UNHELPFUL HELPLINES: INACCESSIBILITY FOR THE DEAF

To the Editor

According to the census of India 2011,[1] the prevalence of disabling hearing deficit and combined hearing and speech deficit are 19% and 7%, respectively, out of the total 26.8 million population with disabilities, comprising approximately 6 million or 0.5% of the total Indian population.[2] It is estimated that there could be more than 500,000 deaf-blind people in India.[3] Hearing impaired people are at increased risk of facing mental health challenges.[4]

COVID-19, in its wake, has disrupted healthcare delivery systems. Routine in-person consultations have been substituted by remote consultations. Additionally, there has been increased recognition of surveillance needs as well as guidance for help-seeking in the disrupted systems. Helplines run by both governmental agencies and non-governmental organisations have tried to link seeking clients to lay counsellors and even mental health professionals downstream. These helplines are voice-based: They are accessed by dialling a phone number. Being voice-based, there remains an accessibility concern for the D/deaf population. No systematic study has been done. However, Sign Language Interpreters (SLI) who have been assisting the D/deaf population and the National Centre for Promotion of Employment of Disabled People (NCPEDP) have found these helplines to be inaccessible. This has hampered the dissemination of healthcare knowledge pertaining to COVID-19 and access to mental healthcare.[5,6]

For D/deaf people, communication with the hearing world requires synchronised sign language interpretation and video captioning. Being excluded from communication possibilities and information sources that hearing people take for granted can have a profound impact.[7] Reduced uptake of healthcare services due to a greater likelihood of negative experiences can be anticipated.[8] It appears that helplines have not been universally designed to include the D/deaf. The recent Telepsychiatry guidelines also do not address universal guidelines or concerns. The KIRAN helpline launched by the Ministry of Social Justice and Empowerment (MSJE) to address COVID-19 related mental health concerns also does not incorporate universal design.[9–11]

We propose that there be a multiplicity of access methods to these services – voice-based, text-based and video-based. Deaf people need experts who are aware of Deaf culture, the lives of Deaf and the way their language, being 3-dimensional plays a role in their communication abilities. Video facility for the helpline that connects the D/deaf to a SLI, deaf expert and a medical professional or counsellor should be incorporated. Text-based access would suit the needs of deafblind persons: using tactile senses, they can interact via electronic refreshable braille-based displays. Telepsychiatry service can similarly incorporate a text-based solution and also recommend the inclusion of SLI during consultation for D/deaf. Other possible strategies which may be applied are empowering the D/deaf volunteers and service users towards peer service delivery and capacity building of SLI to identify mental health emergencies for referrals. Mental health professionals are required to be sensitised of Deaf Culture, mental health concerns and accessibility concerns of D/deaf.

We recommend consensus guidelines on mental health care helplines be drawn up to ensure universal design. Multi-stakeholder consultations with D/deaf, D/deaf service users, Deaf culture experts, SLI, disability rights activists and mental health professionals be held periodically to provide the best services. Systems should retain a scope to improve with service user feedback. A systematic study on the accessibility of available helplines across disabilities should be undertaken. Similar concerns may be echoed across other developing countries. We anticipate the above-mentioned solutions would work just as well across countries.

Even with the best of these methods, there can be no substitution of in-person consultations/reviews. It would be in everyone's best interest to allow for expedited and prioritised in-person reviews when diagnostic or management challenges persist. These systemic changes will have long standing implications beyond the pandemic restriction. These would also aid in Disability Included Disaster Risk Reduction (DIDRR) and disaster mitigation strategies. We anticipate benefits to service delivery for other special populations such as the elderly. Mental health professionals must remember the guiding principles of universal design and accessibility enshrined in the United Nations Convention on Rights for Persons with Disabilities (UNCRPD). Mental health professionals in India should take note of the same principles in the Rights of Persons with Disabilities act (RPWD 2016). Development of care services in the future would do well to adhere to these considerations from their inception.

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