

### Annual Report 2022









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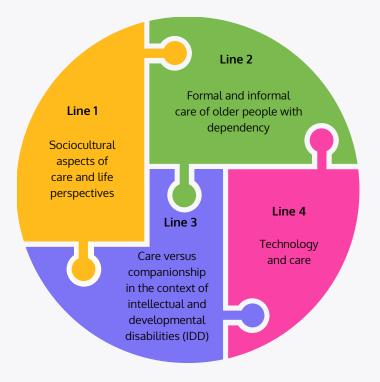
Acknowledgments: This document is the result of the work carried out by MICARE's Research Coordinator, Raffaela Carvacho, under the supervision of the Executive Director, Javiera Gutiérrez. We extend our appreciation to Claudia Miranda, the Director; Marcela Tenorio, the Alternate Director; and Isabel Arteaga, the Executive Assistant, for their revisions.



# INTRODUCTION

The Millennium Institute for Care Research (MICARE) is a center of excellence in frontier research funded by the Agencia Nacional de Investigación y Desarrollo (ANID) [National Agency for Research and Development] through its Millennium Program. MICARE is hosted at Universidad de los Andes (UAndes), Universidad Nacional Andrés Bello (UNAB) and Pontificia Universidad Católica de Valparaíso (PUCV). The objective of MICARE is to generate scientific knowledge about the informal and formal care of older people with dependency (OPD) and people with intellectual disabilities or other developmental conditions (IDD). To achieve this, it focuses on characterizing care from an integral perspective and the generation of appropriate evidence-based interventions.

MICARE is committed to the development of excellent scientific research, focusing on four primary lines of inquiry:



The Institute was founded in 2021. This document outlines how MICARE has continued to expand during its second year of operation. During this time, the Institute has undergone substantial growth, including the addition of new members, the development of a new training program for students, the establishment of new collaboration networks, and a twofold increase in its scientific productivity compared to the previous year.

The MICARE community has grown by welcoming both national and international researchers. Thus, in 2022 it reached a total of 37 researchers across different categories: 7 associate researchers, 7 adjunct researchers, 11 young researchers, 9 senior researchers, and 3 postdoctoral researchers. Furthermore, we have strengthened the executive team, which consists of our director, an alternate director, an executive director, a research coordinator, a communications director, an administration and finance coordinator, and an executive assistant. This team provides us with the necessary management capacity and strategic support for all activities undertaken at the Institute, which is especially important in view of MICARE's accelerated growth. This team also collaborates with our Board of Associates, the rest of the community of researchers and students, our Spokespersons' Office, and our host institutions.

In 2022, the "MICARE Mentoring Program" was established, providing training and support for students dedicated to studying and researching topics related to care. This year, 38 undergraduate and graduate students participated, gaining research experience in various projects of the Institute, participating in training events organized by us and establishing collaborative networks with researchers and other students. Likewise, several of our students attended scientific events as speakers, took part in internships, co-authored scientific articles, and engaged in outreach activities and press articles.

In relation to its connections with other sectors, MICARE has established new informal collaboration networks and formal agreements with research centers. This positioning allows MICARE to enhance its presence within the academic environment and further develop collaborative research opportunities with significant national and international scientific organizations. The Institute additionally established the "Caring Institutions Network", with the goal of fostering collaboration with civil society organizations engaged in care endeavors. Furthermore, the Institute carried out intense work in relation to the provision of services and training to other sectors, mainly healthcare, education and the public sector.

This year, 38 publications affiliated with MICARE were produced, reflecting a 253% increase compared to the previous year. Of this total, 58% were published in journals indexed in WoS, while 18% were published in journals hosted in Scopus. Moreover, 30% and 20% are positioned within the first two quartiles respectively, according to the rankings in WoS and Scopus. Similarly, 95 presentations were delivered at congresses and other scientific events, with 49% of them taking place at international events. In addition, 17 scientific events were successfully organized through intense collaboration between our research lines and between our Institute and other organizations.

In the year 2022, the construction of measurement instruments for the "MICARE Study" was completed. This study involves collecting data in three longitudinal waves on home carers of older people with dependency (OPD) and people with intellectual disability or other developmental conditions (IDD), as well as a cross-sectional investigation of institutional carers of OPD and people with IDD. Data collection will begin in 2023, which will provide up-to-date and relevant evidence on the needs of these groups. It is expected that these results will have a significant impact, as this project is the first of its kind in our country and in Latin America.

In the future, we hope to continue making progress in all the areas described, placing special emphasis on fostering collaboration among all the lines of research and strengthening cooperation among various categories of researchers and MICARE students. Lastly, we also aim to continue directing our efforts towards influencing public policies related to care, contributing scientific evidence to the dialogue and decisionmaking processes that will lead to the creation of a National Care System for our country.





## **Board of Associate Researchers**



### Claudia Miranda | Director.

Psychologist with a PhD in Aging and Mental Health from University College London, UK. Associate Professor at the School of Nursing, Universidad Andrés Bello, and also Associate Researcher at the Millennium Institute for Research in Depression and Personality (MIDAP). She conducts research on the needs and mental health issues of older people, as well as the development of psychosocial interventions for individuals with dementia and their carers.

### Marcela Tenorio | Alternate Director.

Psychologist with a PhD in Psychology from the Pontificia Universidad Católica de Chile. Associate Professor at the School of Psychology, Universidad de los Andes. Researcher specializing in neuropsychology, intellectual and developmental disability, cognitive assessment and literacy.

### María Beatriz Fernández | Associate Researcher.

Sociologist with a PhD in Sociology from the Pontificia Universidad Católica de Chile. Faculty member at the Institute of Sociology UC, and researcher at the Center for Aging and Older People Studies, CEVE UC. She conducts research on subjects pertaining to aging, quality of life and well-being, familial and social relationships among older people, and social gerontology.

### Alejandra Araya | Associate Researcher.

Nurse-midwife specialized in Gerontogeriatrics, with a PhD in Nursing Sciences. Professor at the School of Nursing, Universidad Andrés Bello. Director of the Nursing Science Doctoral Program at Universidad Andrés Bello. She specializes in the study of frailty, well-being and aging, women's health, and secondary prevention of HIV/AIDS.

#### Vanessa Vega | Associate Researcher.

Professor of Special Education, with a PhD in Disability Research from the Universidad de Salamanca, Spain. Professor at the School of Pedagogy, Pontificia Universidad Católica de Valparaíso. Researcher specializing in social inclusion, rights, quality of life, support needs, self-determination, independent living, and cognitive accessibility in individuals with intellectual or developmental disabilities.

### Paulina Arango | Associate Researcher.

Psychologist with a PhD in Psychology from the Pontificia Universidad Católica de Chile. Associate Professor of the School of Psychology at the Universidad de los Andes (Chile) and Director of the master's program in Pediatric Neuropsychology. She researches subjects concerning intellectual disabilities, families, and carers of individuals with intellectual disabilities, neuropsychology, cognitive assessment, and language development.

### Andrés Aparicio | Associate Researcher.



Systems and Computing Engineer, with a PhD in Arts, specializing in Theater Studies and Practices from the Pontificia Universidad Católica de Chile. He conducts research in subjects related to bodily diversity as a complex experience and an epistemological space, technology as both a process and an artifact, and its applications in care and social inclusion.



### **Postdoctoral Researchers**

#### Juan Pablo Robledo

Psychologist with a PhD in Music and Science from the University of Cambridge. Associate Professor at the School of Psychology, University of Lorraine. We are pleased to inform that Dr. Robledo has been promoted to Young Researcher at the end of 2022.

#### Javiera Rosell

Psychologist with a PhD in Psychology from the Pontificia Universidad Católica de Chile. Assistant Director of the Senior Citizen Program of CEVE UC. Faculty member at the School of Psychology, Pontificia Universidad Católica de Chile, and a participant in the Latin American Research Network at the Oxford Institute of Population Aging.

### Francisca Ortiz

Sociologist from the Universidad Alberto Hurtado and PhD in Sociology from the University of Manchester, United Kingdom. Board member of Women in Network Science and the "Red Feminista de las Ciencias Sociales" [Feminist Social Science Network].

### **Senior Researchers**



### Angela Hassiotis

Psychiatrist with a PhD in Psychiatry. Professor of Intellectual Disability in the Division of Psychiatry at University College London (UCL). Honorary Consultant at the Camden Learning Disability Service, United Kingdom.

### Maribel Cruz

PhD in Disability Research. Full-time Research Professor at the Universidad Autónoma de San Luis Potosí, Mexico.

### María del Carmen Pérez

PhD in Nursing Sciences. Full-time research professor at the Universidad Autónoma de San Luis Potosí, Mexico.

### Elaine Acosta

Sociologist with a PhD in International and Intercultural Studies from the Universidad de Deusto, Bilbao. Associate Researcher at the Cuban Research Institute, Florida International University, and Executive Director of Cuido60.

#### Paula Miranda

PhD in Law and Business Administration, Universitat de Lleida, Spain. Associate Professor in the Faculty of Social Sciences, School of Social Work, Pontificia Universidad Católica de Chile.

#### Noelia Flores

Psychologist with a PhD in Psychology. Professor in the Department of Personality, Assessment, and Psychological Treatment at the Faculty of Psychology, Universidad de Salamanca.

#### Cristina Jenaro

Psychologist with a PhD in Psychology. Professor in the Department of Personality, Assessment, and Psychological Treatment at the Faculty of Psychology, Universidad de Salamanca.

### Juanita Hoe

Nurse with a PhD in Mental Health Sciences from University College London. Professor in Dementia Care at the Geller Institute of Aging and Memory, within the School of Biomedical Sciences at the University of West London.

### Andrés Losada

Psychologist with a PhD in Clinical Psychology. Professor of Psychology and Coordinator of the Doctoral Program in Psychology at the Universidad Rey Juan Carlos, Spain.

## **Adjunct Researchers**



### María Soledad Herrera

Sociologist with a PhD in Sociology from the Universidad Autónoma de Madrid. Faculty member at the UC Institute of Sociology.

### María Florencia Herrera

Sociologist with a PhD in Social and Cultural Anthropology, Universidad de Barcelona. Associate Professor at the School of Sociology, Universidad Diego Portales.

### Pablo Marshall

Bachelor of Legal and Social Sciences with a PhD in Law from the University of Glasgow. Pro-Dean of the Law School of Universidad Austral de Chile.

### Rodrigo Cádiz

Civil Engineer with a BA in Music and a PhD in Music Composition from Northwestern University. Professor at the Pontificia Universidad Católica de Chile.

### Pablo Villalobos

Business Administration with a PhD in Public Health from Harvard University. Independent consultant.

### Stella-Maria Paddick

Psychiatrist and Clinical Associate Professor at the Institute for Aging and Health, Newcastle University.



### Young Researchers



### Herminia Gonzálvez

PhD in Social Anthropology and Cultural Diversity, Universidad de Granada. Faculty member and Researcher at Universidad Central de Chile.

### Daniel Muñoz

Sociologist with a PhD in Human Geography from the University of Edinburgh. Postdoctoral researcher, Instituto de la Vivienda [Housing Institute], Universidad de Chile.

### Bárbara Flores

PhD in Economics, University College London. Postdoctoral researcher at the Center for the Study of Conflict and Social Cohesion (COES) and the Millennium Nucleus in Social Development (DESOC).

### Antonia Echeverría Ruiz-Tagle

Occupational Therapist and MA in Health Administration and Management, Universidad de los Andes. Faculty member at the School of Occupational Therapy, Universidad de los Andes.

### Maryam Farhang

Psychologist with a PhD in Psychology. Faculty member of the School of Health and Social Sciences, Universidad de las Américas.

### Cristián Rodríguez

BA in Philosophy and Psychology. PhD in Scientific Psychology, University of California Irvine. Assistant Professor, School of Psychology, Universidad de los Andes.

### Maryam Farhang

Psychologist with a PhD in Psychology. Faculty member of the School of Health and Social Sciences, Universidad de las Américas.

### Jorge Browne

Geriatric physician with a MA in Public Health (MPH) and an MPhil in Epidemiology. Faculty member in the School of Medicine, Pontificia Universidad Católica de Chile.

### Sebastián Rojas

Social psychologist with a PhD in Sociology from King's College London. Researcher in the Psychology department at Universidad Andrés Bello.

### Déborah Oliveira

Nurse with a PhD in Aging from the University of Nottingham. Researcher and consultant in the fields of long-term care, dementia, geriatrics, and stigma.

### María Alejandra Inostroza

Social Worker with a PhD in Management Sciences from the Universidad de Santiago de Chile. Assistant Professor at the School of Social Work, Pontificia Universidad Católica de Chile.

### Camila Sabat



Psychologist with a MA in Psychology from New York University. Director of the master's program in Pediatric Neuropsychology at the Universidad de los Andes.



### **Undergraduate Students**

- José Tomás Ahumada | Line 4
- Nicolás Alfaro | Line 1
- Perla Arrué | Line 2
- Itzel Briano | Line 3
- Catalina Carballeda | Line 1
- Diego Echaíz | Line 1
- Renata Garibaldi | Line 3
- Antonia Gautier | Line 3
- Camila Hernández | Line 3
- María Isabel Ibarra | Line 3
- Carlos Ortega | Line 3
- Eloísa Ortúzar | Line 3
- Magdalena Pinto | Line 3
- Camila Salinas | Line 3
- María Ignacia Silva | Line 3
- Alessandra Trapp | Line 3
- Yael Vargas | Line 1
- Natalia Zipper | Line 1

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### **Graduate Students**

- María Ignacia Azócar | Line 2
- Magdalena Calderón | Line 4
- Beatriz Carrasco | Line 2
- Ketty Cazorla | Line 3
- Luciana Cerna | Line 4
- Carolina Cornejo | Line 1
- Katherine Exss | Line 3
- Félix González | Line 3
- María Camila Guillén | Line 3
- Constanza López | Line 3
- Paulina Lorca | Line 1
- Alba Lozano | Line 2
- Eduardo Marchant | Line 3
- Diego Neira | Line 1
- Natalia Núñez | Line 3
- Catalina Pieper | Line 3
- Thamara Tapia | Line 2
- Solange Vallejos | Line 2
- Gonzalo Varas | Line 4
- Paula Vega | Line 2



### **Executive Team**

Javiera Gutiérrez | Executive Director.

Public Administrator from the Universidad de Chile, with a MA in Social Work from the Pontificia Universidad Católica de Chile.

**Raffaela Carvacho** | Research Coordinator.

Psychologist from the Pontificia Universidad Católica de Chile, with a MA in Health Psychology from the same university, specializing in psychogerontology.

Gabriela Campillo | Communications Director.

Journalist, with a BA in Social Communication from the Pontificia Universidad Católica de Chile and a MA in Digital Media, Culture and Education from University College London, UK.

**Franci Llanes** | Administration and Finance Coordinator.

Public Accountant from the Universidad Cooperativa de Colombia.

Isabel Arteaga | Executive Assistant.

Bilingual Executive Secretary, Instituto de Secretariado (INSEC)

## Spokepersons' Office



Carolina Lucero | Intellectual Disability Spokesperson.

Researcher Cognitive Accessibility at Pontificia Universidad Católica de Valparaíso and a validator at "Lectura Fácil Más Accesible" [More Accessible Easy Reading].

Ricardo Pizarro | Intellectual Disability Spokesperson.

Validator in Easy Reading at the Universidad de los Andes and Spokesperson for the Advisory Council on Mental Health at the Ministry of Health of Chile.

Gonzalo Osorio | Intellectual Disability Spokesperson.

Researcher in Cognitive Accessibility at the Pontificia Universidad Católica de Valparaíso.

Felipe Pierret | Intellectual Disability Spokesperson.

Self-advocate in intellectual disabilities and representative of the group of people with intellectual disabilities.

### Teresita Lira | Dynamizer.

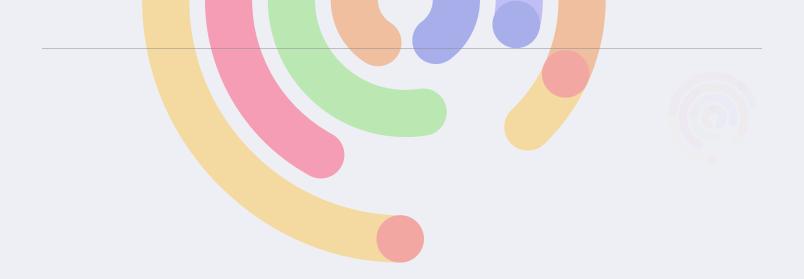
Psychologist with a MA in Disability Inclusion from University College London. She was a Dynamizer for much of the year 2022 and we are very grateful for all her work.

### Florencia Villaseca | Dynamizer.

Psychologist from Universidad Adolfo Ibáñez, specialized in the clinical field and in working with adolescents and adults with intellectual and developmental disabilities.

Florencia joined the team in October 2022 as a Dynamizer. You are most welcome!





## WORK IN OUR LINES OF RESEARCH

## Line 1. Sociocultural aspects of care and life perspectives

### Lead Researcher: María Beatriz Fernández

The main objective of this line of research is to characterize and study how care can increase the economic and social vulnerability of carer women, as well as undermine their physical and mental health.

### **Specific objectives:**



Characterize carers in terms of sociodemographic, economic, labor, physical and mental health variables, social support, use of time, care tasks provided, among others. Establish typologies of carers, according to the type of activities carried out, type of person cared for, among others.



Establish typologies of carers, according to the type of activities carried out, type of person cared for, among others.



Determine how care can increase the economic and social vulnerability of carer women, as well as impact their physical and mental health conditions.



Establish a general overview of the scope of policies and programs currently existing in the country about care.

This year, progress has been made with respect to all the objectives of this line.

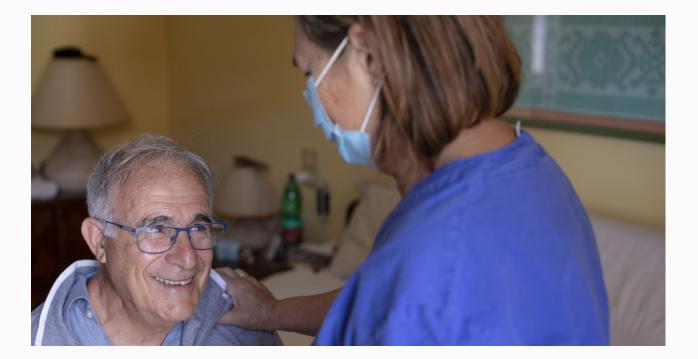
In relation to Objective A, the project led by our Associate Researcher, Beatriz Fernández, FONDECYT 11180287 "**Religiosity and subjective wellbeing of elderly people in Chile**", has been successfully completed, resulting in two publications in 2022. Its results contributed to the knowledge about the importance of religiosity as a protective factor for the health of older people.

Another project within this line, titled "Vivir cuidando: un estudio sobre redes de cuidado de personas mayores" [Living while caring: a study on care networks for older adults] and led by our postdoctoral researcher Francisca Ortiz with the support of Beatriz Fernández and our student Natalia Zipper, has successfully completed the data collection phase, and its preliminary analyses have already been presented at international conferences. This project has contributed to the progress of objectives A and B.

Regarding Objectives A and C, the FONDECYT project "Género y vejez: una etnografía sobre la organización social y moral de los cuidados en la comuna de Peñalolén de Santiago, Chile [Gender and aging: an ethnography on the social and moral organization of care in the Peñalolén commune of Santiago, Chile]" (1201115) continues its development, under the leadership of our Young Researcher Herminia Gonzálvez and with the participation of our student Paulina Lorca. This study aims to analyze issues related to care practices and the experiences of receiving care in individuals living in the Peñalolén commune. This project is currently in the process of article writing and will be concluded by October 2023.

Regarding Objectives A, B, and C, this year a new FONDECYT project titled "**Personal networks and social capital of female carers**" (1230437) was designed and awarded. The lead researcher is Beatriz Fernández, and the co-investigators are María Soledad Herrera (adjunct Researcher), Herminia Gonzálvez (Young Researcher), and Francisca Ortiz (Postdoctoral Researcher). The study involves the collection of primary data on the personal networks and social capital of women carers. Changes over time and the impact of both variables on the well-being and health of this group will be measured. Surveys will be conducted in 3 waves and interviews with women carers over 4 years, from 2023 to 2027.

During 2022, Beatriz Fernández and our Young Researcher Bárbara Flores were granted access to the Social Information Registry (RIS), which belongs to the Ministry of Social Development and Family of



Chile. With access to this registry, the researchers began the project "Geografía de los cuidados de personas mayores dependientes en Chile: Análisis espacial de necesidades, infraestructura y proveedores de cuidados [Geography of care for older people with dependency in Chile: spatial analysis of needs, infrastructure and care providers]". The purpose of the study is to analyze the availability and need for care of older people with dependency in the country, as well as to geographically locate them while considering access gaps and the well-being of the individuals involved. It is expected that this project will contribute to the progress of all the objectives of the line.

This year also marked the beginning of a project to develop a **Map of the care programs and policies available in Chile**, with the support and guidance of CEVE UC researcher Sara Caro, in collaboration with Dr. Beatriz Fernández. This project will create a systematic overview of the existing care services in our country, a much-needed task given the various changes that have taken place in care policies within the country. It is expected that this project will yield tangible outcomes next year, representing significant progress towards Objective D.

Our collaboration network with the project "CUIDO60, Observatory of Aging, Care and Rights", has remained active. Our Senior Researcher, Elaine Acosta, continues to serve as its executive director, and our director, Claudia Miranda, is a member of the observatory's Advisory Council. This year, a collaborative publication between Cuido60 and MICARE has been in development, with an expected release in 2023. In addition, a Cuido60 book will be published next year, co-authored by Line 4 researchers. We would also like to highlight that this year, Young Researcher Sebastián Rojas joined us as the lead researcher of the study "**Caring cities: urban spaces, care and well-being**". This is a part of a FONDECYT project (1231796) that is scheduled to begin implementation in 2023. The project will contribute to Objectives A and D, and its goal is to explore the concept of child-friendly cities by examining spaces created for the well-being and care of children.

Finally, we would like to mention the award obtained by Dr. Fernández in recognition of her contributions to the Conference "Sistema de Cuidados con Enfoque de Género: Experiencias y desafíos [Gender-focused care system: experiences and challenges]", organized by the Observatory for Citizen Participation and Non-Discrimination of the Ministry General Secretariat of Government.



In summary, Line 1 has made satisfactory progress this year. Regarding the MICARE study, where Line 1 plays a coordinating role, challenges were identified in achieving a probability-based representative sample. As a result, adjustments have been made to the methodology to address these challenges. The final methodology of the study will be described in greater detail in the section titled "MICARE Study."

# Line 2. Informal and formal care of older people with dependency

### Lead researchers: Claudia Miranda and Alejandra Araya

This line of research investigate psychosocial aspects of care, considering both the perspective of those who care for older people with dependency and other contextual factors. Its aim is to gather information to design and evaluate suitable interventions for informal and formal carers, and older people.

### Specific objectives:



Determine what are the needs and positive aspects of care from the perspective of informal and formal carers of dependent older people.



Design interventions focused on enhancing the positive aspects and reducing the needs identified by informal and formal carers that allow them, on one hand, to carry out a better care work; and on the other, to improve their well-being and quality of life, and, indirectly, indirectly benefitting the dependent older person.

Progress has been made related to Objective A through the FONDECYT project 1191726, titled "Trajectories and predictors of depressive and anxious symptomatology in family carers of people with dementia: a longitudinal study ", led by our Associate Researcher

and Director, Claudia Miranda. This project aims to identify trajectories of depressive and anxious symptomatology in family carers of people with dementia, and thus determine the profiles of family carers who are more vulnerable to present trajectories with increasing levels of depressive and/or anxious symptomatology. This study has a baseline of 301 participants, and data collection for its second and third waves is currently being concluded.

Further progress regarding Objective A has been made within the framework of the project "Use of technologies in informal carers over 60 years old and its impact on their psychological well-being: differences and similarities with informal carers under 60 years old and non-caregiving older people", which is led by our postdoctoral researcher Javiera Rosell, in collaboration with Associate Researchers Claudia Miranda and Alejandra Araya. This study aims to describe the internet usage among older people and identify factors influencing this behavior. To achieve this objective, a quantitative analysis was conducted this year using data extracted from the latest National Socioeconomic Characterization Survey (CASEN). Next year, a qualitative data collection and analysis phase will be carried out, exploring how older carers use the technology and perceive its benefits.

Regarding Objective B, we highlight three projects:

Antonia Echeverría, our Young Researcher, is the director of the FONIS project SA2010097 "Transcultural and statistical validation in the Chilean context of the VIDA Questionnaire, a tool for the early detection of functional impairment and prevention of dependence in older people". In addition, one of the co-investigators of the project is our adjunct researcher Pablo Villalobos. This year, the process of transcultural validation of the instrument was completed, and an initial pilot study was conducted. We would like to highlight the financial support provided to the researcher to travel to Spain and meet with her co-investigator and author of the original instrument, Dr. Iñaki Martín Lesende, as well as to present her results at the 18th International Congress of Occupational Therapy.

The FONDECYT 3190275 project titled "Adaptation, implementation, and evaluation of the effectiveness of a mindfulness-based yoga intervention for older adults with mild cognitive impairment" is led by our Young Researcher, Maryam Farhang, in collaboration with Claudia Miranda. The objective of this study is to assess the effectiveness of the YBM intervention compared to a control group receiving a psychosocial intervention. This year, the protocol for implementing the randomized clinical trial was published and progress was made in the follow-up process of the first cases.

The study that led to the psychoeducation program "**Take Care Taking Care**" developed by Claudia Miranda in collaboration with our Senior Researcher Andrés Losada, is in its final stage, and we plan to publish the results next year. The educational materials developed within the framework of this program have been used to further train healthcare professionals who wish to enhance their skills in providing support to carers in both Family Health Centers and Memory Centers. In the same vein, Dr. Miranda conducted a large-scale training session with healthcare professionals from across Chile through the Ministry of Health's "Digital Hospital" program. This training focused on enhancing professionals' competencies to support informal carers from a personcentered care approach. Similarly, Dr. Alejandra Araya conducted another training session for nursing professionals from different hospitals across the country through the Digital Hospital program. She also organized a training course for Nursing Technicians at El Carmen Hospital in collaboration with Universidad Andrés Bello. In conclusion, Line 2 has made significant efforts to apply their expertise for the benefit of other sectors of society, particularly in the fields of healthcare and public services.

Regarding collaboration between research lines, Lines 1 and 2 share several projects. Among these, the FONDECYT 1220936 project titled "Isolation and loneliness in older people: determinants and consequences in their quality of life" has made significant progress this year. This study is led by Dr. María Soledad Herrera, adjunct Researcher of Line 1, in collaboration with Associate Researchers Beatriz Fernández, Claudia Miranda, and Alejandra Araya. The project has already completed its first phase of data collection through qualitative interviews, and next year it will proceed to its second phase using quantitative data.

During this year, Lines 1 and 2 also implemented the "**Study on the Labor Market and Skills for the Care of older people with dependency in Chile: towards a model of Training, Qualification and Labor Intermediation for Carers of older people in Chile**". This project is led by Dr. Beatriz Fernández, in collaboration with Drs. Claudia Miranda and Alejandra Araya, and was jointly developed with CEVE UC. The institutions that commissioned the project were the National Older People Service (SENAMA) and the National Training and Employment Service (SENCE), with the intermediation of the OTIC Proforma agency. As a result of this study, recommendations were formulated to improve the training options for both formal and informal carers in public services. These recommendations include proposals on how to connect carers to the job market and enhance their working conditions.

Both lines also collaborate with CEVE UC in the implementation of the "**Diploma in Comprehensive approach to caring for older people**". Dr. Beatriz Fernández leads this training program, and most of the teaching staff comprises researchers from both lines.

We also wish to emphasize the accomplishment of our director, Claudia Miranda, who was included this year in the list of the top 2% of most cited scientists globally. This ranking is based on bibliometric information from the Scopus database, which covers over 200,000 active researchers worldwide, classified into 22 disciplinary fields and 176 subfields. Dr. Miranda stands out in the field of Geriatrics, where she was the second most cited author in Latin America.



Lastly, it's worth noting that we have welcomed new members this year: Young Researchers Jorge Browne and Déborah Oliveira, adjunct Researcher Stella-Maria Paddick, and Senior Researchers Juanita Hoe and Andrés Losada. We are pleased to have these new experts in care topics, who contribute to their understanding from fresh perspectives, expanding our networks at both national and international levels.

# Line 3. Care versus companionship in the context of intellectual and developmental disabilities (IDD)

### Lead Researchers: Marcela Tenorio, Paulina Arango and Vanessa Vega

In this line, we seek to understand positive aspects, tensions and dilemmas faced by families and other stakeholders who accompany children, youth, and adults with intellectual and developmental disability (IDD) in their daily lives. We strive to promote the design of training programs that allow for the full exercise of rights and the effective participation in society of this group of people and their families.

#### Specific objectives:



Comprehend the main needs and positive aspects perceived by carers and/or companions of people with IDD, considering personal and sociocultural variables.



Characterize, from the voice of those who accompany people with IDD, their attitudes towards the condition, towards people with IDD, and towards state agencies and current public policies.



Design, test and disseminate a training program that allows a better accompaniment to people with IDD, incorporating the human rights approach in this matter. This year, we have made progress in all our objectives, especially in B and C, by starting several projects focused on understanding the needs of specific groups, with the aim of creating tailored interventions to meet those needs.

The FONDECYT 1221400 project "Paving the way for autonomy: An interdisciplinary approach to the relationship between early interactions and adaptive behavior in infants with Down Syndrome (DS)" is led by our Associate Researcher, Marcela Tenorio, in collaboration with Dr. Paulina Arango and Dr. Andrés Aparicio. The aim of this study is to analyze the connections between interactions established by parents of babies with Down syndrome and how they influence the development of their adaptive behaviors, and thus develop a comprehensive model to design a multilevel intervention program that can enhance the quality of life of these families. In 2022, the team of assessors underwent training in the application of the MACI (Manchester Assessment of Caregiver-Child Interaction) instrument. We have achieved the recruitment target for the group of babies with Down syndrome and their parents, reaching a total of 163 families, and the intervention design has been completed, with its implementation starting in July 2023.

We have also made progress in the implementation of the FONDECYT 1221349 project "Parenting children and adolescents with intellectual disabilities (ID): Mixed-methods study of the relation between parental attitudes and mental health, and the child's challenging behaviour from a transactional approach". This project is led by our Associate Researcher Paulina Arango, in collaboration with Dr. Tenorio. With the assistance of various organizations and schools, we have evaluated 100 families across the Valparaíso, O'Higgins, Bío-Bío, Araucanía, and Metropolitan region. We expect to enlist families from different regions in 2023.

Both projects are part of a broader initiative called "Interacciones Cuidadosas" [Caring Interactions], resulting from the collaboration and efforts of Lines 3 and 4. This initiative aims to create a virtual space to facilitate the transfer of quality knowledge to communities and families of individuals with IDD, as well as to promote interactions among these communities. It has received a favorable response from the public and we are pleased to announce that we will have a website next year.

Lines 3 and 4 also collaborate in the FONDEF IT2110065 project "**PICTOS**: **A progressive web application for navigation and evaluation of the cognitive accessibility of services in Chile**". This project is led by the Nucleus of Accessibility and Inclusion of PUCV and involves the collaboration of our Associate Researchers Vanessa Vega, Marcela Tenorio, and Andrés Aparicio. This project aims to enhance the cognitive accessibility of public services (both physical and digital) through a web application and an accessibility assessment model. Its goal is to facilitate access and inclusion for the entire population to these services.

We would also like to highlight the FONAPI project P14191-2021 - P14188-2021 - P14229-2021 titled "**DiscaPaís**", which was implemented this year in 12 regions of Chile. This is an inclusive territorial participation program for people with disabilities and their families. As part of this program, workshops were conducted for leadership training; a digital application was created containing information about available services for people with disabilities and the people around them; and a collection of children's and youth stories was developed with the goal of providing leadership tools to girls, boys, and young people with disabilities. The project was led by Marcela Tenorio, Andrés Aparicio and Paulina Arango (Associate Researchers), along with Pablo Marshall and Florencia Herrera (Adjunct Researchers).

Additionally, our postdoctoral researcher Juan Pablo Robledo is developing the project "**Characterizing patronizing speech directed at persons with intellectual disabilities**". This study explores the speech of informal carers towards adolescents with Down syndrome, examining the presence of condescending or infantilizing speech. Data collection has been completed, comprising a sample of 50 mother/parent/ guardian-adolescent dyads. The first round of analyses is currently underway. Preliminary results indicate that carers' speech indeed often includes characteristics traditionally associated with speech to babies. A brief online data collection study will be conducted to eliminate the possibility of any confirmation bias.

The project FONDECYT 1190789 "New challenges for education in Chile: support for independent living of adults with intellectual or developmental disabilities (IDD)" is also being developed. Vanessa Vega is the lead researcher, with the participation of students Felix Gonzalez and Katherine Exss. Based on an inclusive research model, using a qualitative paradigm and a sociocritical approach, the project examines the needs and support opportunities for independent living of adults with IDD. The goal is to create or enhance resources and/ or technological strategies that improve the lives of this group in the dimensions of interdependence, rights, and autonomy. This year, five functional prototype support devices have been developed to enhance independent living in the areas of organization, leisure spaces, romantic relationships, care, and self-care.

Dr. Vega also leads the study "**Researching Together**", a project comprised of a group of researchers with and without intellectual disabilities, including our student Constanza López and our expert by experience, Carolina Lucero. This group is dedicated to research and scientific dissemination related to gender, disability, and human rights issues.

Dr. Vanessa Vega also is co-researcher in the FONDART project 587669 "How is literary reading and creative writing developed in people with intellectual disabilities (IDD)? One step further towards the Rights-Based Approach". Its main objective is to design and disseminate an educational model that promotes the enjoyment of reading and literary creation, empowering individuals with ID and transforming their relationship with literature. The design phase has



been completed, and the project is expected to be concluded next year.

Furthermore, this year, Cristián Rodríguez was welcomed as the new Young Researcher for Line 3. With the support of MICARE and UAndes, Dr. Rodríguez began the project "**Perceptions and attitudes regarding the termination of pregnancy and the identification of Down syndrome**". This project involves the development of three studies aimed at understanding the general population's attitudes towards voluntary pregnancy termination after a prenatal diagnosis of physical, intellectual, or non-lethal congenital disabilities. Through data collection, our aim is to uncover implicit assumptions that individuals hold about the lives of those with disabilities, and also to evaluate the extent to which the state is fulfilling their needs.

Finally, we would like to mention some of our partnerships with other institutions, which we will briefly describe below:

This year we have closely collaborated with the Servicio Nacional de Protección especializada a la Niñez y Adolescencia [National Service for the Protection of Children and Youths], also called "**Mejor Niñez**" [Better Childhood], in training courses for their staff.

The project "**Cuida2**", which is supported by Fundación Isabel Aninat, continues evaluating the effectiveness of our program of manualized training for carers who provide company to people with IDD. This year we have advanced in the implementation of the program to 60 carers in the city of Concepción.

We are also please to highlight the labour of Lines 3 and 4 in the

implementation of the project DiscaPaís with the support of the Servicio Nacional de la Discapacidad (SENADIS) [National Disability Service].

On the other hand, it makes us proud to announce that our Alternate Director, Marcela Tenorio, has been given an award for her academic career, during which she has developed innovative research of high social relevance. This award, called "**Research Excellence Award**", was given by Universidad de los Andes, one of our host universities.

In general, this year we have been able to progress satisfactorily in the achievement of both Objectives B and C. However, in relation to Objective B, we hope to advance more next year once we have data from the MICARE Study. Moreover, we are working to understand better the perspectives of formal carers of people with IDD through qualitative studies that have already been planned and will be carried out next year.

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### Line 4. Technology and Care



#### Lead Researcher: Andrés Aparicio

The objective of this line is to explore the relationship between technology and care, to design and implement technological tools to support the care process that respond to the needs, expectations, and possibilities of the care dyad.

#### Specific objectives:



Characterize, from the position of the dyad, the current forms of use of technology in care, the expectations associated with such use, the criteria that determine good practices in the use of technology, and the main needs for technological support in the process of care.



Design, test and implement technological tools to support the care process, considering the expectations, needs, and good practices identified.



Generate a Manual of Good Practices for the use of technology in care according to the characteristics of the dyad, expected results, and main users.

During this year, we have developed many new projects that provide an answer to the needs identified previously in 2021, thanks to the work of Dr. Andrés Aparicio, Associate Researcher who leads Line 4. Regarding Objective A, new initiatives have been developed, which will be described below:

The project "Experiencias y necesidades de personas cuidadoras: bienestar, servicios de apoyo y tecnología" [Experiences and needs of carers: wellbeing, support services and technology] has as main objective to understand the experiences and needs of carers of people with dependency, their relationship with public or private services, and the use of technology in the provision of care. Based on this data, we hope to come up with suggestions and proposals for the improvement of public policy, and to gather relevant information that can guide future research.

On the other hand, the study "Asistencia y ausentismo en educación especial" [Attendance and absenteeism in special education] describes the patterns of attendance and absenteeism associated to special education in Chile and compares them with the patterns in regular education. Afterwards, we aim to determine the possible sources of the identified differences in order to provide evidence which can inform decision-making in public policy related to Preferential School Subsidy.

Furthermore, we have strengthened our collaboration with the drama group El Otro Cuerpo in the implementation of the project "Toward a poetics of Otherness: Theatrical projects integrated by artists with functional diversity". The project aims at identifying the drama groups formed by performing artists with functional diversity in Valparaiso and Santiago, as well as analyzing their resources, discourses, and contributions to contemporary theatre as modes of an emerging poetics that involves crossing points with care, accessibility, and social participation.

This year, the Young Researcher Daniel Muñoz completed his postdoctoral project titled: "Las movilidades cotidianas de la discapacidad: corporalidad, accesibilidad y sistemas de transporte público" [Everyday mobilities of disabilities: corporeality, accessibility and public transportation systems], from which qualitative and audiovisual data were generated based on the experiences and contradictions suffered by people with disabilities in the public transportation of Santiago, Chile. Furthermore, Dr. Muñoz designed and was awarded the FONDECYT project 3230574 "Cuidar en movimiento: repensando infraestructuras urbanas para relaciones de interdependencia en el caso de personas con discapacidad visual" [Care in motion: rethinking urban infrastructures for interdependent relationships in the case of visually impaired people] as Lead Researcher and will start its implementation in 2023. In this study, the participants will be the cocreators of the project, understanding from ethnographic methodologies how carecan emerge in interdependent relationships through the everyday routes of visually impaired people.

Regarding Objective B, many digital innovations are being developed, among which the following stand out:

The project "Audiographics: sonification for accessibility of quantitative information in graphic format" aims at implementing a web tool to transform quantitative information in graphs of websites to audio, in order to provide access to information of visually disabled people using sonification techniques and AI image analysis.

We are developing "**Dialectdown**", a digital platform to support people with Down syndrome who are learning to read. This system gathers data related to each learning process in order to guide curricular changes and support interventions using consolidation and data analysis techniques. In this project, we collaborated with Fundación Complementa and the Centro de Innovación e Investigación en Lectura (CIIL) [Center for Reading Innovation and Research] of Universidad de los Andes.

We are also collaborating with the CIIL in the FONDEF ID21110196 "Leer+: Mejorando la comprensión, vocabulario e interés por la lectura" [Reading+: increasing reading comprehension, vocabulary, and interest in reading]. This project aims at validating and improving the Leer+ platform. This is a customized and self-managed exercise system, which adapts to the basic reading level of the students. By reading texts and answering comprehension and vocabulary questions, students can improve their reading level.



Furthermore, in Line 3 we are developing a Platform for the management of text creation and adaptation within Lectura Fácil [Easy Reading], in order to provide support to the process of creation and adaptation of texts into Easy Reading using artificial intelligence to generate texts and providing a validation flow through cognitively accessible interfaces.

Other projects contributed to Objectives A and C:

The "**Propuesta de Articulación socio-tecnológica para la Red Local de Apoyos y Cuidados (PRLAC)**" [Proposal for a socio-technological articulation for the local network of support and care] is a project funded by the Public Policy Contest UC. The study included Associate Researcher Andrés Aparicio, Senior Researcher Paula Miranda, Young Researcher Alejandra Inostroza, and student Gonzalo Varas. The project brought in participants from local, regional, and national governance, along with the civil society and the academia. A diagnosis of the needs was prepared, as well as recommendations aimed at distributing better the resources of the program, which include innovative proposals to allow the network to benefit from technology. The results were presented to the public and the coming year a book will be published with all the data from the project.

This year we also started the implementation of the study "**Uso de tecnología en la práctica cotidiana del cuidado**" [Use of technology in everyday care], which analyses the experiences of carers using technology when giving care to people with dependency through the adoption of a participative and creative methodology that uses photography as a means to express ideas and perceptions. In Line 3, we are working on a systematic revision titled "Factores que conducen a intervenciones efectivas de promoción de la participación social para personas con discapacidad intelectual" [Factors that lead to effective interventions in the promotion of social participation of people with intellectual disability], whose objective is to identify and classify the factors associated to interventions that will increase social participation of people with IDD and to develop a set of best practices for future interventions.

A project that contributes to all the objectives of the line is the "Programa Ayudas Técnicas desde la Economía Circular para una transformación de la Economía del Cuidado (PATECC)" [Program of technical support from circular economy for transforming care economy]. Its objective is to implement a sustainable and decentralized system for buying, developing, and repairing technical support and a replicable model that promotes circular economy and community involvement in order to improve access to technical help and transform care economy in the region of Coquimbo, in collaboration of the Regional Direction of SENADIS and the civil society.

We are pleased to note that this year our Associate Researcher, Andrés Aparicio, was given the Excellence Award for Doctoral Thesis in Arts and Humanities. His thesis, titled "**Still bodies: a disability-informed approach to stasis in theatre**", studies in an innovative way the participation of still bodies in the theatre, understood as an instance of participatory sense-making.

Finally, we would like to mention that we are in the process of establishing new collaboration networks with various organizations,

which will allow us to increase our scope and find more people interested in participating in our studies. Moreover, this year we received with enthusiasm our new Young Researcher, María Alejandra Inostroza, who is already collaborating in various project and has proved to be a valuable addition to our team.



# MICARE STUDY

An Executive Committee was created, formed by Associate Researchers Beatriz Fernández, Alejandra Araya, Andrés Aparicio, and Claudia Miranda, with Dr. Fernández as the project Director. The role of the Committee was to implement the technical planning, taking into consideration the opinions of all the other MICARE researchers. As such, he had the responsibility to review the questionnaires developed by the Department of Social Studies of the UC (DESUC) and the estimation of the sample, with the contribution of our consultant Carolina Casas-Cordero, who prepared the terms of reference for the samples.

#### The objectives of the MICARE Study are:



Collecting empirical information on the experiences of carers who provide support in everyday activities or assist in the decision-making of people with intellectual (IDD) and developmental disability, and older people with dependency (OPD) who need it.



Understand positive aspects as well as dilemmas faced by carers/companions of OPD and people with IDD to promote the design of training programs focused on rights and social validity.

### To achieve these objectives, we have developed four instruments:



Cross-sectional Survey for Institutional Carers of Older People with Dependency (OPD).



Cross-sectional Survey for Institutional Carers of People with Intellectual and Development Disability (IDD).



Longitudinal Survey for Home Carers of Older People with Dependency (OPD).



Longitudinal Survey for Home Carers of People with Intellectual Disability and Other Development Conditions (IDD).

The objective populations of the surveys for institutional carers correspond to individuals over 18 years old who work in long-stay facilities providing care services to OPD over 60 years old or support services for people with IDD of 0 or more years that regularly assist to these Centers. A total sample of 1,100 cases to be implemented in 4 regions of Chile (Coquimbo, Valparaíso, Biobío, and Metropolitan) is projected, divided in 550 ELEAM carers and 550 carers of IDD centers.

The home carers will correspond to individual older than 18 years who perform informal care tasks for OPD older than 60 years old or people with IDD of all ages who live in the same home or neighborhood (relatives, neighbors or friends). As in the case of the institutional carer survey, the instruments will be applied in 4 regions of the country (Coquimbo, Valparaíso, Biobío, and Metropolitan), collecting data in three waves between 2023 and 2025. We hope to begin with a sample of 1,100 informal OPD carers and 1,100 IDD carers in the first wave.

The collected data will offer a multidimensional characterization of carers, encompassing variables related to mental health, quality of life, social media, relationship with the care receiver, and other variables.

The implementation will start at the beginning of 2023 in collaboration with the consulting company "Feedback". This will be the first study of its type in Chile and Latin America, and we hope its results have a significant impact in the understanding of the needs and experiences of these groups.



# SCIENTIFIC OUTPUT

In the second year of MICARE, the number of published scientific articles doubled in comparison to the previous year, from 15 to 38. Of all the publications, 58% were published in index journals in WoS, 18% in Scopus 3% in Scielo, 13% were book chapters, and 8% were published in other types of indexations. From the total of articles indexed in WoS, Scopus and Scielo (79%), 30% were located in the first quartile, 20% in the second, 27% in the third, and 23% in the fourth.

A MICARE researcher or student is listed as first author in 63% of the publications, 27% has two or more authors from the Institute, and 18% has the participation of one or more students. Furthermore, we are pleased to note that more than half (61%) of the publications were open access.

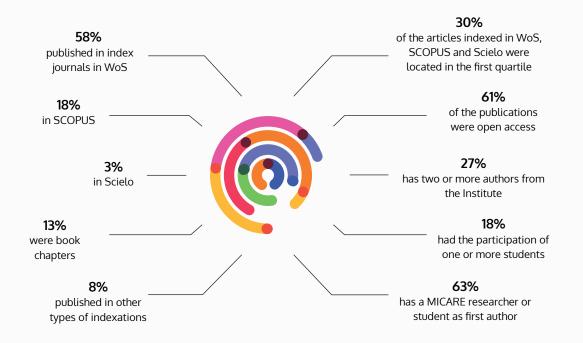


Figure 1. Summary of MICARE productivity during 2022.



### ACADEMIC LECTURES AND ORGANIZATION OF SCIENTIFIC EVENTS

A total number of 95 scientific lectures were delivered in different events, such as congresses, conferences, and seminars, among others. This productivity indicator far surpasses that of previous year, which was 14. Regarding its scope, 49% of them were presented in international events.

We also note the participation of MICARE in the XXXIII Latin American Congress of Sociology (ALAS for its Spanish acronym), in which 2 researchers and one student from Line 1 were involved, as well as 1 researcher and 2 students from Line 3. In this context of key dialogues about social research, our researchers and students positioned topics such as gender inequality in care and independent living of people with IDD.

We also want to show the strong participation of MICARE in the XXVI National Congress of Geriatrics and Gerontology, where 9 researchers of Lines 1, 2 and 4, and 4 students from Line 1, presented their work. This wide representation is a meaningful signal of MICARE's commitment towards the accelerated process of demographic aging in front of the scientific community and other involved actors, especially healthcare professionals, who constitute an important audience of this event.

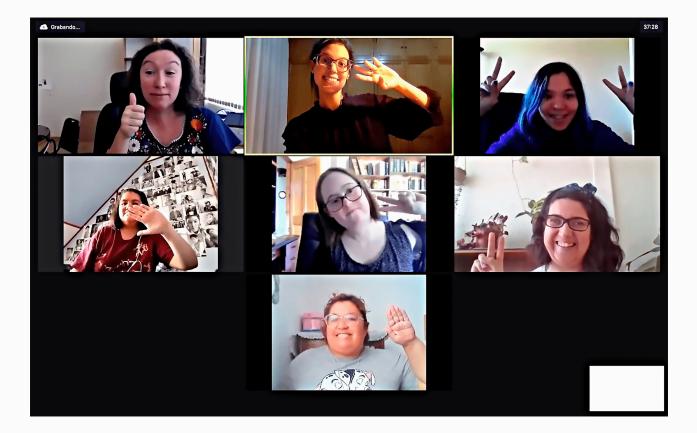
Another important lecture was given in the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD). The lecture was about the impact of early interaction in the development of adaptive behavior in toddlers with Down syndrome and atypical development. The head author and presenter was our Line 3 Postdoctoral Researcher Juan Pablo Robles, and the co-authors were our three Line 3 and 4 Associate Researchers Marcela Tenorio, Andrés Aparicio and Paulina Arango.

On the other hand, we highlight the participation of MICARE teams in the seminar "Justice and Disability", organized by Universidad Austral. Four researchers and two students from Line 3 and 4 presented there, offering a critical approach to the stigma towards people with disability and the low level of access to justice that they attain in our country.

We are pleased to inform that in the year 2022, MICARE organized 17 events that received a total of 745 attendees. The public was formed by carers, people who receive care, students, care activists, researchers, and health and social professionals. 13 of these events had national impact and 4 of them, international; 10 of these events took place online, 3 were face-to-face, and 3 were live-streamed.

The planning of these events involved co-organizing our lines of research, and we received the support of our Spokespersons' Office. Moreover, various events included the collaboration with the civil society. Among them, we highlight a virtual meeting with representatives of organizations that work with carers, older people with dependency and/or people with intellectual disability or other developmental disability from all parts of Chile. Many people attended the meeting, including 28 representatives of organizations from different parts of the country and researchers from all lines.

On the other hand, the organization of many events also included the collaborative work with other scientific institutions. Some of the coorganizers were the Centro de Estudios del Conflicto y Cohesión Social (COES) [Center of Study of Social Conflict and Cohesion], el Instituto Milenio para la Investigación en Violencia y Democracia (VIODEMOS) [Millenium Institute for Research in Violence and Democracy], Cuido60, la Red de Enfermería en la Salud de las Personas Mayores (REDESAM) [Nursing Network in Older People Healthcare], CEVE UC and our three hosting universities. These events were a first approach to collaborating with different organizations and allowed us to strengthen our position in the academy.





# **EDUCATION**

This year we gave priority to our commitment to develop advanced human capital for the country. Hence, in 2022 we launched our Mentoring Program with the goal of promoting academic, ethical, and professional development of undergraduate or graduate students dedicated to the study and research of care. Each one of them has the support of a researcher who acts as mentor, providing support and learning opportunities. Students perform different tasks within the research project of the Institute, acquiring practical experience in the process of data collection, analysis and/or presentation. As a result, many of them had the opportunity to represent MICARE in various scientific events, to participate in our publications, and to do internships and outreach activities.

We started 2022 with 4 students and we ended up with a total of 38, of which 18 were undergraduate students, 8 were MA students and 12 were PhD students. During the year, our students presented in 23 scientific events, were co-authors in 6 scientific publications of the MICARE Institute and participated in 6 articles for press media. Furthermore, 4 internships took place, and 3 theses were successfully defended. We are proud to mention that one of our students, Solange Vallejos, presented in the 6th International Conference on Healthcare and Nursing with the support of our Institute, and obtained first place in the oral presentation category for her lecture titled "Cuidado humanizado: análisis de la contribución de Jean Watson a la enfermería" [Humanized care: analysis of the contribution of Jean Watson to nursing].

As part of the development plan of the Mentoring Program, we organized collective monthly meetings that promoted internal collaboration and student learning. We began these activities with a lecture offered by Dr. Andrés Aparicio. A discussion between two senior researchers and a workshop with the two MICARE postdoctoral researchers took place. Furthermore, two online meetings were organized to provide students the chance of introducing themselves and show their projects for feedback and suggestions. These instances were highly appreciated because the dialogue included various methodological viewpoints and approaches. The participants of the Mentoring Program come from different disciplines, such as psychology, nursing, sociology, law, journalism, social work, design, speech therapy, and anthropology, among others. As a result, the meetings they had were very rewarding.

Moreover, with the aim of promoting relationships beyond the Institute, the Mentoring Program also started establishing links with other training organizations in the country. In 2022, we signed agreements with the UC Sociology PhD and with the Centro de Investigación en Educación Inclusiva de la Escuela de Psicología [Inclusive Education Research Center of the School of Psychology], and the School of Education of the Pontificia Universidad Católica de Valparaíso (PUCV). Furthermore, informal networks were developed with the PhD Program in Nursing Sciences of the Universidad Andrés Bello (UNAB), the UC MA Sociology Program, and the Millennium Nucleus to Improve the Mental Health of Adolescents and Youths (IMHAY). These partnerships enabled students interested in healthcare issues to become familiar and engage with our Institute. As a result, some of them participated in our collective training activities or even became direct participants in our Mentoring Program. At the same time, this provided MICARE students access to exclusive training activities of these organizations.

Finally, since most of the aforementioned collective activities were conducted online, we organized an in-person End-of-Year Gathering that brought together our students and associate researchers. This provided an opportunity for many of them to meet in person for the first time and also served as a platform for reflection, allowing the students to share their experiences and opinions about the activities carried out throughout the year. The results of this meeting were important feedback for the planning of next year's activities.

One of the challenges for the coming year is to systematize these experiences and develop a curriculum of knowledge around Care and basic skills, which each MICARE student is expected to achieve.





### FORMAL COLLABORATION NETWORKS

This year, we have established twelve collaboration agreements with different organizations, creating partnerships with a long-term perspective. These networks come from the private and public sectors, as well as from the scientific and civil societies.

In relation to public services, we highlight partnerships with three institutions:

We signed an agreement with the **National Service for the Protection of Children and Youths**. MICARE developed and offered courses for 70 professionals of this service, providing training n care and support for children and adolescents with IDD, with special emphasis on the full recognition of their rights.

In the same vein, the collaborations with the **Servicio nacional del Adulto Mayor (SENAMA)** [National Service for the Older People], which started in 2021, came to fruition this year through the "Estudio sobre el Mercado Laboral y Competencias para el Cuidado de las personas mayores con dependencia en Chile: hacia un modelo de Formación, Acreditación e Intermediación Laboral para Cuidadores de personas mayores en Chile" [Study on the Market and Skills for the Care of Older People with Dependency in Chile: Towards a Model of Training, Skill Development, and Job Placement for Carers of the Older People in Chile].

Likewise, we hope to continue collaborating with the **Servicio Nacional de la Discapacidad (SENADIS)** [National Disability Service], with whom we have already worked through DiscaPaís and their Regional Office in Coquimbo. We are working to formalize this collaboration through a signed agreement.

We are proud to collaborate with these national services, since they are of great relevance in the field of support for children, adolescents, and older people with some degree of disability or dependency. We will continue cooperating with these entities in the long term, as we aim to make meaningful contributions and to influence public policy.

Regarding the private sector, we emphasize partnerships with the following entities:

We have signed a collaboration agreement with **Fundación COANIL** [Intellectually or developmentally disabled Child Aid Corporation Foundation, COANIL for its Spanish acronym], with the objective of developing studies of common interest for the benefit of people with IDD and their families, according to the needs identified by COANIL. Furthermore, our Associate Researchers Marcela Tenorio and Vanessa Vega are members of the National Board of the foundation, contributing with their academic expertise.

Likewise, we have signed an agreement with **Fundación Geroactivismo** [Geroactivism Foundation], which is dedicated to promoting an integral approach to aging, fighting against agism through the dissemination of knowledge and outreach activities.

On the other hand, thanks to our partnership with the Colegio de Abogados [Chilean Bar Association], we have had the opportunity to work with the judicial power, developing training activities for judges and lawyers in order to improve the understanding of people with IDD within the legal system.



We also emphasize the initiation of formal collaboration networks with scientific research centers:

The **Centro de Gerociencia, Salud Mental y Metabolismo (GERO)** [Center of Geroscience, Mental Health and Metabolism] investigates the aging process by combining approaches from basic and clinical sciences, addressing phenomena from molecular to social factors. As such, GERO and MICARE share study areas and have signed an agreement to collaborate in these areas.

In a similar manner, the **Centro de Investigación para una Educación Inclusiva (EduInclusiva)** [Center of Research for an Inclusive Education] studies topics such as inclusion, quality of education and public policy in Chile, which means we have established a partnership that will strengthen us both.

Finally, we are pleased to announce that this year we have launched the **Red de Instituciones Cuidadoras** [Network of Care Institutions], from which we hope to generate and promote collaboration spaces that allow us to share information and knowledge, maintain dialogues, and invite and be invited to participate in events, training and research projects. The Network has a coordinator, Karen Fernández Pichara, and thanks to her efforts this Network has incorporated collaborating institutions such as:

- Centro de Apoyo al Síndrome de Down [Down Syndrome Support Center], also known as SENDAS.
- Interactivamente, Centro de Gestión de aprendizaje y alfabetización [Learning and Literacy Management Center Interactivamente].
- Fundación Chilena para el Síndrome de Down [Chilean Down Syndrome Foundation], also known as Complementa.
- Fundación Chilena para la Discapacidad [Chilean Foundation for Disability]
- Fundación Educativa Creatividad Aprendizaje & Innovación [Creativity Learning & Innovation Educational Foundation], also known as Fundación CAI.



### Other Collaborating Networks:

Some of our informal networks have been operating since the beginning of the Institute and will remain active next year. These are the institutions with which we have been working:

- CEVE UC is a center of interdisciplinary research dedicated to promoting quality of life for the older people. Together we have implemented many of the projects mentioned above.
- The Fundación Isabel Aninat [Isabel Aninat Foundation] is dedicated to support initiatives for care, education, and integration of vulnerable groups. In this context, they support the project "Cuida2" through an agreement with our host university, Universidad de los Andes.
- The Observatorio de Envejecimiento, Cuidados y Derechos, Cuid060 [Observatory of Aging, Care, and Rights], with whom we have strong collaboration links and common ongoing projects.
- We are collaborating with the Núcleo de Accesibilidad e Inclusión [Accessibility and Inclusion Center] of the PUCV in the implementation of the PICTOS project, mentioned above.
- In the same way, we continue working for the theatre company Otro Cuerpo Teatro e Investigación ["Another Body" Theater and Research].

On the other hand, this year we have established informal networks with new institutions. Among them we mention:

- The Centro de Estudios del Conflicto y Cohesión Social (COES) [Center for the Study of Conflict and Social Cohesion], with whom we share affinities in topics such as genre, human rights, and work.
- We have co-organized an event with the Red de Enfermería en la Salud de las Personas Mayores (REDESAM) [Nursing Network in Older People Healthcare], a national and international network that articulates the exchange of experiences, knowledge, and scientific evidence production in nursing in order to contribute with older people healthcare and care.
- The Millennium Institute for Research on Violence and Democracy (VIODEMOS), with whom we share common topics, such as the study of discrimination, gender, and human rights.
- We have started an informal network with the Millennium Nucleus to Improve the Mental Health of Adolescents and Youths (IMHAY for its Spanish acronym), with the goal of supporting each other in the training of our students and organizing joint activities for them.
- We have also initiated collaborations with the Institute of Design of the Umeå Universitet, to explore the possibility of doing joint research on food systems in the context of care.

- The Municipality of Huechuraba has made efforts to strengthen the service network for the older people in their commune. In this context, we have collaborated with them developing outreach activities.
- We are working with the Laboratory for Innovation for meaningful learning: Sôki, developing a new project titled "Interacciones Lingüísticas Tempranas" [Early linguistic interactions].
- In the same vein, we have developed connections with the Universitat Autònoma de Barcelona [Autonomous University of Barcelona] to train our team in the use of Piccolo, a method for coding early interactions.
- We also began working with Clínica Universidad de los Andes [Universidad de los Andes Clinic], creating a route of collaboration that will allow us to implement research projects within the context of the Clinic, both with its collaborators and with its users.



We are also pleased to have contributed to the design of the project **Millennium Nucleus Studies on Disability and Citizenship (DISCA for its Spanish acronym)**, thanks to the work of some of our researchers. This center will be officially inaugurated in 2023 and will address the construction of citizenship for people with disabilities in areas such as political participation, the exercise of sexuality and reproduction, and access to health, in addition to exploring the challenges of using inclusive and participatory methodologies in disability research. As such, this center will explore topics related to ours, and we hope to collaborate with them and sign an agreement next year.



## CONNECTION WITH OTHER SECTORS

As described in the previous sections on scientific output, the number of generated connections this year, totaling 38, is twice that of the previous year. This growth can be attributed to the efforts made during the first two years to engage with organizations from other sectors of society. As a result, we have been receiving spontaneous requests from many of them for knowledge transferring and consulting.

In regard to this, we have provided various free services to organizations of the civil society. These services were provided directly to healthcare and education professionals, as well as to informal carers. Among them we highlight:

- A course for nursing technical staff from El Carmen Hospital on care of the hospitalized geriatric patient.
- A training course for primary healthcare professionals in Santiago.
- A course given to teachers at Colegio Cumbres on how to support students with autism spectrum disorder.
- Training for professionals of the San Miguel Residence, which is part of the National Service for the Protection of Children and Youths.
- Training for professionals at the Nuble Health Service on how to promote self-care strategies in carers.

- Two extensive training sessions for healthcare professionals at the national level were conducted through the Ministry of Health Digital Hospital Program.
- Training for member of Fundación Complementa on parenting children with Down syndrome.

Some of the training sessions in the healthcare sector, such as those carried out in hospitals, primary healthcare centers, the Digital Hospital platform, and several other healthcare services, reached a great number of healthcare professionals throughout Chile. In this sense, we recognize the contributions of Line 2, led by our Director Claudia Miranda, and our associate Alejandra Araya, who have worked steadily to establish relationships of trust with the Ministry of Health and other public health entities. As a result, various services and healthcare centers turn to our Institute for knowledge transfer and guidance, enabling our Institute to fulfill its mission of contributing to the country through high-level knowledge transfer.

Another way of contributing to other sectors of our society is through the advice and consulting provided by our experts in various contexts, such as the following:

- Mesa Técnica Regional de Demencia [Regional Dementia Technical Committee]. Secretary of Public Health of the Metropolitan Region, Ministry of Health.
- Comisión Asesora en Demencia [Dementia Advisory Committee], Ministry of Health.

- Comité Asesor Centro de Investigación de Envejecimiento Saludable (CIES), Consorcio Universidades Estatales [Advisory Committee of the Center for Research on Healthy Aging, Consortium of State Universities].
- International Expert Advisory Group in the Living Alone with Cognitive Impairment Project (LACI).
- National Directory of COANIL.
- Advisory Council of CUIDO60, Observatory of Aging, Care and Rights.

It is also of special interest to us to contribute to the development of local policies. In this regard, Line 3 and 4 carried out intense work to influence some of the technical guides for the "Mejor Niñez" National Service, ensuring that the approach to care for children and adolescents whose rights have been violated is truly comprehensive.

On the other hand, it is a priority objective for our Institute to achieve greater financial autonomy by seeking additional sources of funding in addition to the funds provided by the Millennium Science Initiative. We are also interested in developing attractive products for the education and training market. During this year, we have advanced in this direction when by becoming, for the first time, a provider of a continuing education program for a state agency, the National Service for the Protection of Children and Youths. Our goal is to continue offering services of this type in the coming year and to continue expanding our partnerships in this area. We also want to strengthen the efforts of our researchers to influence public policy. For instance, many of our researchers have participated in various events to contribute evidence and play an informative role in the process of proposing a new constitution for Chile. Likewise, our challenge for the coming year is to actively participate in the proposal and development of a National Care System for our country.

We would like to highlight our Spokespersons' Office, formed by Gonzalo Osorio, Carolina Lucero, Felipe Pierret, and Ricardo Pizarro.

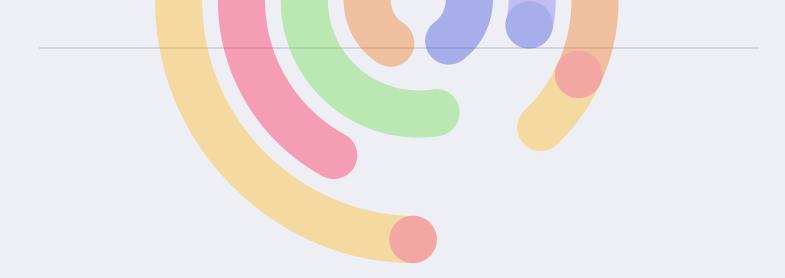


They are our Experts by Experience, who contribute to our research supervising and assessing the entire process, from data collection and analysis to how the results are returned to the community. They also play a role in educating communities from other areas. For example, this year they visited university schools to educate future health professionals about the challenges faced by people with intellectual disabilities in clinical care settings. However, its most important role is to represent the group of people with intellectual disability in the defense and promotion of their rights. For this, they participate in activities that influence in public policy through outreach activities and meetings with field experts. Among them, we highlight that this year Ricardo Pizarro became a member of the Mental Health Advisory Council of the Ministry of Health, which advises the authorities on the future Ley de Salud Mental Integral [Comprehensive Mental Health Law]. Another relevant achievement was the meeting held by Ricardo Pizarro, Marcela Tenorio, Paulina Arango and Claudia Aldana (Director of the Foundation "Una Escuela para Todos") with the Minister of Education, Marco Ávila, where they presented a document with demands related to the need for better school inclusion and support for the transition to independent adulthood for people with intellectual disabilities. In the same way, Gonzalo Osorio met with Daniel Van Sant, Director of Disability Policy in the Harkin Instituto (Universidad de Drake), to present the work of the Spokespersons' Office.

The Spokespersons' Office also has a Dynamizer who provides support to the work of the spokespersons. Since 2021, Teresita Lira has played an outstanding role in this function, contributing to the creation and consolidation of the office. As of October 2022, Florencia Villaseca has assumed these responsibilities. We would like to thank Teresita for her valuable work and wish her all the best, while we give the warmest welcome to Florencia.

In sum, we want to emphasize that our spokespersons play a key role in expanding our collaboration networks and connections with other sectors, both in academia and civil society. Therefore, we hope to continue to expand this office by adding new members from the group of carers and older people.





## PRESS AND SOCIAL MEDIA

Firstly, we consider it important that our communication strategy is consistent with our mission to develop inclusive research. This means that our information flow must not only be complete, close and empathic, but must also take into account the diversity of needs that our audiences may have. That is why we take pride in ensuring the highest possible accessibility on each of our communication platforms. This means including Easy Reading, alternative text, subtitles, graphical adaptability, and sign language where appropriate, as well as prioritizing physical accessibility in all our events.

As for this 2022, we are pleased to report that we participated in 42 outreach activities and generated 86 media publications, including regional, national, and international media. This year we also launched the podcast "Cuidando", which allows us to explore less traditional ways of communicating our content. In the podcast, different topics related to careare discussed from different perspectives, and from the voices of national and international experts.



Regarding our social media, this year we have been able to reach more than one million people, with more than 7,700 followers, and we have been able to obtain more than 640,000 interactions, including likes, comments, and retweets. Furthermore, we have maintained our social media strategy, which seeks to provide audiences with useful information to help them form their own opinions on care-related issues. Therefore, we developed contents and information campaigns that include, among others, statistical data, summaries of different bills, social benefits for carers and data from studies on gender, aging and inclusion.



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