

A detailed summary of the Zoom Meeting on Aphasia August 26th' 2024

Theme: Awareness of Aphasia in Family and Society (Spanish-speaking countries)

Present : 39 persons Paula Ryan, Gaby, Helena Briales, Fondation Argentina de Afasia, Silvia Rubio, Juan Carlos Crippa, Ramiro Ledezma, Marian turreiro (marianaturreiro@outlook.com), Patrizia Suarez, Cadirola Nilda, Claudio Leyes, Rogelio Gaona, Gabriela, Marta Laszeki, Jacqueline Cuellar Vaca, Afasia Vital, Dani Rey, Sonia Mejia, Irving Retamozo, Florencia Elia, Diego Glas, Adri, Giuseppe Bobbo, Wilfredo Medina, Ignacio, Roberto, Florencia Elia, Jesi, Diego Glas, Suzana Bernarda, Doreen Mendez Sierra, Jean Marie Annoni ...

The September 2, 2024 Zoom meeting brought together healthcare professionals, association representatives, and people affected by aphasia from several countries, including France, Spain, Bolivia, Argentina, and Mexico. The discussion focused on the challenges faced by people with aphasia and the initiatives underway to raise awareness and improve their care. Here is a detailed summary of the key points discussed at the meeting.

1. Presentation and importance of aphasia

- Prevalence of aphasia: Aphasia is a frequent consequence of stroke, affecting around 40,000 people every year in France. This figure illustrates the problem's scale, which healthcare systems often underestimate.
- Lack of official recognition: One of the major challenges identified is the lack of recognition of aphasia in disability categories. This prevents many people from accessing appropriate aids and services, especially in developing countries.

2. Challenges faced by people with aphasia

- Social isolation and lack of awareness: Many participants spoke of the sense of isolation felt by people with aphasia. General ignorance about aphasia leads to misunderstandings, even within families, and a lack of appropriate support.
- Communication difficulties: testimonials highlighted the specific difficulties associated with communication for people with aphasia. For example, a participant from the USA shared her experience of frustration when trying to communicate with therapists, who did not understand her condition.
- Lack of Information: It was noted that even in developed contexts, such as the USA, patients are not always properly informed about their condition, adding to their anxiety and isolation.

3. Current initiatives and proposals

- Raising awareness through education: Several educational initiatives have been put forward. In Spain, a children's book on aphasia is used in schools to raise awareness among young pupils. This approach helps create understanding from an early age.
- Use of Media and Art: An ongoing project involves the creation of a commercial film about aphasia, directed by the Dardenne brothers in Belgium, aimed at raising awareness among the general public in an accessible and emotive way. In addition, the idea of producing plays in collaboration with aphasics has been proposed as a means of expression and awareness-raising.

- Community support and group therapy: Associations, notably in Bolivia, have set up resocialization workshops to help aphasics regain a sense of belonging. These groups enable participants to share their experiences, receive emotional support, and practice their communication skills in a supportive environment.

4. The role of families in supporting people with aphasia

- Family training: In Spain, a key initiative is training the families of aphasic patients. Regular sessions are organized to explain the specific challenges of aphasia, how to cope, and how to support relatives. This support is crucial, as families play a central role in the recovery and day-to-day management of aphasia.

- Testimonials of Difficulties: Several participants shared testimonials of the difficulties families face in understanding and accepting the condition of their aphasic loved one. It was emphasized that aphasia involves not only loss of speech but also problems with memory, concentration, and emotional changes.

5. Proposals for the future

- Legal and institutional recognition: We discussed the need to lobby the authorities to recognize aphasia as a disability in its own right, with specific rights. Such recognition would enable better access to services and financial aid.

- International collaboration: The meeting also highlighted the importance of international collaboration to exchange practices and resources, and to strengthen global support for people with aphasia. For example, joint efforts between the Argentine Aphasia Foundation and Bolivian organizations have already shown promising results.

- Creating local resources: The meeting encouraged the creation of local aphasia centers and resources, as has been done in Bolivia. These centers could offer workshops, support groups, and training for families while being supported by public or private funding.

6. Conclusion and Call to Action

- Continuing to raise awareness: Participants committed to continuing their efforts to raise awareness, whether through media campaigns, interventions in schools, or the production of artistic content.

- Strengthening Community Support: A call was made to strengthen community support networks and to include more people with aphasia in the design and implementation of projects that concern them.

- Next Steps: It was agreed to meet again to discuss progress and to continue exchanging ideas on how best to raise awareness and support for people with aphasia worldwide.