

Brief Biography

My name is María Isabel Matute Willemsen. I am a Sociologist, Master in Public Health, Postgraduate in Design and Evaluation of Social Programs and Projects and Diploma in Regional Studies. I am currently pursuing a PhD in Public Health.

Although I have experience in health research, my relationship with rare diseases arose only in 2020, when Dr. Gabriela Repetto, from the Genomics and Genetics Center of the Universidad del Desarrollo, invited me to lead one of the objectives of the project "Solving the unsolved: an interdisciplinary evaluation of personal, social and health system effects of the use of genomic strategies for rare diagnosis disorder". This project began to be executed during 2021, which has implied that I have become increasingly involved with the subject, contributing from a sociological and epidemiological perspective.

In terms of my professional career, since 2012 I am a teacher and researcher at the Center for Epidemiology and Health Policies (CEPS) of the Faculty of Medicine Clínica Alemana - Universidad del Desarrollo, in Chile. As part of my functions I am: Academic Coordinator of the Diploma in Field Epidemiology, professor of quantitative methodology in the Interuniversity Master in Bioethics developed by the Bioethics Center of the Universidad del Desarrollo in academic agreement with the Institut Borja de Bioética - Universidad Ramón Llull of Barcelona, teacher of Public Health and methodological tutor of undergraduate theses.

My research interests are linked to equity in access to health services, social determinants of health, quality of life, informal caregivers and policy evaluation, as well as methodological aspects for research in epidemiology and public health. As I have already said, recently I have become involved in the area of Rare Diseases (RDD), the diagnostic odyssey of patients and their families and the importance of access to diagnosis and treatment, where genomics occupies a fundamental place. Thus, I am developing my doctoral thesis project on issues of well-being and health-related quality of life in caregivers of people with RDD and I am also participating in the project "Solving the unsolved: an interdisciplinary evaluation of personal, social and health system effects of the use of genomic strategies for rare diagnosis disorder", directed by Dr. Gabriela Repetto and financed by the National Fund for Scientific and Technological Development of Chile (Fondecyt).

As a previous background of my career, between 2003 and 2012 I worked in the Ministry of Health of Chile, first in areas related to HIV/AIDS and then in the Department of Epidemiology, where I was in charge of the development of Regional Diagnostics with a focus on Social Determinants of Health, I collaborated in the surveillance of non-communicable diseases and participated as technical counterpart of various studies and population surveys. I have also collaborated in consultancies for UNAIDS and the Pan American Health Organization. In addition, I have participated in several studies on communicable and non-communicable diseases, as well as in the design, implementation and analysis of population-based health surveys.