Général des

Bouches-du-Rhône, 4, quai d'Arenc, 13304 Marseille, France.

^d Aix Marseille Université, CEReSS (Centre d'Études et de Recherche sur les Services de

Santé et la Qualité de Vie), 13385 Marseille, France

^e PMI (Protection Maternelle et Infantile), Conseil Départemental des Bouches-du-Rhône,

4, quai d'Arenc, 13304 Marseille, France.

* Corresponding author: brimbelle.roth@gmail.com

Funded by Protection Maternelle et Infantile, Conseil Départemental des Bouches-du-Rhône, France.

No communication or preliminary publication.

Abstract

Background

Since the law of February 11, 2005, in France, the number of children with disabilities enrolled in ordinary schools has increased steadily. As a result, the amount of personal support provided by a special needs assistant (personal support) is also increasing. The aim of the study was to describe the diseases and impairments of disabled children aged 2–6, enrolled in mainstream schools and benefiting from personal support for schooling by special needs assistants in the Bouches-du-Rhône (France) in 2014.

Methods

A cross-sectional descriptive study was performed. Children included were benefiting from either an individual or shared personal support. Physicians from the territorial organization in charge of disability coded diseases and deficiencies using the International Classification of Diseases, 10th revision, and nomenclature inspired by the International Classification of Functioning, Disability and Health.

Results

Medical data were coded for 990 children out of 1260 of the total population. These young disabled children were most frequently children with pervasive developmental disorders (23.3%), lack of expected normal physiological development (19.9%), or mixed specific developmental disorders (13.5%), and most often had behavioral, personality, and relational skills disorders (61.8%), psychomotor function impairments (51.9%), or written or oral language learning impairment (43.2%). Finally, the two main types of impairments most represented among these children were psychological impairments (86.7%) and language and speech impairments (79.8%).

The children were most often supported by an individual personal support (for one child only) than by a shared personal support (60% vs. 40%). They were mainly boys (almost 75%).

Conclusion

This study provides working guidelines for the management of health policies relating to disability at the territorial or even national level.

Keywords: Disabled children – Mainstreaming (education) – Health status – Health policy – Schools – Child, preschool

1. Introduction

Since the entry into force of the law of February 11, 2005 "for equal rights and opportunities, participation and citizenship of people with disabilities"[1], there have been major changes in the schooling policy for children with disabilities in France. The effect of this law has been to increase the number of these children attending school in ordinary schools and the personal support allocated to them. By 2014, three-quarters of students with disabilities were enrolled in mainstream schools and the remaining one-quarter in hospitals or medico-social institutions [2]. The number of children with disabilities for School Inclusion, CLIS) increased from 58,812 in 2004 to 103,908 in 2014 (+76.7%) [2]. These factors contribute to making the support and care of children with disabilities in schools a real public health issue.

Indeed, the law defines disability as follows: "Any activity limitation or restriction of participation in society suffered by a person in his environment due to a substantial, lasting or permanent impairment of one or more physical, sensory, mental, cognitive or psychological functions, a multiple disability or a disabling health disorder constitutes a disability within the meaning of this law." This is therefore not only a person, in this case a child, with an impairment or disorder, but a disability situation where the environment is not adapted to that child. The school must adapt to this child's needs and expectations and personal support can be provided to ensure its success [3].

A territorial organization called "Maison Départementale des Personnes Handicapées" (MDPH) was created by this law and is the backbone of the allocation of this personal support to schooling: a special needs assistant, named "Accompagnant des Elèves en Situation de Handicap" (AESH) in French (formerly "Auxiliaire de Vie Scolaire" or AVS)

4

[4]. An AESH is a person in charge of personal assistance for the student's schooling, support, socialization, and safety of disabled students or with disabling health conditions.

When the multidisciplinary evaluation team called "Equipe Pluridisciplinaire d'Evaluation" (EPE) of the MDPH elaborates a Personalized Schooling Project called "Projet Personnalisé de Scolarisation" (PPS) for a child whose family has initiated a care request, it can recommend the allocation of three different types of support to schooling: (1) individual personal support: AESH-i; (2) shared personal support: AESH-m; and (3) collective support in ULIS (Localized Units for School Inclusion): AESH-co. AESH-i meets the needs of students who require sustained and continuous attention. Support can be provided on a full-time or part-time basis. AESH-i supports one child only. AESH-m meets the needs of students who do not require sustained and continuous attention. They can work with several students simultaneously.

There are annual data on disabled children enrolled in primary and nursery school [5], but the information available, particularly medical information, is limited. To our knowledge, no study has yet been carried out specifically on the health of children who benefit from an AESH, whereas the National Health Strategy 2018–2022 [6] defined by the French Government recommends in its focus on "improving the support and social integration of disabled children" to "develop research to improve the taking into account of disability in an inclusive society." A better knowledge of the distribution of diseases and impairments in the population of a region receiving aid can help to draw up lines of thought for the adjustment of health policies concerning disability.

1.1 Main and secondary objectives

The aim of the study was to describe the diseases and impairments of disabled children aged 2–6, enrolled in mainstream schools and benefiting from personal support for schooling by a special needs assistant (AESH) in the Bouches-du-Rhône in 2014.

The secondary objectives were: to assess the allocation of the type of AESH according to different regions in the Bouches-du-Rhône and according to the diseases and impairments presented by the children, to estimate the prevalence of the diseases and impairments presented by these children, and finally to describe the distribution by sex and age for each disease or impairment.

2. Material and Methods

2.1 Type of study conducted

A cross-sectional descriptive study was carried out of all children born from January 1, 2008 who had a notification of AESH, who were included in the Bouches-du-Rhône (13) MDPH registers on July 1, 2014.

In this study, children were benefiting from either individual personal support (AESH-i) or shared personal support (AESH-m).

2.2 Allocation of an AESH to a disabled student: operating mode (Figure 1) [7–10]

2.2.1 File set-up

The educational team (family, school, school psychologist, school physician, etc.) initiates the written request to the MDPH. The multidisciplinary evaluation team (EPE) of the MDPH, composed of health, medico-social, and education professionals, then assesses the needs of the disabled child. This assessment relies on several elements provided by the educational team: (1) a form containing the "life project" expressed by the family; (2) the guide to assessing educational needs (GEVA-Sco); and (3) the medical certificate and other elements (neuropsychological assessments, speech therapists, occupational therapists, psychometricians, school evaluation reports, medical letters).

2.2.2 Personalized Schooling Project (PPS) elaboration

The EPE then develops a Personalized Compensation Plan called "Plan Personnalisé de Compensation" (PCP), which includes two components: a financial assistance component (AEEH, "Allocation d'Education de l'Enfant Handicapé"; and PCH, "Prestation de Compensation du Handicap); and a school component, which is the PPS. The "Commission des Droits et de l'Autonomie des Personnes Handicapées" (CDAPH) takes the final decision on the benefits and guidance of persons with disabilities. This decision is made on the basis of the evaluation of the EPE, and communicated to the family and individuals concerned.

2.2.3. PPS monitoring and support

The PPS is sent to the referent teacher called "Enseignant Référent" (ER) and the School Inspector. The school monitoring team, termed "Equipe de Suivi de la Scolarisation" (ESS; teachers, AESH, professionals who follow up the child), supports and facilitates the implementation of the PPS. It meets at least once a year under the guidance of the ER, which leads the meeting and coordinates the team. The ER is limited to a geographical area. His or her mission is also to inform parents and teachers.

2.3 Data collection

The previously anonymized data were extracted from the medical–administrative register DAPHNEE, used by MDPH 13 (authorized by the Commission Nationale de l'Informatique et des Libertés, CNIL).

The sociodemographic data included gender, date of birth, type of AESH assigned, and postal code of the child's place of residence. The postal codes have been grouped into five geographical areas corresponding to the regions defined by the MDPH 13: North Marseille, South Marseille, Etang de Berre-Salon, Pays d'Aix, Pays d'Arles.

The medical data were coded by two MDPH physicians, based on the medical certificates sent to the MDPH, and additional elements available (GEVA-Sco, neuropsychological

assessments, speech therapists, occupational therapists, psychomotor therapists, school evaluation reports, medical letters). This coding has not been carried out exhaustively owing to the workload represented.

2.4 Classifications used

The ICD-10 classification (International Classification of Diseases, 10th revision) was used to code diseases; the CNSA nomenclature (Caisse Nationale de Solidarité pour l'Autonomie) was used to code impairments. This nomenclature comes from the manuals accompanying the evaluation guides for MDPHs, drawn up by the CNSA and inspired by the CIF classification [11] (International Classification of Functioning, Disability and Health).

2.5 Statistical analysis

Qualitative variables are described by the number and percentage of each modality. Continuous variables are described by their mean and standard deviation.

The prevalence (of a disease, an impairment) and the proportion of children benefiting from an AESH were estimated by relating the number of children in the study population presenting this disease, disability, or allocation of AESH to the number of children of the same age group born in the Bouches-du-Rhône, i.e., born between January 1, 2008 and December 31, 2011 (2.6–6.5 years) based on data from the INSEE (Institut National de la Statistique et des Etudes Economiques).

A frequency of strictly higher than 1% was used to define the most frequent impairments or diseases. Comparisons of continuous variables between impairments or diseases were made using the Student t test or a one-factor analysis of variance. For the qualitative variables, comparisons were made using the chi-square test (or Fisher's exact test when necessary). IBM SPSS® software version 20.0 was used. The significance threshold was set at 5% in two-sided testing.

3. Results

3.1 General characteristics of the population (Table 1)

A total of 1260 children born from January 1, 2008 were registered as having had an AESH allocation by MDPH 13 on July 1, 2014. The mean age was 5 ± 1 years (minimum 2.4 years; maximum 6.5 years). Children with AESH-i were significantly younger than those with AESH-m (mean 4.8 \pm 0.9 years vs. 5.2 ± 1 years; p < 0.001). Children in Marseille Sud were significantly younger than those in Pays d'Arles (4.8 ± 1 years vs. 5.2 \pm 0.8 years, p=0.016). The gender distribution by MDPH territory did not show a statistically significant difference.

3.2 Prevalence of AESH (all types) depending on region

The proportion of children benefiting from an AESH in Bouches-du-Rhône, regardless of the type of AESH, was 12.2% (per 1000 children born in Bouches-du-Rhône in the same age group), ranging from 10.5% in Pays d'Aix to 13.7% in North Marseille.

3.3 Allocation of AESH type depending on region

The frequency of AESH-i allocation was significantly different according to the MDPH regions in the Bouches-du-Rhône (p=0.002) (Figure 2). North Marseille had a significantly lower rate of AESH-i than the other territories combined (55.2% vs. 61.6%, p=0.034). However, Pays d'Arles and Etang de Berre-Salon had a significantly higher rate of AESH-i than the other territories combined (72.7% vs. 58.5%, p=0.006 and 66.4% vs. 57.8% p=0.012).

3.4 Diseases and impairments

Diseases and impairments were coded for 990 children out of the 1260 of the total population.

The only significant differences that were found between children with (n=990) and without (n=270) a coded disease and/or impairment were age and AESH-i rate: children

with at least one coded disease or impairment were younger (4.8 \pm 0.9 years vs. 5.5 \pm 1 years, *p*<10-3) and had more frequent AESH-i ratings compared with children without disease or disability coding (62.2% [*n*=616] vs. 50% [*n*=135], *p*<10-3).

The most frequent diseases (>1%) in the study sample are presented in Table 3, with their frequency, prevalence, proportion of boys, mean age of children involved, and proportion of AESH-i per disease.

The number of diseases per child ranged from 0 to 3: No disease was coded for 0.2% (*n*=2) of children; most children had only one coded disease (73.9% [*n*=732]); two diseases were coded for 18% (*n*=178) of children; three diseases were coded for 7.9% (*n*=78) of children. The most frequently coded disease (23.3% [*n*=231]) was pervasive developmental disorder (PDD, ICD-10 code = F84). Of the children having this disorder, 83.1% (192) were male. It was also the disease with the highest frequency of AESH-i allocation (78.4%).

Conductive or sensorineural hearing loss (ICD-10 code = H90) was the only disease for which girls were most affected (51.7%).

The frequency of AESH-i allocation was significantly lower for children with a diagnosis of mixed specific developmental disorders (F83) compared with children without this condition (44% [n=59] vs. 65.1% [n=557]; p<10-3).

The same was found for children with specific developmental disorders of speech and language (F80) (41.8% [n=23] vs. 63.4% [n=593]; p=0.001) or specific developmental disorders of scholastic skills (F81) (26.1% [n=6] vs. 63.1% [n=610]; p<0.001).

Other diseases not listed here (frequency <1%) consisted of 153 different ICD-10 codes.

The most frequent impairments (>1%) in our sample are presented in Table 4, with their frequency, prevalence, and proportion of AESH-i for each of these disabilities.

The number of impairments per child ranged from 0 to 9 and averaged 2.8 ± 1.2 impairments per child. No impairments were coded for 1.7% (*n*=17) of the children. Only

8.8% (n=87) of children had only one coded impairment. The majority had two or three impairments (31.5% [n=312] and 32.7% [n=324], respectively). Four impairments were coded for 16.7% (n=165) of the children. Children with five or more impairments represented 8.6% (n=85) of the population.

The most common impairment found in children was behavioral, personality, and relational skills disorders (CNSA Code = 2.2), with a frequency of 61.8% (n=612) of children. Just over half of the children had a psychomotor impairment (n=51.9%).

The assignment of AESH-i was significantly less frequent among children with written or oral language learning impairments (56.8%), and also among children with perception or attention disorders (46.8%), compared with children without these disabilities.

Other impairments not listed here (frequency<1%) consisted of 46 different CNSA codes.

With reference to the CNSA nomenclature (Figure 3), 86.7% (*n*=858) of children had at least one psychological impairment, and 79.8% (*n*=790) had at least one language and speech impairment.

4. Discussion

4.1 Frequency and prevalence of diseases and impairments

For PDD, the prevalence calculated in this study is significantly lower than in other studies. Indeed, the prevalence was 2.2‰, while it is estimated at 4.1‰ according to the French register RHEOP 2013 (Registre des Handicaps de l'Enfant et Observatoire Périnatal) [12], 6.2‰ at the European level for individuals under 18 years of age in a literature review [13], and 7.2‰ in a 2015 meta-analysis [14] including 41 studies in 18 countries for individuals under 27. This lower prevalence estimate for PDDs can be explained by a restricted study population: only children attending school, benefiting from an AESH, and whose ages ranged from about 2.5–6.5 years. Furthermore, the children included in the study are younger than those from the 2013 RHEOP data, where children

are registered at 7 years of age, and the diagnosis of PDD is more likely to be confirmed at a later age.

The prevalence of Down syndrome calculated in our study (0.4‰) was similar to that estimated using data from RHEOP [12] (0.3–0.5‰ depending on the territory studied). Indeed, in the context of this disease (unlike PDD), the diagnosis is made at an early age. Children in the study population had less frequent intellectual impairment (7.7% vs. 30%) and more frequent psychological impairment (86.7% vs. 27.2%) compared with children with disabilities attending nursery and primary school in ordinary class in France in 2014 [2].

The coding method may explain this difference. Multiple coding was used in our study, allowing for the coding of as many diseases or impairments as necessary. Whereas a single and primary coding is used for the national DEPP (Direction de l'Evaluation de la Prospective et de la Performance) data, performed by the child's referent teacher[15], who will decide what type of primary impairment the child has (and the only one reported). As Le Laidier [16] explains in the context of PDD, children are associated with a major disorder that can be classified as an intellectual or psychological disorder. In our study, children with PDD were most likely to have an associated psychological impairment and language and speech impairment (96.5% and 94.4%, respectively), and a small proportion of associated intellectual impairment (7.7%).

The method used in this study also differs from that used in other studies of children with disabilities with an MDPH notification in the Bouches-du-Rhône [17,18], where each child was associated with only one primary impairment.

By employing multiple coding of impairments by MDPH physicians in this study, the information about children with a disability is much broader and not limited to a primary impairment.

12

As Vigan [19] pointed out in 2013, it would be interesting in the future for MDPH to have this medical information available on a routine basis. This would make it possible to carry out a qualitative analysis of the population with disabilities and their needs for each territory. And, thereby, to have national statistics that represent a decision-making tool for disability policies. However, it should be stressed that the collection and entry of these data require a significant amount of work, particularly in terms of medical data entry.

4.2 Support by an AESH

In France, just over half of disabled children enrolled in primary and nursery school receive personal support (51.8%) [2]. Children in the study population were accompanied by an AESH-i in almost 60% of cases, which is slightly lower than nationally (75%, enrolment in all primary and nursery education)[2].

AESH-i were significantly less frequently assigned than AESH-m for children with a diagnosis of mixed specific developmental disorders (F83, admixture of specific developmental disorders of speech and language, of scholastic skills, and of motor function, but in which none predominates sufficiently to constitute the prime diagnosis), specific developmental disorders of speech and language (F80), and specific developmental disorders of scholastic skills (F81). It may indeed be less severe than the other diseases studied, and therefore not requiring sustained and continuous attention in personal support.

The same applies to written or oral language learning impairments and perception or attention impairments (impairments 3.2 and 2.5).

In order also to promote the pupil's autonomy, this type of mutualized support is systematically recommended for children with specific developmental disorders of scholastic skills in the 2018 ministerial report on personal support for pupils with disabilities [20].

13

4.3 Coding / Classification

In our study, diseases and impairments were coded, respectively, according to two complementary classifications: the ICD-10, usually used for medical, health, and statistical purposes; and the CNSA nomenclature derived from the ICF, a classification model adapted to the definition of disability as presented in the 2005 French law.

As a 2018 ministerial report on human support [20] points out, "[...] the definitions of classification headings may lead to approximations or even misunderstandings. The knowledge of the disabilities they provide constitutes an extremely broad framework, including 'intellectual and cognitive disorders' and 'psychic disorders', covering very different realities in terms of nature and intensity. It is true that, in this area, classifications alone cannot account for the diversity and complexity of many disorders." Especially since psychological disorders are the most represented in this study (86.7%).

This problem exists particularly for coding according to the ICD-10 classification by the physician who produces the medical certificate. In some situations, it is very difficult to diagnose a disease, especially for a young child whose disorders are not necessarily fixed, particularly in the field of mental health.

In addition, the ICD-10 codes most frequently found in our study were imprecise and broad codes, which could include a multitude of diagnoses. For example, lack of expected normal physiological development (R62) was the second most frequently coded disease (19.9%, n=197). This code is quite imprecise and may mainly correspond to a delayed attainment of the expected physiological developmental stage, late talker or walker, failure to gain weight or to thrive, among others. The majority of these children were coded as having a psychomotor functions impairment (2.4; in 65% of cases).

In fact, the use of an ICD-10 code, sometimes imprecise, does not seem essential when considering a request for the MDPH, as the assessment is based on the needs of the child,

which can present great inter-individual variability for the same diagnosis. On the other hand, the information remains relevant for medical information purposes concerning this population, including for adapting AESH professional training, for example.

The majority of children in the study population had two or three coded impairments (64.2%). A child in school with a disability who benefits from an AESH therefore most often has several impairments at the same time.

Considering the complexity of the association of disease(s) and impairment(s) for the same child, as well as the severity of the impairment not taken into account in these classifications, it is difficult to imagine a general scheme using this classification system to facilitate decisions in the allocation of human support to schooling. Each situation is unique and requires an adapted response. However, the qualitative assessment of the child's needs by the multidisciplinary MDPH team, which makes it possible to satisfactorily identify the child's needs, represents a significant workload, inevitably resulting in long processing times. In addition, for each disease or impairment, there is a high degree of inter-individual variability that does not appear in these classifications, including their severity.

4.4 Gender disparity

The sex ratio in our study is largely in favor of boys, with almost three boys to one girl benefiting from an AESH. This proportion of boys is slightly higher than at the national level for the same year for children aged 3–6 attending regular classes [2] (74.5% vs. 69.5%). In the literature on children with disabilities, whether in or out of school, this gender disparity is found almost systematically, with a general ratio of 15 disabled boys to 10 girls [21,22].

For children with a diagnosis of PDD, our study found a ratio of approximately five boys to one girl, corresponding to the ratio usually found in the literature [23].

However, boys were not in the majority (49.3%) regarding conductive or sensorineural hearing loss (ICD-10 code = H90). This result seems consistent with the results of a French study on 8-year-old children with severe or profound bilateral deafness, where no significant difference was found between boys and girls for this condition[24], as well as with the results of a study on a panel of disabled pupils born in 2001 or 2005 [16] (45% of pupils with hearing disorders were girls).

To our knowledge, the reasons for this gender disparity in children with disabilities in general have not been documented to date. On the other hand, in the context of autism spectrum disorders, a later and less frequent identification of girls could explain this disparity, due to a different clinical presentation from that of boys (girls have fewer changes in social behaviors and fewer repetitive behaviors) [25].

4.5 Geographical disparities

The frequency of AESH-i allocation was significantly different across the MDPH territories (p=0.002). The territory of North Marseille had a lower rate of AESH-i compared with the rest of the Bouches-du-Rhône (55.2% vs. 61.6%, p = 0.034). However, in this territory, the frequency of diseases or impairments associated with the allocation of an AESH-m (diseases F83, F80, F81, and impairments 3.2 and 2.5) was the same as in other territories. On the other hand, the territories of Pays d'Arles and Etang de Berre-Salon had a higher rate of AESH-i compared with the rest of the Bouches-Du-Rhône (respectively, 72.7% vs. 58.5%, p=0.006, and 66.4% vs. 57.8% p=0.012). In this territory, however, the frequency of diseases or impairments associated with the allocation of an AESH-i (F84, disabilities, 3.1, 6.21, 5.4 and 7.9) was the same as in other territories.

A greater difficulty in setting up shared support by an AESH-m probably exists in these two territories because they are larger, and the number of children with disabilities is lower, making them more dispersed. Indeed, an AESH-m intervenes simultaneously with several students.

4.7 Limitations

The first limitation of this study concerns the study population, which, although exhaustive, included children with disabilities attending mainstream schools and benefiting from AESH. The results of this study cannot therefore be extrapolated to children with disabilities who are not in school, or who are in school but do not benefit from AESH. Because of this study population, the different prevalence rates of diseases and impairments estimated in the Bouches-du-Rhône are a priori lower than the actual prevalence rates of diseases and impairments of all disabled children of the same age in the Bouches-du-Rhône, including those not in school.

The finding that children with a diagnosis and/or impairment coded by MDPH physicians (n=990) are younger (4.8 ± 0.9 years vs. 5.5 ± 1 years, p<0.001) and have a more frequent allocation of AESH-i (62.2% vs. 50%, p<0.001) than children without a diagnosis or coded impairment (n=270) may suggest a selection bias. These differences could be explained by the method of selecting the files (sorted and therefore coded in increasing order of age: thus, the youngest children and therefore those who most often benefit from an AESH-i could benefit primarily from the coding of diseases and impairments).

Finally, as already mentioned, the limits related to the coding of a disease according to the ICD-10 classification are important in the context of disability: Medical diagnoses coded according to the ICD-10 classification were not very precise, the most frequently used codes were truncated codes (e.g., R62), which correspond to the title of a section that can regroup several different diseases. The use of a very general code may thus reflect the

absence of a precise medical diagnosis (when the medical certificate is made), but may also be linked to an under-use of the classification by MDPH physicians when collecting or entering diagnoses.

5. Conclusion

Young children with disabilities supported at school in the Bouches-du-Rhône are most frequently children with pervasive developmental disorders (PDD) (23.3%), lack of expected normal physiological development (19.9%), or mixed specific developmental disorders (13.5%), and most often have behavioral, personality, and relational skills disorders (61.8%), psychomotor functions impairments (51.9%), or written or oral language learning impairment (43.2%). Finally, the two main types of impairments most represented in these children are psychological impairments (86.7%) and language and speech impairments (79.8%).

These children are most often supported by AESH-i than AESH-m (60% vs. 40%, respectively). They are mainly boys (almost 75%). This study suggests that children living in larger territories with fewer children with disabilities in school are more likely to be helped by AESH-i.

The study sheds light for the first time on certain characteristics of this specific population of young disabled children in school benefiting from AESH, from a medical point of view and in terms of the modalities of support for schooling according to their place of residence and their diseases and impairments. Finally, it contributes to our understanding about the information system, and its limitations that must be taken into account. These contributions could supply working guidelines for the management of health policies relating to disability at the territorial or even national level.

This study also highlights that each disability situation is unique, and it is difficult to make recommendations based only on classifications such as the ICD-10. In particular, the

geographical location of the child and his or her socioeconomic environment must be considered.

Finally, the socioeconomic aspect is important in this context. Limited results were obtained in an exploratory analysis (due to data availability) of the child poverty rate of the study population (data not shown). Obviously, further studies are needed on this topic.

References

- [1] Loi n°2005-102 du 11 février 2005.
- https://www.legifrance.gouv.fr/
- [2] Direction de l'évaluation de la prospective et de la performance (DEPP). Repères & Références Statistiques sur les enseignements, la formation et la recherche (RERS).
 2015.

https://www.education.gouv.fr/reperes-et-references-statistiques-sur-les-enseignements-la-formation-et-la-recherche-2019-3806

- [3] Article 11 de la Loi du 11 février 2005.
- https://www.legifrance.gouv.fr/
- [4] Décret n° 2014-724 du 27 juin 2014 relatif aux conditions de recrutement et d'emploi des accompagnants des élèves en situation de handicap.

https://www.legifrance.gouv.fr/

[5] MENESR-DEPP et MENESR-DGESCO, Enquête n° 3 relative aux élèves porteurs de maladies invalidantes ou de handicaps scolarisés dans le premier degré. https://www.education.gouv.fr

- [6] Ministère des Solidarités et de la Santé. Stratégie Nationale de Santé 2018-2022. https://solidarites-sante.gouv.fr/IMG/pdf/dossier_sns_2017_vdef.pdf. [accessed 13.02.19], 2017
- [7] Décret n°2012-903 du 23 juillet 2012.
- https://www.legifrance.gouv.fr/

[8] Article D.351-16-2 et -3. Décret n° 2012-903 du 23 juillet 2012 https://www.legifrance.gouv.fr/

[9] Article D. 351-12. Modifié par Décret n°2009-378 du 2 avril 2009 - art. 8 https://www.legifrance.gouv.fr/ [10] Arrêté du 6 février 2015.

https://www.legifrance.gouv.fr/

[11] Organisation Mondiale de la Santé. CIF. Classification internationale du fonctionnement du handicap et de la santé 2001. 2001 https://www.who.int/classifications/icf/en

[12] Registre des Handicaps de l'Enfant et Observatoire Périnatal. Rapport d'activité
 2013 : évolution du registre et résultats. Enfants avec déficience sévère - génération
 2004. 2013. https://rheop.univ-grenoble-alpes.fr/

- [13] Elsabbagh M, Divan G, Koh YJ, et al. Global Prevalence of Autism and Other Pervasive Developmental Disorders: Global epidemiology of autism. Autism Res 2012;5:160–79.
- [14] Baxter AJ, Brugha TS, Erskine HE, Set al. The epidemiology and global burden of autism spectrum disorders. Psychol Med 2015;45:601–13.
- [15] Bulletin officiel de l'éducation nationale. Circulaire n° 2018-032 du 27-2-2018.
 https://www.education.gouv.fr/bo/18/Special2/MENP1804987C.htm
- [16] Le Laidier S. Les enfants en situation de handicap, Parcours scolaires à l'école et au collège. Éducation Form 2017;95:33–57.
- [17]] Jimeno MT. Les enfants en situation de handicap dans les Bouches-du-Rhône, avancer vers un langage commun sur le handicap, données générales et médicales analysées à partir de la base informatisée de la CDES au 1er septembre CDES des Bouches-du-Rhône 2002; 2002;36–49.
- [18] de Montaigne L, Bernard O, Da Fonseca D, et al. Étude des notifications à la Maison départementale des personnes handicapées chez les enfants placés à l'Aide sociale à l'enfance dans les Bouches-du-Rhône. Arch Pédiatr 2015;22:932–42.
- [19] Vigan E. Codage des pathologies et déficiences. Parce que les MDPH peuvent être des observatoires... J Action Sociale 2013; 2: 36-7.
- [20] Inspection générale des affaires sociales, Inspection générale de l'éducation nationale, Inspection générale de l'adminitration de l'éducation nationale et de la recherche.
 Évaluation de l'aide humaine pour les élèves en situation de handicap. rapport IGEN-IGAENR-IGAS n° 2018-055, juin 2018

https://www.education.gouv.fr/evaluation-de-l-aide-humaine-pour-les-eleves-en-situation-de-handicap-4958

- [21] Delobel-Ayoub M. Prévalence des déficiences sévères chez l'enfant en France et évolution au cours du temps. BEH 2010;5:16-7
- [22] Kayser E, Funes A, Marival C, et al. HandiDonnées PACA 2017. CREAI Paca et Corse (Centre Régional d'Etudes, d'Actions et d'Informations en faveur des personnes en situation de vulnérabilité). Marseille, Mai 2017.

http://www.creai-pacacorse.com/_depot_creai/documentation/163/163_17_doc.pdf

- [23] Fombonne E. Épidémiologie de l'autisme. Elsabbagh M, Clarke ME, eds thème. In: Tremblay RE, Boivin M, Peters RDeV, eds. Encyclopédie sur le développement des jeunes enfants [sur Internet]. Montréal, Québec: Centre d'excellence pour le développement des jeunes enfants et Réseau stratégique de connaissances sur le développement des jeunes enfants; 2012:1-5. Disponible sur le site:
- http://www.enfant-encyclopedie.com/documents/FombonneFRxp1.pdf. http://www.enfant-encyclopedie.com/autisme/selon-experts/epidemiologie-delautisme. [accessed 13.02.19]
- [24] Delobel-Ayoub M, Klapouszczak D, Cans C, et al. Données épidémiologiques sur les surdités bilatérales sévères et profondes en France pour les générations 1997 à 2005.
 BEH 2015;42-43:8.
- [25] Haute Autorité de Santé (HAS). Recommandation de bonne pratique : Trouble du spectre de l'autisme. Signes d'alerte, repérage, diagnostic et évaluation chez l'enfant et l'adolescent. 2018.

https://www.has-sante.fr/jcms/c_468812/fr/trouble-du-spectre-de-l-autisme-signes-d-alerte-reperage-diagnostic-et-evaluation-chez-l-enfant-et-l-adolescent

	% (n)				
Age (group)					
\leq 3 years	19.1 (241)				
4 years	29.5 (372)				
5 years	35.4 (446)				
6 years	15.9 (200)				
Gender					
Boy	74.5 (939)				
Territory (MDPH)					
North Marseille	31.0 (391)				
South Marseille	29.2 (368)				
Etang de Berre-Salon	20.6 (259)				
Pays d'Aix	11.3 (143)				
Pays d'Arles	7.9 (99)				
Type of AESH					
AESH-i	59.6 (751)				
AESH-m	40.4 (509)				
Number of hours per					
week of AESH	$0.70 (\pm 8.31)$				
(mean ± standard	9.19 (± 0,31)				
deviation)					

<u>Table 1:</u> General characteristics of the population (*n*=1260)

MDPH: maison départementale des personnes handicapées; AESH: accompagnant des élèves en situation de handicap; AESH-i: individual personal support (supports one child only); AESH-m: shared personal support

<u>Table 2</u> : Distribution of the most frequent diseases in the study population (*n*=990)

D'anna	ICD-10	ICD-10 Frequency Prevalen		Boys ^b	Age ^c	AESH-i ^d % (n)	
Disease	Code % (n) (% <i>o</i>)		(‰)	% (n)	$\overline{m} \pm SD$		
Pervasive developmental disorders	F84	23.3 (231)	2.2	83.1 (192) ^e	4.8 ± 0.9	78.4 (181) ^e	
Lack of expected normal physiological development	R62	19.9 (197)	1.9	67 (132) ^e	4.7 ± 0.9 f	59.4 (117)	
Mixed specific developmental disorders	F83	13.5 (134)	1.3	70.9 (95)	4.9 ± 0.8	44.0 (59) ^e	
Unspecified behavioral and emotional disorders with onset usually occurring in childhood and adolescence	F989	12 (119)	1.2	90.8 (108) ^e	$5.0\pm0.8~^{\rm f}$	63.0 (75)	
Specific developmental disorders of speech and language	F80	5.6 (55)	0.5	58.2 (32) ^e	5.1 ± 0.7 f	41.8 (23) °	
Down syndrome	Q90	4.4 (44)	0.4	59.1 (26) ^e	$4.6 \pm 1.0^{\rm f}$	75 (33)	
Unspecified disorder of psychological development	F89	3.1 (31)	0.3	87.1 (27)	4.7 ± 0.8	58.1 (18)	
Conductive and sensorineural hearing loss	H90	2.9 (29)	0.3	48.3 (14) ^e	4.8 ± 0.8	75.9 (22)	
Other strabismus	H50	2.4 (24)	0.2	75 (18)	4.9 ± 1.1	70.8 (17)	
Epilepsy	G40	2.4 (24)	0.2	62.5 (15)	4.9 ± 0.9	58.3 (14)	
Cerebral palsy	G80	2.4 (23)	0.2	60.9 (14)	4.8 ± 1	69.6 (16)	
Specific developmental disorders of scholastic skills	F81	2.3 (23)	0.2	91.3 (21)	5.5 ± 0.6 f	26.1 (6) ^e	

^aPrevalence of the disease, calculated per 1000 children born in the Bouches-du-Rhône between 01/01/2008 and 31/12/2011.

^bFrequency of boys with the disease.

^cAge of children with the disease: mean $(\sqrt{n}) \pm$ standard deviation $(\pm$ SD).

^dFrequency of the allocation of an AESH-I (individual personal support) for children with the disease.

 ${}^{e}p$ <0.05; chi-square tests comparing the frequency of boys or the frequency of AESH-i allocation in children with the disease versus those without the disease.

^fp < 0.05; Student's *t* test comparing the average age of children with the disease versus those without it.

ICD-10: International Classification of Diseases, 10th revision; AESH: accompagnant des élèves en situation de handicap; AESH-i: individual personal support (supports one child only).

Terrestownerd	CNSA	Frequency	Prevalence	AESH-i ^b
Impairment	Code	% (n)	a (%0)	% (n)
Behavioral, personality, and relational skills disorders	2.2	61.8 (612)	5.9	63.9 (391)
Psychomotor functions impairment	2.4	51.9 (514)	4.9	59.7 (307)
Written or oral language learning impairments	3.2	43.2 (428)	4.1	56.8 (243) ^c
Unspecified language or speech impairments	3.9	25.9 (256)	2.5	63.3 (162)
Severe communication impairment	3.1	15.4 (152)	1.5	76.3 (116) ^c
Perception or attention disorders	2.5	16 (158)	1.5	46.8 (74) ^c
Urinary elimination impairment	6.32	15.5 (153)	1.5	83.0 (17) ^c
Digestive function impairment	6.21	14.2 (141)	1.4	80.1 (113) ^c
Other impairment of visual functions (strabismus, color	5.4	3.8 (38)	0.4	78.9 (30) ^c
vision) not otherwise coded				
Emotional or volition impairment	2.3	3.6 (36)	0.3	75.0 (27)
Other motor impairments not coded elsewhere	7.8	2.6 (26)	0.2	76.9 (20)
Cognitive disorders without mental retardation, acquisition and	1.15	2.2 (22)	0.2	72.7 (16)
learning disorders		()		()
Unspecified intellectual impairments	1.9	2.3 (23)	0.2	73.9 (17)
Unspecified motor impairments	7.9	2.7 (27)	0.3	81.5 (22) ^c
Other motor coordination impairment	7.62	2.1 (21)	0.2	71.4 (15)
Motor impairments by neurological control impairment	7.2	1.4 (14)	0.1	78.6 (11)
Unspecified mental retardation	1.19	1.8 (18)	0.2	72.2 (13)
Unspecified visual impairments	5.9	1.4 (14)	0.1	71.4 (10)
Consciousness and vigilance impairment	2.1	1.1 (11)	0.1	63.6 (7)
Eye mobility impairment (nystagmus)	5.3	1 (10)	0,1	80,0 (8)

<u>Table 3</u>: Distribution of the most frequent impairments in the study population

(*n*=990)

^aPrevalence of impairment, calculated per 1000 children born in the Bouches-du-Rhône between 01/01/2008 and 31/12/2011.

^bFrequency of AESH-i (individual human support) allocation for children with impairments.

 ^{c}p <0.05; chi-square test comparing the frequency of AESH-i allocation in children with impairments versus those without impairments.

CNSA: Caisse Nationale de Solidarité pour l'Autonomie; AESH: accompagnant des élèves

en situation de handicap; AESH-i: individual personal support (supports one child only).

Figures

Figure 1: Allocation of an AESH to a disabled student: operating mode

Figure created with Piktochart ®

MDPH: Maison Départementale des Personnes Handicapées

CDAPH: Commission des Droits et de l'Autonomie des Personnes Handicapées

Geva-Sco: Guide to assessing educational needs

PPS: Personalized Schooling Project

AESH: accompagnant des élèves en situation de handicap

<u>Figure 2</u>: Individual AESH rate (AESH-i) and number of children aged 2-6 years with disabilities benefiting from an AESH, depending on the MDPH territories in Bouches-du-Rhône

¹AESH: person in charge of human assistance for the student's schooling, support, socialization, and safety of disabled students or with disabling health conditions.

²AESH-i: individual AESH (supports one child only)

MDPH: Maison Départementale des Personnes Handicapées

Figure 3: Frequency of types of impairments by category according to the CNSA nomenclature (*n*=990)

CNSA: Caisse Nationale de Solidarité pour l'Autonomie

Conflicts of interest: none

Acknowledgments: The authors would like to thank the MDPH and the Conseil

Départemental of Bouches-du-Rhône staff who participated in the steering committee and,

for some of them, in data collection.





