Addressing Communication Disorders in Unserved and Underserved Populations

Addressing Communication Disorders in Unserved and Underserved Populations

Sandra Levey and Pamela Enderby (Editors)

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Preface

This book has been authored by members of the International Association of Logopaedics and Phoniatrics (IALP), now called The International Association of Communication Sciences and Disorders, which was established in 1923. The objective of the IALP is to bring together professionals from various fields to promote research and clinical practice to support the needs of populations who lack health and other basic services. This book aims to celebrate the centenary of the IALP by presenting ideas that will assist practitioners working with unserved and underserved communities to improve services for these populations.

Introduction

The goal of this book is to inform readers of the needs of unserved and underserved populations, those who either live in areas that lack adequate health services or who cannot access existing health services. The chapters of this book present strategies to address disorders and conditions in the areas of communication, health literacy, autism, hearing loss, dysarthria (difficulty for controlling speech), aphasia, cleft lip and palate, fluency, and dysphagia (swallowing difficulties). These are conditions that affect everyday activities, relationships, interaction, education, and employment. Chapters describe the literacy needs of millions of children across the globe who lack reading skills that impact later reading abilities and employment. Other chapters describe the needs of those with aphasia, a growing condition as the world's population increases in age. Other chapters describe those with speech sound disorders, autism, hearing loss, cleft palate, and swallowing disorders that require assessment and intervention to support their ability to function in social interaction, education, and employment. One of the chapters addresses the need for augmentative and alternative communication (AAC) intervention for those with severe communication disorders to allow them to communicate with others. Another argues for providing support to those from diverse cultural and linguistic backgrounds so that they can access health care, education, and employment to improve their wellbeing.

About IALP

Vision

IALP has a global vision to facilitate better understanding, knowledge and care of all those with communication and swallowing disorders.

Mission

The mission of IALP is to improve the quality of life of individuals with disorders of communication, speech, language, voice, hearing and swallowing.

IALP will:

- (i) Facilitate science, education, and clinical practice through international cooperation and collaboration
- (ii) Create and share knowledge, skills and information
- (iii) Provide a platform for international networking and advocacy.

About the Authors

José G. Centeno is Professor in the Master of Science in Speech-Language Pathology Program in the Department of Rehabilitation and Movement Sciences, Rutgers School of Health Professions, USA. Dr Centeno conducts research that responds to the clinical needs of the growing ethnoracially diverse geriatric populations with chronic age-related disabilities. His research is at the intersection of neurolinguistic theory, aphasia services, and ethnogerontology. Dr Centeno specifically conducts research in post-stroke aphasia in bilingual Spanish-English speakers and clinical management of communicatively-impaired ethnogeriatric neurorehabilitation caseloads. Dr Centeno has participated in national and international professional committees in aphasia and multicultural issues.

Maria Christopoulou is Assistant Professor in the Department of Health and Sciences, European University Cyprus, and Director of the Speech Language Hearing Clinic. Her research focuses on pediatric language development, ASD, motor speech disorders, school readiness, mentoring and training new professionals, and supporting clinicians working with multicultural populations. She is a member of the International Association of Communication Sciences and Disorders (IALP), the IALP Autism Committee, and member and delegate of the World Health Organization platform of ASD. Her research has been published in scientific journals and she has participated in international conferences on language disorders, early language development, and ASD.

Shakila Dada is Professor and Director at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria, South Africa. She is a speech language therapist with research and teaching in AAC and Early Childhood Intervention. Her focus is on graphic symbol-based augmentative and alternative communication (AAC) systems that can be used to facilitate language comprehension and learning for individuals with complex communication needs and also to facilitate their participation in society. She is an associate editor of the *Augmentative and Alternative Communication (AAC)* journal.

Bronwyn Davidson is a Principal Fellow in the Department of Audiology and Speech Pathology, University of Melbourne, Australia. Dr Davidson has extensive experience as a clinician, academic and researcher and has authored 10 book chapters and 75 peerreviewed journal articles. Her professional work in speech pathology spans the fields of aphasia and practice education, including an interest in professional education in speech-language pathology and services for people with communication disability in underserved communities and countries. Her work with Speech Pathology Australia has a focus on professional standards and culturally responsive practice. Dr Davidson is a Fellow of Speech Pathology Australia.

Pam Enderby is Emeritus Professor of Community Rehabilitation at the University of Sheffield. She has Chaired the Board of the Royal College of Speech and Language Therapists and has been President of the Society for Research in Rehabilitation. She is currently President of the International Association of Communication Sciences and Disorders (IALP). She has authored 14 books and published 230 peer-reviewed journal articles, with a focus on outcome measurement, assessment, technology in rehabilitation, and evaluation of rehabilitation and speech and language therapy. Awards include a Fellowship of the College of Speech Therapists and an OBE for services to Speech and Language Therapy.

Helen Grech is Professor and founder academic of the Department of Communication Therapy at the University of Malta. Besides being appointed Head of the Department, she was Deputy Dean of the Faculty of Health Sciences and chaired the University Research Ethics Committee. She is a practising audiologist and speech-language pathologist. Helen Grech has been awarded several research funds including the prestigious Marie Curie Research Fellowship of the European Commission. She has published many papers in scientific journals and has contributed several chapters in books. She is Former President and Honoured Member of the International Association of Communication Sciences and Disorders (IALP).

Suzanne C. Hopf is Head of Discipline (Speech Pathology) at Charles Sturt University, Australia. An Australian-Fijian citizen based in Fiji, Suzanne's publications and presentations describe how the contextually unique barriers and facilitators for supporting people with communication disability are created and reinforced by individual, community, and societal factors. Her Communication Capacity Research and Culturally Responsive Teamwork Frameworks provide starting points for developing evidence-informed and culturally responsive communication specialist services in unserved areas of the world.

Thomas Law is an assistant professor and deputy chief of the Division of Speech Therapy, Department of Otorhinolaryngology, Head and Neck Surgery, and the Assistant Director of the Institute of Human Communicative Research at The Chinese University of Hong Kong. He is a member of the fluency committee of the International Association of Communication Sciences and Disorders (IALP). His research includes intervention outcomes and epidemiology in stuttering, voice disorders, linguistic factors associated with stuttering, the perceptual evaluation of voice, and factors associated with treatment outcomes.

Sandra Levey is Professor Emerita at the City University of New York. She is editor of six books, co-author of three books, and 27 book chapters that focus on multilingualism and multiculturalism. Dr Levey has presented at global conferences, received research grants in Nigeria and the Slovak Republic, and has conducted research on multicultural differences in the impact of noise-induced hearing loss. She is a Board Recognized Specialist in Child Language of the American Speech-Language-Hearing Association Council for Clinical Specialty and a member of Sigma Xi Scientific Research Honor Society, the American Association for the Advancement of Science, and the IALP.

Kate Margetson is a speech-language pathologist, PhD student and project officer for

the VietSpeech research team at Charles Sturt University, Australia. She has worked clinically supporting multilingual children and their families for over 10 years. She has been a speech pathology trainer, clinical educator, and technical consultant for AAC in Vietnam with the Trinh Foundation and the Kianh Foundation. Her PhD research focuses on speech-language pathology support for Vietnamese-English-speaking children.

Sharynne McLeod is Professor of Speech and Language Acquisition at Charles Sturt University in Australia. She is a Life Member of Speech Pathology Australia, has received Honors of the American Speech-Language-Hearing Association, is Chair of the Child Speech Committee of the International Association of Communication Sciences and Disorders (IALP), Co-Chair of the International Expert Panel on Multilingual Children's Speech, and an Executive Council Member of the Asia Pacific Society for Speech, Language and Hearing. She has co-authored 11 books and over 230 journal articles and chapters focusing on children's speech acquisition, speech sound disorders, and multilingualism.

Sharon Moonsamy (PhD) is a Speech-Language Pathologist, Audiologist, and a Remedial Education Consultant. She is an Associate Professor at Wits University and is Head of the School of Human & Community Development. Her professional experience relates to education, health, and higher education. Her teaching and research include child language, literacy, and cognition and are centered on social justice. Her belief is that, given the opportunity, all individuals can achieve according to their potential. Creating access to services for those from marginalized populations furthers this perspective. Teacher-therapist workshops, conference presentations, journal and book publications contribute to her scholarly profile.

Angela T. Morgan is the Dame Kate Campbell Professorial Fellow of Speech Pathology at the University of Melbourne, Royal Children's Hospital and Murdoch Children's Research Institute in Melbourne Australia. Angela is Chair of the Motor Speech Disorders Committee for the International Association of Communication Sciences and Disorders (IALP). Angela has over 240 peer-review journal papers and book chapters on childhood speech and language disorders. Recent work has focused on identifying genetic aetiologies for severe childhood speech disorder. Awards include a National Health and Medical Research Council Elizabeth Blackburn Award and a Speech Pathology Australia Elizabeth Usher award for original research contribution.

Janice Murray is Professor of Communication Disability at Manchester Metropolitan University, UK. Her research and clinical work are focused on atypical language acquisition, augmentative and alternative communication (AAC) tools and strategies, and literacy development using AAC. She is former Chair of Communication Matters (ISAAC UK), former Chair of Council of the International Society for Augmentative and Alternative Communication (ISAAC) and a Board member of IALP (now the International Association for Communication Sciences and Disorders, IALP). She has received several research funding awards and has published extensively on clinical decision making in AAC, language and cognitive demands of AAC. Awards include a Fellowship of the College of Speech Therapists, and a national AAC researcher of the year.

Michelle Pascoe is an Associate Professor in the Department of Health and Rehabilitation Sciences at the University of Cape Town. She is an experienced speech and language therapist whose current projects focus on cross-cultural adaptation of speech and language assessments, typical and atypical speech, and language acquisition in the languages of Southern Africa, multilingualism, and ways to support clinicians working with families from diverse language and cultural backgrounds. Michelle is an associate editor of Child Language Teaching and Therapy and Logopedics Phoniatrics Vocology, co-author of two books and several chapters, and author of more than 30 peer-reviewed papers.

Valerie Pereira is Assistant Professor at the Department of Otorhinolaryngology, Head and Neck Surgery, The Chinese University of Hong Kong. She holds an Honorary Assistant Professor position with the Faculty of Dentistry, The University of Hong Kong, as the Speech Therapist for the Cleft Cinic. She has been an invited speaker at international conferences and has published several book chapters and peer-reviewed papers. Her clinical and research areas of interest include perceptual and instrumental measures, outcome measurement, and impact of orthogonathic surgery and speech. She is Chair of the Cleft Palate and Craniofacial Conditions Committee and Board Member of the International Association of Communication Sciences and Disorders (IALP).

Kakia Petinou is a Professor and Chair of the Department of Rehabilitation Sciences, School of Health Sciences, Cyprus University of Technology. She is a member of the International Association of Communication Sciences and Disorders (IALP) and Chair of the Autism Spectrum Committee (ASD) of IALP. Dr Petinou is the founder and director of the THERALAB research laboratory and member of the Association of Speech Therapists of Cyprus, and was its President from 2010-2013. Her research focuses on late onset of expressive language, developmental language disorders, apraxia, speech sound disorders, autism spectrum disorders, narrative skills, and evidencebased treatment in speech sound disorders.

Ben Pham is senior lecturer at the Division of Speech-Language and Hearing Impairment, Faculty of Special Education, Ha Noi National University of Education, Viet Nam and adjunct research fellow at Charles Sturt University, Australia (December 2018-December 2021). She is a member of the International Expert Panel on Multilingual Children's Speech, and the Child Speech Committee of the International Association of Communication Sciences and Disorders (IALP). Her main research interests are on children's speech and language acquisition, speech sound disorders, and developmental language disorders.

Mershen Pillay is an Audiologist and Speech Therapist that believes clinical practice is political - mainly pleasing Eurocentric desires. Currently, he is programme coordinator (Speech-Language Therapy) at Massey University (New Zealand), and honorary associate professor (University of KwaZulu-Natal, South Africa). He has worked mainly in South Africa, the UK, United Arab Emirates, New Zealand, with short posts in African/Asian countries. He has two clinical/practice interests. In SLP he works with persons with swallowing disabilities to achieve food sovereignty, and as an audiologist he practises conservation of informal workers' hearing. Overall, Mershen works toward equitable practices with people in vulnerable contexts.

Dua Qutishat is Assistant Professor of speech pathology at the University of Jordan, Department of Hearing and Speech Sciences, Faculty of Rehabilitation Sciences. She is a certified speech therapist in Jordan and in the UK. She is a member of the IALP motor speech disorders committee and studies global voice and neurogenic communication disorders, the SLP profession in Jordan, and the management of vocal health and vocal pathology. Dr Dua has published on the management of dysarthria, presented at global conferences, and has conducted research on voice disorders and adults' neurogenic communication disorders.

Wiebke Scharff Rethfeldt is a Full Professor in Speech-Language Therapy and director of Therapeutic Sciences BSc programme at the City University of Applied Sciences Bremen, Germany. She is Chair of the Multilingual-Multicultural Affairs Committee and Board member of the International Association of Communication Sciences and Disorders (IALP). She worked clinically as a qualified SLT with linguistically and culturally diverse populations, received her master's at Newcastle University, and her doctorate at Oldenburg University, with both dissertations focusing on bilingualism. Her teaching and research interests focus on clinical assessment of Developmental Language Disorder in multilingual children with or without a migration or refugee background.

Debbie Sell is an Honorary Senior Research Fellow at Great Ormond Street Hospital for Children in London, UK, Founder/Co-Director of Speech@Home (www.speech@home. org), and Visiting Reader, University of Surrey. She worked as a Clinician-Researcher/ Lead Therapist in the North Thames Cleft Team, and as Head of Department. Debbie has published over 100 peer-reviewed publications, 16 chapters and co-edited two textbooks. Her PhD study, based in Sri Lanka, led to the establishment of the SLT training course and profession there. She is currently one of Transforming Faces' global advisors on solutions for comprehensive cleft care. Awards include a Fellowship of the Royal College of Speech and Language Therapists and an OBE for services to the National Health Service.

Martine Smith is Professor in Clinical Speech and Language Studies at the University of Dublin, Trinity College. Her research and clinical work are focused on supporting language, literacy, and communication participation, particularly in the context of severe communication impairment and augmentative and alternative communication (AAC). She is a Past President of the International Society for Augmentative and Alternative Communication (ISAAC) and a former Board member of IALP (now the International Association for Communication Sciences and Disorders, IALP). She has published extensively on language-literacy links and AAC, and is a former Editor of the AAC journal.

B. Subramaniyan is an Associate Professor at the Department of Speech Language and Hearing Sciences, Sri Ramachandra Institute of Higher Education and Research (DU) Chennai, India. He is the director of a cleft care programme in rural South India. He has been part of the multidisciplinary team involved in cleft care at Sri Ramachandra Cleft and Craniofacial Centre. Dr Subramaniyan has served as international faculty in workshops and conferences and international cleft care missions. He has been a part of the team that developed a dedicated mobile application used for monitoring services provided in rural community-based programmes.

Triona Sweeney worked at Temple Street Children's University Hospital, Dublin as a Manager and Clinical Specialist in Cleft Palate. She was an Adjunct Professor at the University of Limerick where she taught modules in cleft palate/craniofacial anomalies, clinical phonetics, and speech sound disorders. Triona is a Consultant Cleft Specialist Speech and Language Therapist and co-founder of Speech@Home. Her research includes development and evaluation of perceptual and instrumental speech assessments in cleft palate, cleft speech audit, and parent-led therapy. She has worked with speech and language therapists in Ethiopia with Operation Smile Ireland and Transforming Faces, and was involved as an advisor in the development of the Ethiopian speech therapy training course at Addis Ababa University.

Van Tran is a postdoctoral researcher at Charles Sturt University and a NAATI-accredited translator. She has been teaching English language and linguistics, translation and interpreting, and Vietnamese language at University of Wollongong, Western Sydney University, and Defence Force School of Languages. She hosts SBS Vietnamese's weekly show on maintaining home language for Vietnamese-Australian children. Her research focuses on home language maintenance among Vietnamese-Australian families, multilingualism, and multilingual children's speech and language acquisition.

Sarah Verdon is an Associate Professor of speech-language pathology at Charles Sturt University, Australia. Her research focuses on children's speech, language, and communication development in culturally diverse contexts. She is co-chair of The International Expert Panel on Multilingual Children's Speech which advocates culturally responsive practice with multilingual children. She oversaw the development the Speech Pathology Australia national position paper and clinical guidelines for culturally responsive practice. Sarah applies her research and skills in volunteer capacity as director of the Trinh Foundation Australia, an Australian-based international not-for-profit organization whose mission is to develop speech therapy in Vietnam.

Yvonne Wren is Director of Bristol Speech and Language Therapy Research Unit, Associate Professor of Speech and Communication at the University of Bristol, and Reader in Speech and Language Therapy at Cardiff Metropolitan University in the UK. She is currently Chair of the Child Speech Committee of the International Association of Communication Sciences and Disorders and a member of the International Expert Panel on Multilingual Children's Speech. She founded the UK and Ireland Child Speech Disorder Research Network and has been an invited speaker at international conferences including Portugal, South Africa, the USA, and Australia. She is also Senior Research Advisor to the UK Royal College of Speech and Language Therapists.

Christine Yoshinaga-Itano is a Research Professor, Institute of Cognitive Science, Professor Emerita, Department of Speech, Language & Hearing Sciences, at the University of Colorado, Boulder, and Visiting Professor, University of Witwatersrand, South Africa, Centre for Deaf. Her research for over 45 years has focused on universal newborn hearing screening and predictors of developmental outcomes of children with hearing loss with an emphasis on children and families with socio-economic and linguistic challenges and has assisted state and national departments of health and education in the US and globally in the development of their early hearing detection and intervention systems.

1 Unserved and Underserved Populations

Sandra Levey and Pamela Enderby

Introduction

The International Association of Logopaedics and Phoniatrics (IALP), now called The International Association of Communication Sciences and Disorders, held its inaugural conference in 1923. The objective of the IALP is to bring together all professions working with individuals with communication and swallowing disorders with the goal of fostering research and clinical practice. Our mission is to improve the quality of life of individuals with disorders of communication, speech, language, voice, hearing, and swallowing. Much has been achieved to extend our knowledge of disorders but there is still a need to increase the understanding and awareness of these difficulties in marginalized communities.

Unserved and underserved populations

Unserved and underserved populations are those that lack access to health services, education, or other aspects of wellbeing. Across the globe, millions face difficulties due to poverty, political conditions, civil unrest, or climate change that has an impact on the economy, agriculture, and living conditions. In some countries, inequalities are based on structural or systematic bias and discrimination that results in inequalities in education, healthcare, and income.

Unserved and underserved populations frequently consist of migrants, refugees, asylum seekers, along with native populations in countries. Migrants are individuals who seek to establish a better life in a new location or country. Refugees are those forced to leave a country because of war, persecution, political instability, or poverty (Gönültas & Mulvey, 2019; International Organization for Migration, 2018).

Asylum seekers are those who have fled their home country because of conflict, war, or other factors that bring danger to themselves or their families. Whilst forced displacement occurs when individuals are compelled to escape a region or country, voluntary migration is defined as the choice to relocate. Forced migration occurs when populations are compelled to flee a natural disaster, unemployment, famine, persecution, and conflict (Grech, 2019; Immigration Data Portal, 2020; United Nations Refugee Agency, 2017).

Vulnerable unserved and underserved populations face a high risk of health and education challenges. These populations are faced with limited financial and housing