

Available online at [www.sciencedirect.com](http://www.sciencedirect.com)

Public Health

journal homepage: [www.elsevier.com/puhe](http://www.elsevier.com/puhe)

## Short Communication

# Access to care in sign language: the French experience

B. Drion <sup>a,b,c,d,\*</sup>, L. Buhler <sup>a,b,c,d</sup><sup>a</sup> Univ Nord de France, F-59000, Lille, France<sup>b</sup> UCLille, F-59000, Lille, France<sup>c</sup> Groupement des Hôpitaux de l'Institut Catholique de Lille / Faculté Libre de Médecine, F-59000, Lille, France<sup>d</sup> Réseau Sourds et Santé, France

## ARTICLE INFO

## Article history:

Received 6 June 2014

Received in revised form

19 August 2015

Accepted 21 January 2016

Available online 27 February 2016

Three nationwide investigations have recently estimated the number of deaf sign language users in France: 44,000,<sup>1</sup> 75,000<sup>2</sup> and 80,000,<sup>3</sup> or expressed per thousand inhabitants, 0.7/1000, 1.1/1000, and 1.2/1000 respectively. For the purpose of this work, the population of deaf signing persons living in France was thus considered to be 1 per 1000 inhabitants. In the health care setting for the deaf, demands for information mainly come from these people who use sign language as their primary (or unique) linguistic tool for daily life activities. These sign language users feel they belong to a minority linguistic community. Several medical, linguistic, cultural and social factors are known to affect care for deaf people who communicate in sign language, hampering their understanding of their own state of health.<sup>4–6</sup> Many lack the necessary prerequisites for understanding their health-related problems that are globally more important than in the general population due to late diagnosis, insufficient care for chronic disease, and lack of access to primary care and prevention.<sup>7,8</sup> Furthermore, health care professionals are

unfamiliar with delivering care to deaf patients and almost always unaware of these problems. The consequence is poor one-way communication, even in the presence of an interpreter, a source of much misunderstanding.

A nationwide network of specific structures has been developed in France to facilitate access to care in sign language. The most significant measure was the creation of specific hospital units for deaf people offering access to care in sign language: the UASS-LS (*Unités d'Accueil et de Soins des Sourds – Langue des Signes*).<sup>9</sup> These UASS-LS are financed by public funds listed in the national budget for hospital missions; they have had a significant impact, inciting interesting initiatives.<sup>10</sup>

## Thirteen specific hospitals units for deaf people offering access to care in sign language

The first UASS-LS were created in Paris (1995 for access to mental health care and 1997 for access to somatic care), the fruit of sustained efforts by a few professionals backed by patient associations. The success of these early initiatives helped improve awareness among public authorities, leading to the creation of several other UASS-LS in the 2000s: Bordeaux and Grenoble in 2001, Lille, Montpellier and Strasbourg in 2002, Marseille, Nancy and Toulouse in 2003, Nice in 2004, Nantes in 2010, and Poitiers in 2011.

A ministerial decree stated that the main mission of these units is to 'guarantee equal access to care, as in the general population. The patient shall no longer have to adapt to the

\* Corresponding author. GHICL, Hôpital Saint-Philibert, Réseau Sourds et Santé, Rue du Grand But – BP249, F-59462 LOMME Cedex, France. Tel.: +33 3 20 22 38 03; fax: +33 3 20 22 38 01.

E-mail address: [drion.benoit@ghicl.net](mailto:drion.benoit@ghicl.net) (B. Drion).

<http://dx.doi.org/10.1016/j.puhe.2016.01.018>

0033-3506/© 2016 The Royal Society for Public Health. Published by Elsevier Ltd. All rights reserved.

language of health care professionals; it is the duty of the team in charge of care to adapt to the patient's communication abilities'.<sup>11</sup> This decree describes the required personnel and their mandatory bilingual skills in French and sign language. Headed by a signing medical doctor, each unit is staffed by bilingual secretaries, psychologists and social workers (one or more of each category for each unit). To date, none of the head practitioners is deaf, but several psychologists and social workers are deaf signers. There are also two other specific categories of personnel: certified interpreters and deaf practitioners who play an important role of mediation. If the deaf patient has difficulty understanding the medical narrative, deaf practitioners can act as mediators, using their perfect fluency in sign language to reformulate the message and adapt it to the patient's specific communication abilities. They work in cooperation with interpreters and have a function similar to the Certified Deaf Interpreters (CDI).<sup>12</sup> They also play an important role in therapeutic education.

### Community-based networks and other structures

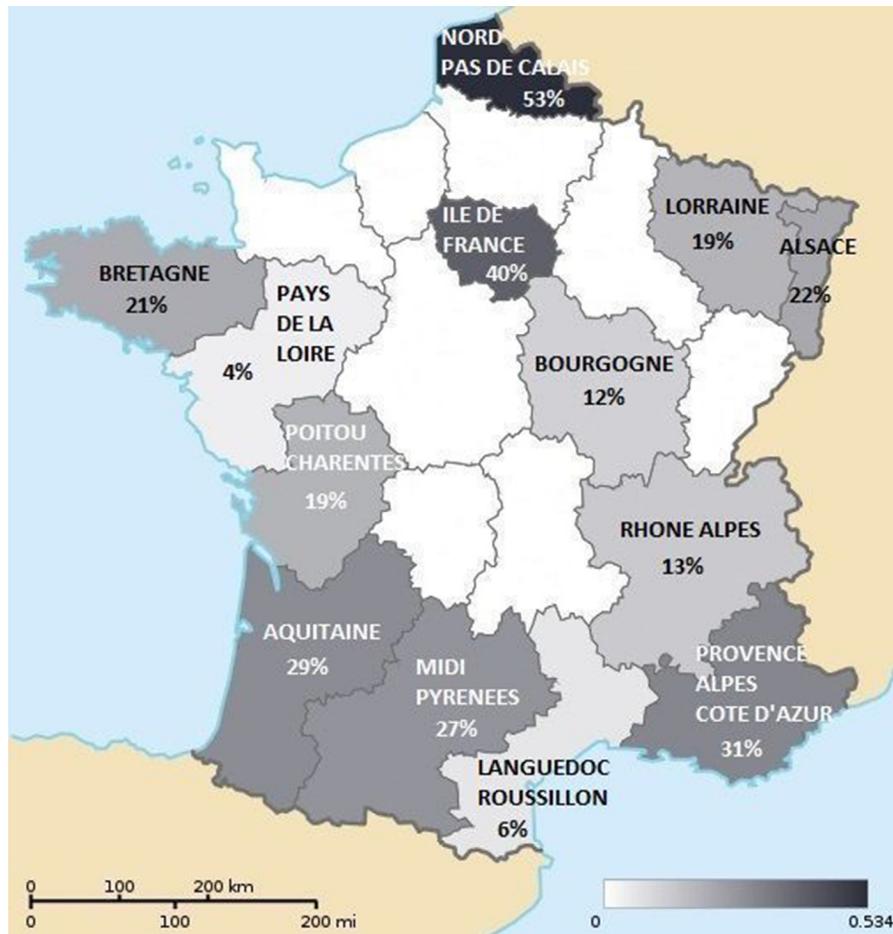
The impulse produced by the UASS-LS revealed to all the need for care in sign language, leading to the creation of a whole series of schemes currently in development. Two community-based networks are defined by the Public Health Code<sup>13</sup> and financed by public funding determined by the regional authorities. 'Their objective is to favour access to care and the coordination, continuity or interdisciplinarity of health care, particularly specific actions involving certain populations, diseases, or health activities. They ensure that care is adapted to the needs of the person, in terms of health education, prevention, diagnosis and care delivery. They can participate in public health actions. [...] they are established between private practitioners, occupational medicine specialists, health care institutions, groups of health care cooperation, health care centres, social or medicosocial institutions, and organisations committed to health or social activities, as well as with user representatives'. These community-based networks differ from the UASS-LS in that they are basically mobile units operating in a given geographical area, with or without a fixed hospital unit. In this community network setting, the patient does not have to attend a specific unit in one specific hospital to seek care. It is the unit delivering care in sign language that is mobile, the patient deciding where to seek care. In the Nord-Pas de Calais region, which has 4,052,156 inhabitants, a network dedicated to deaf people and health works in coordination with the region's UASS-LS. It organises support for access to care in sign language, irrespective of the type of healthcare provider (private, public). From the UASS-LS harboured in the Lille hospital, this network also organises access to other hospitals located in Lomme, Dunkerque, Arras and Valenciennes. Through 2013, this network has provided support for 2163 deaf people, a number which corresponds to 53% of the estimated population of deaf people in the region. Another network has been operating in Bourgogne since

October 2011. Through the end of 2013, the recruitment has included 189 users. The Brittany UASS-LS harboured in the Rennes University Centre operates with nearly the same modalities as a health care network. These UASS-LS facilitate access to care in hospitals of Saint-Brieuc, Dinan and Brest. Through 2013, 505 deaf people have consulted at the Rennes University Centre and 187 in the partner hospitals. In different areas in the Rhône-Alpes region two private practitioners offer complementary services. One has been working in Saint-Etienne since 2011 in partnership with user groups. This scheme has received public funding and has recruited 141 deaf people through 2013. In Chambéry, a similar scheme operating since 2012 has provided care for 126 deaf patients. The public authorities in Marseille (*Conseil Général des Bouches du Rhône*) developed a care in sign language programme in 2013. For its first year, a specialised centre organised screening of sexually transmissible diseases for 30 deaf patients. A family planning centre has provided gynaecological and contraception consultations for 20 deaf patients. The Provence-Alpes-Côte d'Azur region opened the Mediterranean ambulatory mental health unit for deaf persons in 2007. It receives funding from the regional authorities (*Agence Régionale de Santé*). As of the end of 2013, 302 patients have attended consultations. Finally, in Paris, a therapeutic unit for deaf patients is available at the regional centre for psychiatric care for children and adolescents. The recruitment reached 225 deaf patients at the end of 2013. This unit in the Ile-de-France region is the only one proposing psychiatric care for deaf children.

### Activity and findings about precarious cultural and linguistic context

By the end of 2013, the different networks described above had recruited 13,596 deaf patients, corresponding to 27% of the estimated deaf population in the regions concerned. The age groups attending these consultations are similar to those in the general population, with the exception of children, seen less often. This occurs because 95% of deaf children have hearing parents who feel their children do not need special care in sign language. The main activity of these networks is to organise consultations in sign language with a trained practitioner or to organise French-sign language interpretation for consultations with practitioners unfamiliar with sign language. A total of 28,477 such consultations were organised through 2013. Regions, that have developed community-based structures, whether health care networks or other, have a higher rate of recruitment than regions offering only hospital-based structures. In Nord-Pas-de-Calais where care offer associates a hospital-based UASS-LS and a community-based network, the recruitment rate is 53% of the deaf population (see Fig. 1). Unfortunately, this care offer is still not nationwide. In 2013, budget priorities left 8 of the 21 French regions out of the picture, with no specific scheme for care in sign language.

Two elements drawn from the data produced by the Nord-Pas de Calais network reveal the precarious cultural and linguistic situation of the deaf population.



**Fig. 1 – Cumulative proportion of the deaf population attending a hospital UASS-LS or any community-based structure providing access to care in sign language (based on an estimate of 1 deaf person per 1000 inhabitants).**

Need for a mediator: the French-sign language interpreter intervenes only to faithfully translate the narrative of each participant, from sign language to oral language or inversely, without participating in the conversation. In routine practice, interpretation is sufficient when the deaf patient is sufficiently familiar with sign language and has a cultural background allowing him/her to understand the narrative of the health care professional. Nevertheless, there is always a discussion between the patient and the health care team to determine whether a mediator is needed to work with the interpreter. The decision can always be revised if the patient or caregivers express changing needs. The mediator adapts the communication to the patient's personal cultural and linguistic situation. It was observed that 34% of deaf persons attending consultations in 2008, and 38% in 2013, needed a mediator in addition to the interpreter. This need reveals the precarious situation of these patients.

Need for complementary explanations: patients are encouraged to attend regular medical consultations, access to routine care being facilitated by the availability of interpreters and mediators proposed by the network. If they wish, they can also consult a French-sign language bilingual practitioner. In 2013, 62% of the consultations with bilingual physicians were

second-level consultations, the patient being referred by another physician who conducted the first consultation with an interpreter. This percentage reveals the need for further explanations or reformulation. Patients do not always have the cultural prerequisites necessary to comprehend the narrative of health care professionals, even with the help of an interpreter. Among other consultations performed directly in sign languages, 16% were follow-up consultations for diabetic patients; disorders commonly encountered in general medicine accounted for only 22% of the consultations.

In conclusion, the nationwide organisation of access to care in sign language for the deaf population operating in France has thrown new light on this important issue. Services currently available are still not distributed well over the entire country. In regions with available networks, 27% of the estimated deaf population attend specialised consultations. The activity level of these networks underscores the precarious cultural and linguistic situation in which deaf people find themselves when adapted care is not available. The distribution of the deaf population throughout the country justifies a well-organised system of community-based networks. The success of these different initiatives recalls the necessity of continuing education for the medical professions.

## Author statements

### Acknowledgements

We thank the leaders of the different networks who provided data on their activities.

### Ethical approval

Not required. This work is an activity report on the French units for deaf people and concerns only their recruitments and modalities of care, on a completely anonymous way. It was based on the answers of medical coordinators without any direct participation of deaf people. Not any personal data is registered.

### Funding

None.

### Competing interests

None declared.

## REFERENCES

1. Sander MS, Lelievre F, Tallec A. Le handicap auditif en France: apports de l'enquête Handicaps, incapacités, dépendance, 1998–1999. *Etudes et Résultats*:1–8 [Online]; 2007 [cited 2015 02 24]. Available from: <http://drees.social-sante.gouv.fr/IMG/pdf/er589.pdf>, 2007 Aug;589.
2. ARCEP. *Evaluation des besoins des personnes sourdes ou malentendantes* [Online] [cited 2015 02 25]. Available from: [http://www.arcep.fr/uploads/tx\\_gspublication/etude-access-handicap-serv-tel-janv2011.pdf](http://www.arcep.fr/uploads/tx_gspublication/etude-access-handicap-serv-tel-janv2011.pdf); 2010.
3. Ministère du Travail drsdlfdlsedlV. *Plan 2010–2012 en faveur des personnes sourdes et malentendantes* [Online] [cited 2015 02 24]. Available from: [http://www.social-sante.gouv.fr/IMG/pdf/Plan\\_en\\_faveur\\_des\\_personnes\\_sourdes\\_ou\\_malentendantes\\_-\\_10\\_02\\_2010-2.pdf?wb48617274=3E1CBEA7;2010](http://www.social-sante.gouv.fr/IMG/pdf/Plan_en_faveur_des_personnes_sourdes_ou_malentendantes_-_10_02_2010-2.pdf?wb48617274=3E1CBEA7;2010).
4. Steinberg AG, Barnett S, Meador HE, Wiggings EA, Zazove P. Health care system accessibility: experiences and perception of deaf people. *J Gen Intern Med* 2006 Mar;21(3):260–6.
5. Fellingner J, Holzinger D, Pollard R. Mental health of deaf people. *Lancet* 2012 Mar 17;379(9820):1037–44. [http://dx.doi.org/10.1016/S0140-6736\(11\)61143-4](http://dx.doi.org/10.1016/S0140-6736(11)61143-4).
6. Alexander A, Ladd P, Powell S. Deafness may damage your health. *Lancet* 2012 Mar 17;379(9820):979–81. [http://dx.doi.org/10.1016/S0140-6736\(11\)61670-X](http://dx.doi.org/10.1016/S0140-6736(11)61670-X).
7. Emond A, Ridd M, Sutherland H, Allsop L, Alexander A, Kyle J. Access to primary care affects the health of deaf people. *Br J Gen Pract* 2015 Feb;65(631):95–6. <http://dx.doi.org/10.3399/bjgp15X683629>.
8. Emond A, Ridd M, Sutherland H, Allsop L, Alexander A, Kyle J. *BMJ open*. 2015 Jan 25;5(1):e006668. doi: 10.1136/bmjopen-2014-006668. [cited 2015 02 25]. Available from: <http://www.bmjopen.bmj.com/content/5/1/e006668.full>.
9. Laubreton J, Morvan R, Roblot P. Développons les consultations hospitalières pour les sourds. *Presse Med* 2013 Nov;42(11):1427–9. <http://dx.doi.org/10.1016/j.lpm.2013.05.002>.
10. Amoros T, Bonnefond H, Martinez C, Charles R. Un dispositif ambulatoire pour la santé des sourds en soins primaires. *Sante Publique* 2014 Mar-Apr;26(2):205–15.
11. Santé Mdl. [www.sante.gouv.fr](http://www.sante.gouv.fr). [Online].; 2007 [cited 2015 02 25]. Available from: [http://www.sante.gouv.fr/IMG/pdf/circulaire\\_163\\_200407.pdf](http://www.sante.gouv.fr/IMG/pdf/circulaire_163_200407.pdf).
12. Professional Standards Committee. RID – use of a certified deaf interpreter (CDI) [Online] [cited 2015 02 25]. Available from: <http://www.rid.org/UserFiles/File/pdfs/120.pdf>; 1997.
13. Legifrance. *Code de la Santé Publique – article L6321-1* [Online] [cited 25 02 25]. Available from: <http://www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT000006072665&idArticle=LEGIARTI000006691334&dateTexte=&categorieLien=cid; 2003>.