

Practices and exclusion of a singular minority: the speakers of Tactile Sign Language. Example of the Usher Deaf People in France.

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In, International conference, « *Minority languages spoken or signed and inclusive spaces* », organisé par l'INSHEA les 10-12 mai 2020 à Paris.

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Summary :

Speakers of French Tactile Sign Language (LSFT), mainly Deaf people with progressive visual difficulties, constitute a linguistic minority, whose mode of communication, although very rich, is often perceived as limited.

Based on a study of the daily life of people with Usher syndrome in France, we describe the profile and practices of these LSFT speakers. We question the question of the "passage to tactile", and the identity and sociological questions associated with it. It implies an identity of Deafblind and a different relationship to touch.

In spite of the linguistic works in progress, these speakers are victims of discrimination from deaf people refusing any projection, or by negative anticipation of the families and the professionals, slowing down various activities thought unsuitable, of which the LSFT. Invested as a marker of a collective anguish, the potentialities of this language struggle to be recognised.

Keywords : Tactile French Sign Language, Deafblind, deafblindness, Usher's syndrome, Discrimination

Practices and exclusion of a singular minority: the speakers of Tactile Sign Language. Example of the Usher Deaf People in France.

People who use Tactile French Sign Language (TFSL) are in a unique situation in terms of linguistic practices and accessibility. In a minority position in their country, they are also a minority within a minority, within the community to which they belong, that of the French Sign Language (LSF) speakers. This observation is shared at the international level. Tactile Sign Language (TSL) speakers are often born deaf, practicing a TSL and investing the tactile register due to progressive visual difficulties¹, notably linked to Usher syndrome (Arndt et al., 2016; Hersh, 2013; Kyle et al., 2012; Wahlqvist et al., 2016).

The international literature now shows the richness of LS-T. Linguistic research describes similar adjustments in different LS (USA, Japan, Nordic countries, Australia, Italy or France) and strategies for linguistic exploitation of the tactile register (Bono et al., 2018, Checchetto et al., 2018, Collins, 2004; Edwards, 2014a; McAlpin, 2017; Mesch, 2000; Mesch et al., 2015; Schwartz, 2009; Willoughby et al., 2019). This research also focuses on the work of LS-T interpreters and the management of interactions (Berge et al., 2013; Frankel, 2002; Gabarro-Lopez et al., 2020; Metzger et al., 2004; Raanes et al., 2017). They follow the emergence of local and international networks of deafblind people where these practices and a reflexivity about them are developed. Today, a distinction is made between tactile codes of interaction and contextual information, or Haptic (Lahtinen et al., 2008; Danish Association of the Deafblind, 2012), communication practices in LS adjusted to tactile perception, and linguistic strategies exploiting tactile and bodily resources, or Protactile (Clark, 2014; Granda & Nuccio, 2018; Edwards, 2014b).

The conditions of appropriation of these practices remain poorly described, as do the associated identity and sociological issues. This contribution explores these questions based on a study in the social sciences and humanities conducted in France on the life paths and daily lives of people with Usher syndrome².

The Usher-Socio study

The data come from a questionnaire on the life paths of deaf people with visual difficulties, offered in written French, in video LSF and in LSFT in association. Among the respondents with Usher syndrome, 46 people, aged 22 to 76, reported using LSFT. We mobilize data from a Sociological Intervention group³ bringing together, on several occasions, people with Usher syndrome with diversified linguistic practices, and ethnographic observations with Deaf Usher people at different moments of their daily

¹ It is a night blindness and a progressive reduction of the visual field that can begin in adolescence.

² It was financed over 5 years by the ANR Investissement d'avenir program (15-RHU-001Light4deaf: <http://www.ushersocio.org>) and the Fondation Maladies Rares, in support of the DePsySurdi project (<http://depsysurdi.fr>) with which the questionnaire was shared.

³ The synthesis of the work is available in French and LSF here: <http://ushersocio.org/resultats.html>

lives (diversifying the linguistic experiences of the researchers). A corpus of thematic interviews includes 27 of them as well as 13 interpreters and intermediaries⁴ in LSFT.

"Going tactile", a practice under constraint

Whether it is in the scientific literature or in the words of the professionals and the persons concerned, the recourse to the LSFT would be a practice imposed by a degradation of the vision not allowing to do otherwise. Strongly associated with the idea of constraints, even of dependence, imposed by a total deafblindness, "going tactile" means to be seen as deafblind. This passage to a new practice, learned and foreign to the first identity, would mean the entry in another world. However, this representation is contradicted by the variability of practices and the diversity of profiles. It also ignores the positive springs of adjustment to deafblindness and the integrative nature, by definition, of identity work, which questions this rupture.

Variability of blindness and language practices

Responses to the questionnaire show that, among people with Usher syndrome, LSFT is learned later than LSF: 17% of them learned it before the age of 18, compared to 74% of LSF speakers (Figure 1)⁵. Beginning at all ages, the practice of LSFT is associated with reduced vision and/or contact with peers. Half of the respondents reporting blindness are LSFT speakers (Figure 2). But people with excellent, good, or average vision may also be blind. Statistically, those who are not sighted at all are in the minority. Although not representative, these data reveal the importance of an objective diversity of situations, observed and described in interviews. Tubular vision implies the maintenance of a distance between the interlocutors, which is sometimes difficult to respect. Good daytime vision does not prejudge night vision or vision in the dark, nor the management of glare. These changes in vision conditions and the visual exploration of the environment generate fatigue, leading to a momentary switch to tactile. The blindness being contextual, the conditions of communication variable and the entourage variously opened to this communication, many alternate between visual and tactile LSF. All these factors explain why half of the LSFT speakers with Usher syndrome report good or average vision (Figure 3).

Opening up to touch, a process of reversing stigma

These contextual and pathway issues explain why people who practice LSFT may also say that they have not yet "gone tactile", as this would imply that they think they are deafblind. "Language acts are acts of identity" (Tabouret-Keller, 1998). This refers not only to vision but to identity issues associated with the gaze of others and a risk of isolation. The representations and experiences of LSFT are diverse, and presented as demanding and tiring by interpreters, mediators and LSF speakers, by the adjustments to be made and the physical contact between interlocutors. However, declaring oneself deafblind can also participate in a negotiation of these communication practices within these networks, as this person (in LSF) testifies: "being visually impaired means that

⁴ Deaf language mediation professionals.

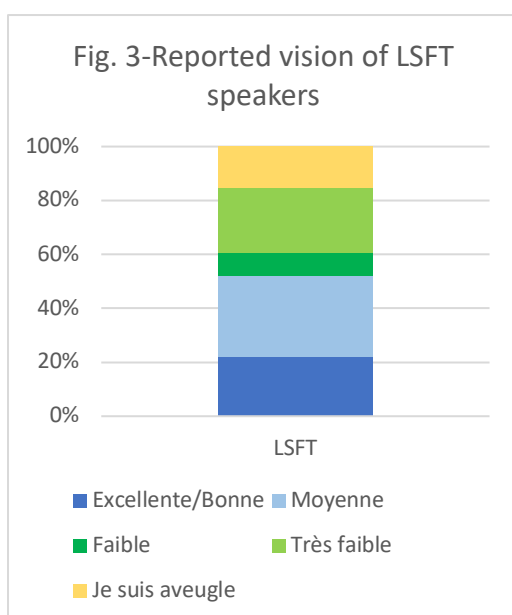
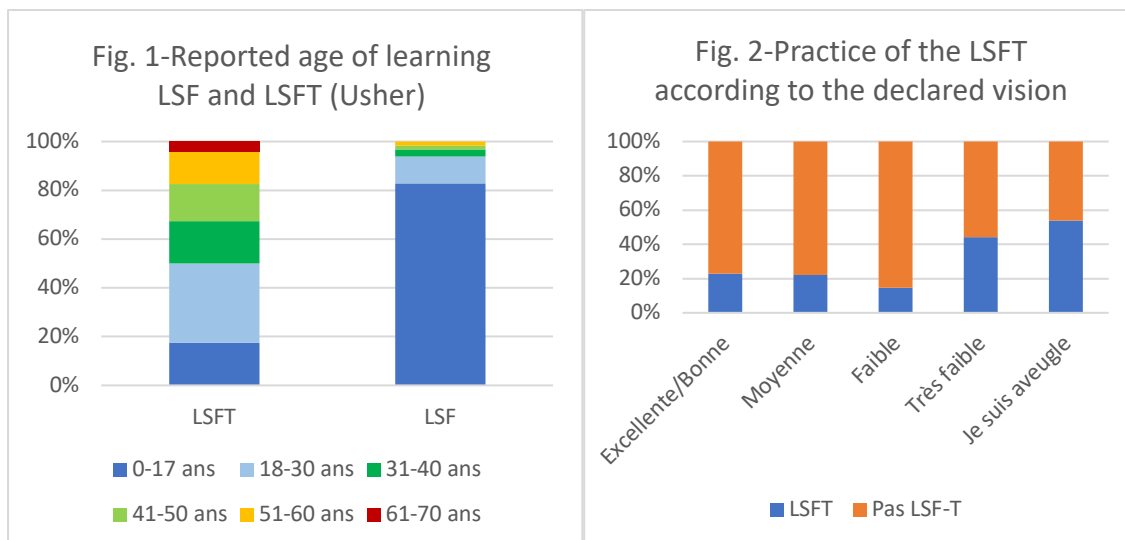
⁵ The figures are at the end of the text.

one still uses one's sight, but I, typically, in the evening I can't see anything. So I'm not one or the other, I prefer to say "I'm deafblind. "That's how I operate. Then, if I can't see, I have a cane and if I don't need one, I don't have one. Maybe in an hour I'll need tactile LSF, but at least the stage is set and we're ready to accept." The passage to the status of deafblind person works here a continuity of course and prepares conditions of social participation. It allows to negotiate back and forth between visual and tactile. This stigmatizing language becomes a language of "comfort", "easy", which "arrives directly from the hands to the brain", "a natural communication", "not really learned", "practiced with friends", "become a habit". It is an enabling language drawing on local sign language and the experience of deafblind people.

A discrimination by refusal of projection and by negative anticipation

However, this tactile adventure, not all want to play it. The discriminations lived by the speakers of LSFT depend on the cultural learning of another relation to the touch. But they also refer, in the deaf people, to refusals of projection in an experience of blindness, to the abandonment of the visual reference marks and practices in the center of the deaf cultures, as this intermediary recognizes it: " Yes, yes, I am a little paranoid with my eyes. I am afraid, yes. The colors, it is my life, the communication, it is my life... I am afraid, yes. I don't want to imagine... I don't want to think that it could happen to me one day. I don't want to think that it could ever happen to me, ever. "While these fears will not always prevent interactions, they do impact the assessment of what is possible for and with a deafblind person. Going tactile may mean no longer taking responsibility, no longer working, no longer moving around alone, not because it is no longer possible, but because the people close to the person (including spouses) associate it with risks of misunderstandings or misjudgments and cannot live with it. While positive adjustments and repositioning are possible in the face of the ordeal of progressive deafblindness (Arcous et al., 2020), socially constructed obstacles reinforce the belief that life as a deafblind person is impossible. This same logic explains a process of discrimination by negative anticipation by relatives and health and education professionals, towards those who do not yet have visual difficulties, including children, consisting in preventing activities considered unsuitable with future deafblindness, such as travel or sports activities, training for certain professions, or communication practices such as visual LSF or LSFT, which cannot - and should not - be invested "until you need it". Invested as a marker of a collective anguish, the potentialities of tactile sign language struggle to be recognized, and with them, those of its speakers.

Quoted figures



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