



Annual
Report
2021

micare

Millennium Institute for Care Research



ANNUAL REPORT 2021.

Millennium Institute for Care Research, MICARE Chile.

República 252, Santiago, Metropolitan Region.

www.micare.cl

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Design: Ignacio Meneses and Dominique Gago.

General coordination: Alejandra Araya and Vanessa Vega.

Communications support: Gabriela Campillo and Natalia Correa.

Translation to English: Vicente Menares.



**MILLENNIUM
INSTITUTE
FOR CARE
RESEARCH**

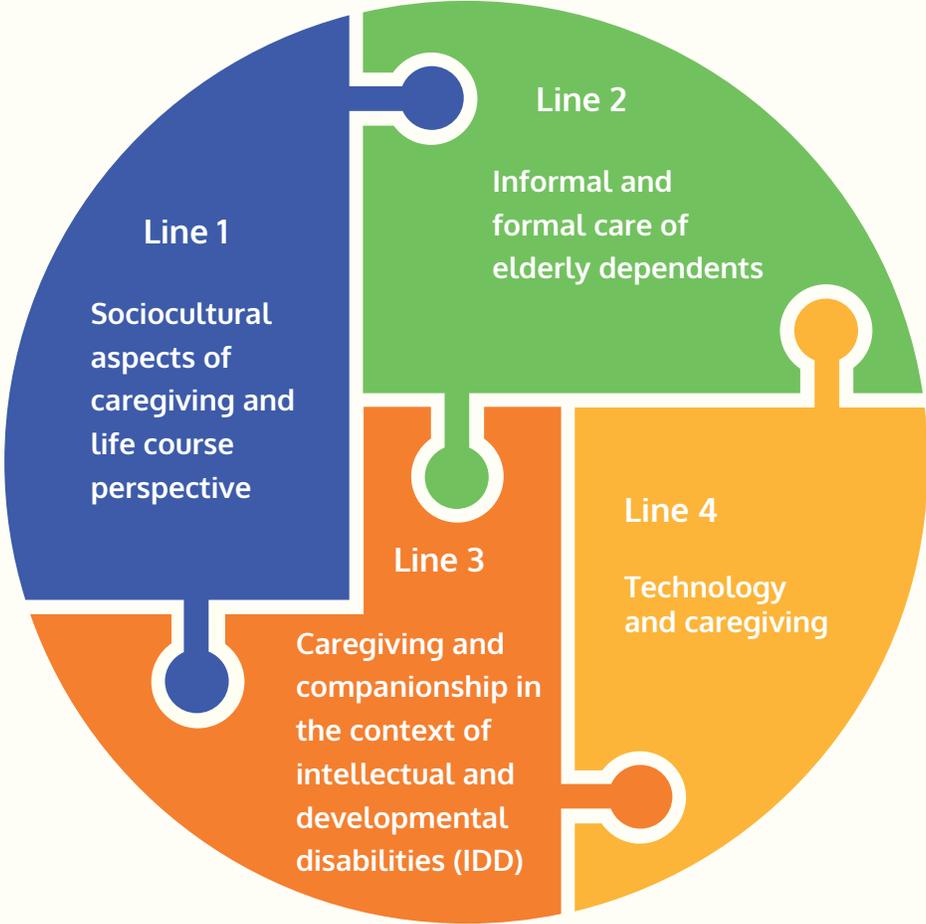


The Millennium Institute for Care Research (MICARE) is a center of excellence in frontier research funded by the Agencia Nacional de Investigación y Desarrollo (ANID) [National Agency for Research and Development] through its Millennium Program (Subdirectorate for Centers and Associative Research). MICARE is based out of the Pontificia Universidad Católica de Valparaíso, Universidad Andrés Bello and Universidad de los Andes.

Our Institute was created to generate scientific knowledge on the informal and formal care of elderly dependents and people with intellectual disabilities and other developmental conditions by typifying care from a holistic perspective and developing appropriate evidence-based interventions.

MICARE began operations in 2021. During this period, we created the Foundation for Care Research to generate a platform for interaction with the community. We also held the first Board of Directors meeting and made progress in the financial organization of the Institute. In terms of implementation, we highlight the process of hiring the management team through an open competition, emphasizing the transparency in the hiring of personnel. We also highlight the implementation of the Spokesperson's Office, which has helped strengthen ties with the community and represent the voice of the groups that we serve.

MICARE has contributed to the development of scientific knowledge with publications in our four lines of research:



We are pleased to highlight the publication of 15 scientific research articles, which are directly related to the objectives of our Institute. In addition, in 2021, interdisciplinary work was carried out to create the measurement instrument to be used in the Longitudinal Study. This is an innovative longitudinal survey of caregivers of dependent elderly adults and people with intellectual and developmental disabilities (IDD) in Chile.

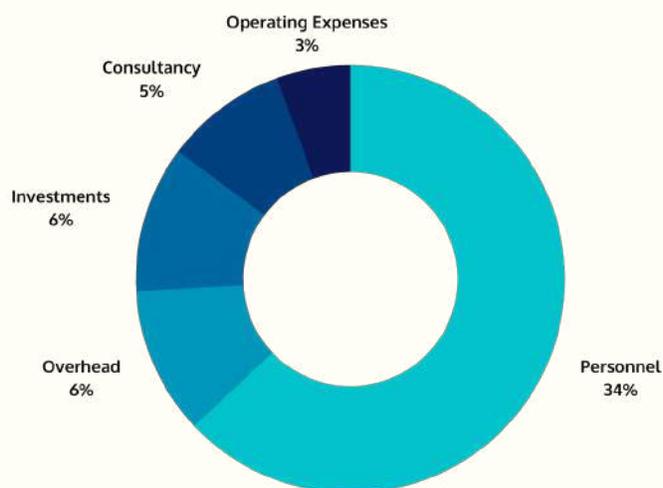
We will survey caregivers across the country in three instances, with fieldwork planned for late 2022. This is a groundbreaking study in Latin America and will provide unprecedented information on care trajectories and the characteristics of this phenomenon in Chile.

In 2021, we also established our offices at the República Campus of Universidad Andrés Bello and at the San Carlos de Apoquindo Campus of Universidad de los Andes.

In addition to the physical facilities, we have created and consolidated our website (www.micare.cl) in Spanish and English, which also includes an Easy Reading certified version. This is also complemented by the constant promotion of our social media and dissemination of our scientific knowledge in the media. In 2021, MICARE researchers contributed to more than 67 appearances in print and digital media, as well as in radio and television.

From a financial point of view, MICARE only received funding from the Iniciativa Científica Milenio - ANID [Millennium Science Initiative], with a fund of US \$500,000,000. The following is a summary of expenditures in 2021:

Item	Amount	Percentage Achieved
Personnel	\$171.781.929	34%
Overhead	\$30.000.000	6%
Investments	\$29.547.716	6%
Consultancy	\$22.686.075	5%
Operating Expenses	\$15.973.568	3%
Total	\$269.989.288	





TEAM



Board of Research Associates



Claudia Miranda,
Director.

"I am a Psychologist with a Master's degree in Clinical Psychology, and Ph.D. in Aging and Mental Health from University College London, UK. I'm Arican through and through, and I enjoy tea with lemon verbena. At MICARE I do research on informal and formal care of elderly dependents."



Marcela Tenorio,
Alternate Director.

"I'm a Psychologist with a Ph.D. in Psychology from the Pontificia Universidad Católica de Chile. I'm Colombian and have been in Chile for more than 15 years. I'm the proud mom of a boy who wants to work at NASA. At MICARE I do research on care and companionship in the context of intellectual and developmental disabilities."



**María Beatriz
Fernández,**
Research Associate.

"I have a Ph.D. in Sociology from the Pontificia Universidad Católica de Chile, where I am also a professor. I have 2 daughters, and I used to swim before the pandemic, a sport I have loved since I was a child. At MICARE I do research on sociocultural aspects of caregiving and life course perspective."



Alejandra Araya,
Research Associate.

"I'm a Nurse-Midwife with a degree in Adult Nursing and a specialization in Gerontology and a Ph.D. in Nursing Science from the University of Illinois, Chicago. I'm from outside Santiago and am optimistic by nature. I love making ceramic utensils and knitting. At MICARE I do research on informal and formal care of elderly dependents."



Vanessa Vega,
Research Associate.

"I am a Professor of Special Education at the Universidad de Playa Ancha and I have a Ph.D. in Disability Research from the University of Salamanca, Spain. I am a huge fan of sugar-free dark chocolate. At MICARE I do research on care and companionship in the context of intellectual and developmental disabilities."



Paulina Arango,
Research Associate.

"I have a Ph.D. in Psychology at the Pontificia Universidad Católica de Chile and I am a Psychologist who graduated from the Universidad Pontificia Bolivariana, Colombia. Crocheting, reading, and dancing helped me to cope with the pandemic. At MICARE I do research on care and companionship in the context of intellectual and developmental disabilities."



Andrés Aparicio,
Research Associate.

"I have a degree in Systems and Computer Engineering and a Ph.D. in Arts with a specialization in Theater Studies and Practices at the Pontificia Universidad Católica de Chile. I have lived in several different places, am Colombian, a migrant, and proud father of an inquisitive 7-year-old boy. At MICARE I do research on technology and caregiving."



Executive Team



Javiera Gutiérrez
Executive Director 2022.

"I have a degree in Public Administration from the Universidad de Chile and a Master's degree in Social Work from the Pontificia Universidad Católica de Chile. I am very happy to be part of MICARE. I believe that the research carried out by the Institute is essential to generate knowledge about the reality experienced by thousands of people in Chile."

Isabel Contrucci,
Executive Director
in 2021.

Sociologist from the Pontificia Universidad Católica de Chile with a Master's degree in Public Administration from the London School of Economics. She served as Executive Director from April 2021 to April 2022. MICARE is grateful for her contribution.

Josefa Palacios,
Research Director
in 2021.

Sociologist from the Pontificia Universidad Católica de Chile with a Master's Degree in Epidemiology and Public Health and a Ph.D. in Political Science. She was the Research Director between July 2021 and March 2022. MICARE is grateful for her contribution.



Gabriela Campillo,
Head of Communications.

"I am a Journalist, with a degree in Social Communication from the Pontificia Universidad Católica de Chile and a Master's degree in Digital Media, Culture and Education from University College London, UK. I have always worked on the "B-side" of communications, supporting non-profit organizations and institutions to better communicate their work. I love reading, writing, and drawing. I am a Maipucina to the core, a lover of the city and maps."



Franci Llanes,
Administration and
Finance Coordinator.

"I am a Public Accountant, Colombian, and have been living in Chile for 7 years. I want to specialize in Tax Management and assist organizations in optimizing management of their resources. I love the south of Chile because it reminds me of my beautiful country. I ride my bike to work and in my free time I like to take care of my plants, enjoy a good book, go to the movies, and dance."

Postdoctoral Researchers



Juan Pablo Robledo.

"I am a Psychologist who graduated from the Pontificia Universidad Católica de Chile, with an MPhil and a Ph.D. from the University of Cambridge, and Research Associate at the University of Lorraine. I'm completely in love with my significant other and our baby. My research up until now has focused on nonverbal vocal communication between adults or between adults and infants. At MICARE I seek to deepen what is known about caregiver communication towards people with intellectual disabilities, as well as its impact on their well-being."



Javiera Rosell.

"I am a Psychologist and have a Ph.D. in Psychology from the Pontificia Universidad Católica de Chile with a Master's degree in Psychogerontology from the Universidad Maimónides, Argentina. I am deputy director of "Programa Adulto Mayor" [Elderly People Program] UC, and professor of Psychology at UC. I participate in the Latin American Research Network of the Oxford Institute of Population Ageing. I enjoy playing musical instruments, video games, and board games. AT MICARE I seek to contribute to the study on the impact of the use of technology on older caregivers, with a focus on mental health."



Francisca Ortiz.

"I am a Sociologist who graduated from the Universidad Alberto Hurtado, with a Master's degree from the Pontificia Universidad Católica de Chile and a Ph.D. from the University of Manchester, UK. I have been involved in research all my life and I am fascinated by mixed methodological development, as well as conducting research with a social impact. I am a board member of Women in Network Science and the "Red Feminista de las Ciencias Sociales" [Feminist Social Science Network]. In my spare time, I enjoy photography, drawing, and recording podcast episodes. At MICARE I seek to contribute to the understanding of the personal networks of elderly people and caregivers in Chile."



Spokespersons' Office



Carolina Lucero,
Intellectual disability
spokesperson.

"I am a Researcher in Cognitive Accessibility at Pontificia Universidad Católica de Valparaíso and a validator at "Lectura Fácil Más Accesible" [More Accessible Easy Reading]. I would like to get trained to teach other people with disabilities so that they too can be spokespersons and defend their rights."



Ricardo Pizarro,
Intellectual disability
spokesperson.

"I am a validator in Easy Reading at the Universidad de los Andes and an administrative assistant at ABCDin. I want to be a spokesperson for people who need to be heard, so they can have more opportunities and participate in public policies."



Gonzalo Osorio,
Intellectual disability
spokesperson.

"I am a Researcher in Cognitive Accessibility at the Pontificia Universidad Católica de Valparaíso. I would like civil society to learn to listen to us as spokespeople because if they listen and support us, they will accept people with disabilities and stop excluding us."



Felipe Pierret,
Intellectual disability
spokesperson.

"I am a self-advocate for people with intellectual disabilities. I hope to represent the community of people with disabilities and make society support us and not discriminate against us."



Teresita Lira,
Dynamizer.

"I am a psychologist who graduated from the Pontificia Universidad Católica de Chile, with a Master's degree in Special and Inclusive Education from University College London and more than eight years of experience supporting the inclusion and emotional well-being of people with intellectual disabilities. I am sure that the Spokespersons' Office will be a space where people with intellectual and developmental disabilities can find a spokesperson to represent them and work towards real inclusion."





WORK IN OUR LINES OF RESEARCH



Line 1. Sociocultural aspects of caregiving and life course perspective



Lead Researcher: María Beatriz Fernández

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

Specific objectives:



1 Characterize caregivers in terms of sociodemographic, economic, labor, social support, use of time, care tasks provided and physical and mental health variables, among others.



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



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



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

In this first year, progress was made in objectives 1, 2 and 3 of line 1. An analysis of secondary data sources was performed, including: Encuesta de Caracterización Socioeconómica CASEN [CASEN Socioeconomic Characterization Survey] (Ministry of Social Development and Family), Encuesta de Bienestar Social [Social Welfare Survey] (Ministry of Social Development and Family), Encuesta de Protección Social [Social Security Survey] (Undersecretary of Social Security), Encuesta de Dependencia [Dependency Survey] (National Service for the Elderly) and Encuesta de Calidad de Vida en la Vejez [Survey of Quality of Life in Old Age] (UC-Caja Los Andes). This analysis has allowed progress to be made on these objectives, but information that provides greater depth will be needed. For this reason, Line 1 has been leading the collaborative work between MICARE lines of research in order to design and implement a Longitudinal Study of Care.

In 2021, work was carried out on the design of the questionnaire for the "Encuesta sobre cuidadores domiciliarios e institucionales de personas mayores dependientes, y de personas con discapacidad intelectual y del desarrollo" [Survey of home and institutional caregivers of dependent elderly people and people with intellectual and developmental disabilities]. This instrument will provide updated information on the needs of this group, based on the collection of information from a sample of 2,200 cases nationwide, with a follow-up of three groups. This is the first study of its kind to be conducted in Chile.

Regarding objective 4 of line 1, this has been worked on in a cross-cutting manner in all MICARE lines. The challenge for the second year will be to consolidate it into a complete map of the care services available in the country.



In 2021, a collaborative relationship was also established with the project "Observatorio de Envejecimiento, Cuidados y Derechos, CuidO60" [Observatory of Aging, Care and Rights, CuidO60], led by Elaine Acosta, visiting scholar at Florida Atlantic University and senior researcher at MICARE. This collaborative relationship materialized when Claudia Miranda (Director of MICARE) joined the Advisory Council of the observatory. She is expected to contribute with suggestions and new ideas, make the work visible and provide international connections and links.

We worked on a proposal for a monographic issue for Revista de Sociología de la Universidad de Barcelona, titled "Care and women in Latin America: studies on gender inequality". This issue aims to shed light on the current situation of care from a gender perspective in the region, addressing the various challenges in the area. It consists of a series of articles covering the study of these challenges, reviewing how women in Latin America take care of different social groups, i.e., the elderly, people with disabilities, and children.



The Professional Certificate in long-term care for the elderly: with emphasis on care in long-stay facilities, day centers and home care was also developed and implemented in collaboration with Agencia Chilena de Cooperación Internacional para el Desarrollo (AGCID) [Chilean Agency for International Development Cooperation], Servicio Nacional del Adulto Mayor (SENAMA) [National Service for the Elderly] and Centro de Vejez y Envejecimiento (CEVE-UC) [Center for Old Age and Aging] of the Pontificia Universidad Católica de Chile. The objective of this professional certificate course was to provide tools and knowledge in long-term care to professionals and/or technicians from Chile and Latin America involved in the design, implementation, evaluation and direct work with the elderly in Long-stay Facilities, Day Centers and Home Care. A total of 270 professionals participated, 67 men and 209 women, of whom 208 were Chileans and 62 were from abroad.

We hope in the short term to continue strengthening the joint work with the Network of Collaborating Researchers of MICARE, adding joint research work and dissemination activities.

In 2021, the topic of family obligations or, more specifically, filial obligation also emerged as an area of relevance for MICARE. These obligations may motivate the decision to care for an elderly dependent relative in Chile, but they are also strongly feminized expectations, which is a central pillar for this line of research. The specific challenge will be to gain a better understanding of this phenomenon and to advance scientific production on the subject.

The first year of work at MICARE brought a number of positive consequences for the Line 1 team. We highlight the development of a project on aging and networks that has been formulated and is seeking funding, as well as the undergraduate course "Hacia un Estado cuidador: políticas de cuidado para personas mayores con dependencia funcional" [Towards a caregiving state: care policies for functionally dependent elderly people] at the Pontificia Universidad Católica de Chile. This course proposes an introduction to the topic of elderly care from a rights-based approach. It aims to question and generate proposals for a political framework that makes it possible to progress towards a State that cares, based on the collaborative work of undergraduate students from different disciplines. The course was held in the first semester of 2022.



Line 2. Informal and formal care of elderly dependents

Lead Researchers:

Claudia Miranda and Alejandra Araya

This line of research seeks to delve into the psychosocial aspects of caregiving, considering both the perspective of those who care for dependent elderly people and the contextual factors that influence this work.

Specific objectives:



Determine what the needs and positive aspects are of caregiving from the perspective of informal and formal caregivers of dependent elderly people.



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

Due to the synergy of resources, Objective 1 has made visible progress. The fieldwork of the FONDECYT 1191726 project, titled "Trajectories and predictors of depressive and anxious symptomatology in family caregivers of people with dementia",

led by Claudia Miranda (MICARE Director), has contributed to this objective. During the reference period, 266 family caregivers of people with dementia were surveyed in the first stage, 72 in the second and 13 in the third.

The information collected has provided specific information on the most frequently met and unmet needs of dependent elderly people with dementia in Chile. It has also provided information on the sociodemographic and mental health characteristics of family caregivers, showing depressive and anxious symptoms and overload, but also positive aspects of caregiving that are valued.



The fulfilment of objective 1 will be complemented with the information collected with the Longitudinal Survey on home and institutional caregivers of dependent elderly people and people with intellectual and developmental disabilities, which is led by line 1, but in which all MICARE Research Associates converge.

In regard to objective 2, it is important to mention the progress of Cuidar Cuidándose [Take care taking care], a randomized controlled pilot trial which evaluates the efficiency of the psychoeducational program based on evidence in a group of family caregivers of people with dementia. The program was trialed with 73 people, and the results were especially positive in reducing dysfunctional thoughts, stress, and the perception of symptomatology severity. Currently, we are working on the analysis and the timely publication of these results.

In relation to the collaborative work with other research groups led by the team of this line, we highlight the following partnerships: Living Alone with Cognitive Impairment (LACI) Project (Stanford University), International Loneliness and Isolation Research Network (I-LINK), Latin-American and The Caribbean Consortium in Dementia (LAC-CD), and Dementia and Neurodegenerative Disorders (DemaNDs) Research Group (University of Newcastle). These collaborations have led to articles and presentations at diverse international congresses.

The consultancy services of Evelyn Iriarte were also hired. She worked in products developed by MICARE for the "Professional Certificate in long-term care for the elderly: with emphasis on care in long-stay facilities, day centers and home care" which the creation of a chapter of the teaching material for Module 3.



Michel Madrid and Eduardo Castillo, both psychologists, were also hired to serve as facilitators of the Psychoeducational Programme "Cuidar Cuidándose". Their purpose was to conduct two trainings on the program: one for psychologists that work in Primary Care at the Health Service of Ñuble; and a second for psychologists of the Red Nacional de Unidades de Memoria [National Network of Memory Units].

Taking into account the political context of Chile during 2021, the need to focus both attention and insight on the position of caregiving in the political agenda of the presidential candidates emerged. For this reason, a collaboration agreement was signed by Professor Pablo Villalobos, who led work related to this topic, and an article about this was written and sent to review.

Objective 1 has been partially answered in relation to the study of dyads of caregivers and people with dementia. The challenge that remains is to achieve more depth in the knowledge and analysis of the needs and positive aspects of caregiving, from the point of view of informal and formal caregivers of dependent older people. Moreover, it will also be challenging to align the information gathered in the MICARE Longitudinal Study in intervention and continuing training programs for professionals.

We also highlight positively the work of the National Servicio Nacional del Adulto Mayor [National Service for Older People] (SENAMA), with which a broad collaboration agreement was signed for the coming years of implementation of MICARE.

Finally, a lecture was delivered in the Constitutional Convention, specifically in front of the Commission of Fundamental Rights, on the importance of the right to caregiving. This contributed to the approval of the article written about this in the proposal for the new constitution.



Line 3. Caregiving and 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, adolescents, 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 caregivers 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 towards current public policies.



Design, test and disseminate a training program that allows better support for people with IDD, incorporating the human rights approach in this task.

During 2021, objective 1 was partially accomplished, related to the understanding of the needs and positive aspects that caregivers and/or companions of people with IDD perceive, considering personal and sociocultural variables. The greater part of the work for this objective has been related to the design of the instrument to be used in the MICARE Longitudinal Study, whose application begins in 2022.

In order to build knowledge around objective 1, studies were developed. Here, we highlight the study on early interactions of parents with their children with Down syndrome, which has been useful to develop knowledge in a very special way about the role of parents in upbringing. We also want to bring to the forefront the study on dependence in people with intellectual and developmental disabilities, promoted from line 3 with the collaboration of two MICARE Senior Researchers. In addition, we highlight the study about literacy environments in the homes of children with Down Syndrome in Chile.

In general terms, these studies begin to show that there are significant differences in the caregiving role of fathers versus mothers, as well as in the influence of the socioeconomic status, as those families with higher socioeconomic status usually are the ones who most isolate and limit the development of their children with IDD.

Regarding objective 2 related to the perception and attitudes of the caregivers toward the IDD and public policies and programs, progress has been made thanks to the synergy created by Psychiatry Department team of University College London.



Specifically, progress was made in the study of the manifest stigma towards people with intellectual and developmental disabilities in Chile. It has been possible to adapt and test some of the instruments for measuring stigma in Chile, and a narrative study on manifest stigma towards IDD in Latin America and a study on stigma towards IDD in people of the general public in Chile were published.

In relation to objective 3, design, testing and dissemination of programs to provide companionship to people with IDD with a rights-based approach. The program Cuida2 also stands out, developed with the support of the Isabel Aninat Foundation (through an agreement signed with the Universidad de los Andes before the creation of MICARE). It is a manualized 68-hour program that includes elements of psychoeducation and self-care. It was implemented in the O'Higgins Region with 30 assistants, and we are currently analyzing the results.



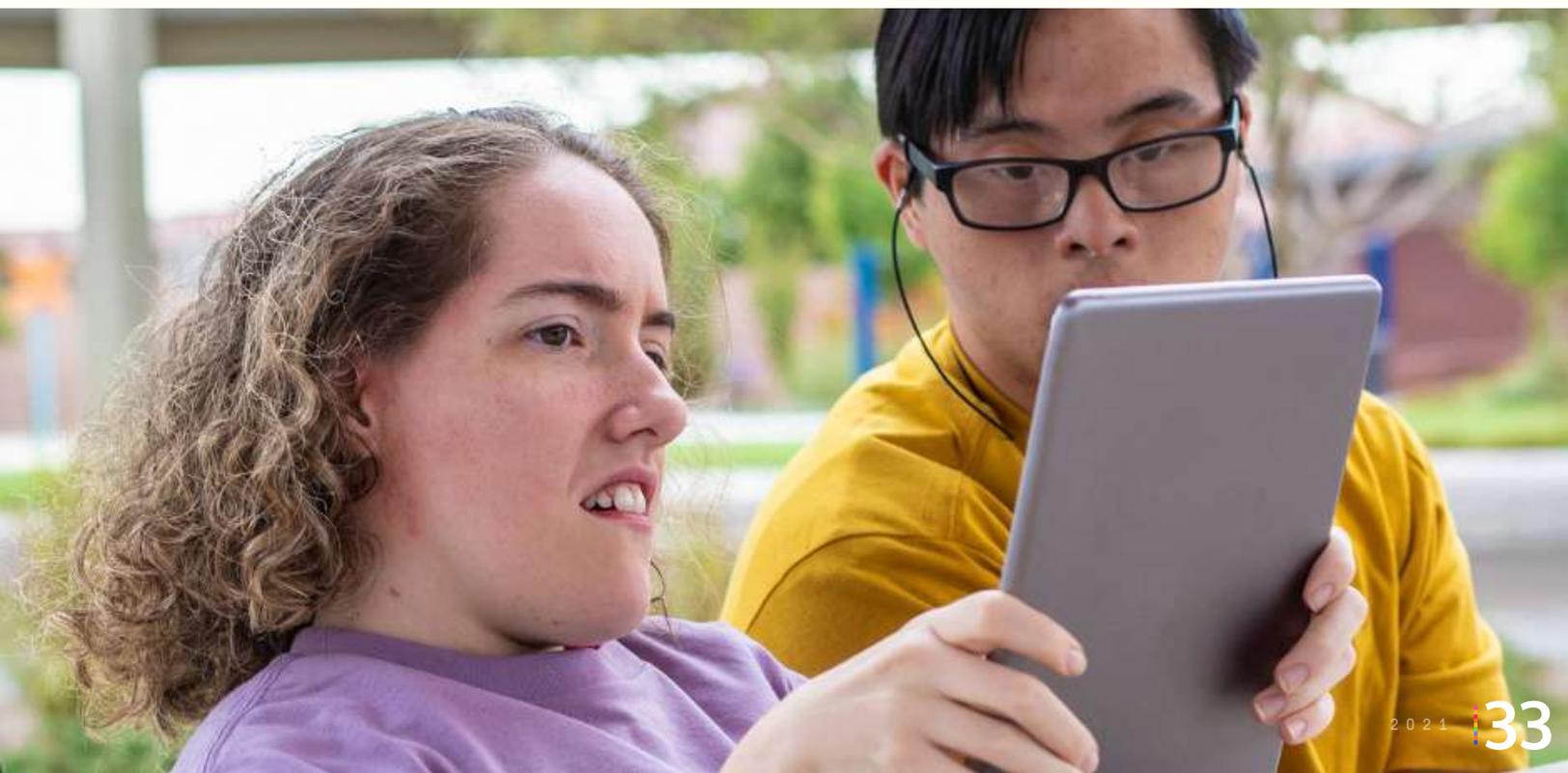
We also highlight the creation of DiscaPaís, an initiative in which research associates (Marcela Tenorio, Paulina Arango and Andrés Aparicio) and adjunct researchers (Pablo Marshall and Florencia Herrera) converge. DiscaPaís will help design and test the impact of a leadership training program for people with disabilities and associated stakeholders. The implementation will be done in 12 regions of the country during 2022.

We would also like to highlight the collaborative work of line 3 with its senior researchers Angela Hassiotis, Cristina Jenaro, Noelia Flores, María del Carmen Pérez and Maribel Cruz. Furthermore, we value the networking with the Law School of the Universidad Austral de Chile and with the School of Sociology of Universidad Diego Portales, which has led to DISCA, a project submitted to the Núcleos Milenio 2022 bid. Collaborative work has progressed with Professor Meghan Burke from University of Illinois (Urbana-Champaign), with whom we have promoted scientific production in relation to parents in upbringing. Finally, it is important to highlight the call to form DiscaRed, a space designed to generate synergies between researchers related to disability in Chile.

The line 3 team also during 2021 the need to advance the study and understanding of the practices of self-care in people with IDD during 2021. That is to say, to take the attention from the caregivers and place it on the very people with IDD. In order to accomplish this new challenge, we conducted in-depth interviews to 60 adult people with IDD. Preliminary results have shown that women with IDD conceive self-care centered on the general vulnerability of their rights. We are working on a scientific communication article with these results and have initiated a focused work with women with DID.

Line 3 work during 2021 has brought positive results. Its influence in the Constitutional Convention has made it possible to include content and regulate the need to have an Easy Reading version of the text.

It is also important to mention the creation of a collaboration roadmap with the Servicio Mejor Niñez, Fundación Coanil and the Chilean Bar Association.



Line 4. Technology and caregiving

Lead Researcher: Andrés Aparicio

The objective of this line is to explore the relationship between technology and care, in order 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:



1 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.



2 Design, test and implement technological tools to support the care process, taking into account the expectations, needs, and good practices identified.



3 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 the reported period, line 4 made progress in different work fronts in relation to its objectives and achieved some specific goals.



The design and implementation of the Adjusted Communal Vaccination Center program (VAC for its acronym in Spanish), along with the Municipality of Puente Alto, and the National Secretariat for the Human Rights of Persons with Disabilities (SENADIS) stand out in relation to objective 2. VAC is a manualized process that enables intervention in healthcare services in order to create vaccination spaces fitted to the sensory needs of children and adolescents with intellectual disabilities or other neurodevelopmental disorders.

Regarding progress during this period, line 4 began exploratory activities in relation to new projects and collaborations, and its researchers participated in the development of research and social intervention projects.

Among the exploratory activities, we highlight the collaboration with professors from the School of Social Work and the Institute of Economics of the Pontificia Universidad Católica de Chile, an alliance that resulted in the application to the 2022 Public Policy Competition of the UC Public Policy Center.



This project seeks to contribute to the creation of a proposal for the socio-technological articulation of the government program "Red Local de Apoyos y Cuidados" to enrich the implementation of the program "Programa Red Local de Apoyo a los Cuidados" (objectives 1, 2 and 3).

We also highlight the participation in the application to the 2021 X Technological Research Contest - IDeA FONDEF in partnership with the Pontificia Universidad Católica de Valparaíso, Universidad de los Andes and the Municipality of Puente Alto, with the project "PICTOS": Service for navigation and evaluation of the cognitive accessibility of services in Chile.

Finally, among the research and social intervention projects in progress in which line 4 participates, DiscaPaís must be highlighted. This project is financed by the National Secretariat for the Human Rights of Persons with Disabilities (SENADIS) within the framework of the 2021 Inclusive Territorial Participation Program, in which Universidad de los Andes and Universidad Austral also participate. This project's objective is to promote the knowledge and the collective empowering of people with disabilities, with an emphasis on women, children and adolescents through four types of intervention, with a strong technological component (objectives 2 and 3).



The objectives proposed for line 4 are long-term and require activities with short-term goals. Some of these goals are not directly related to the main objectives, but contribute to the development of an adequate methodological and practical foundation to support the future work oriented towards them.

During this period, line 4 also enriched previous relationships with other research groups, collaborated with other lines of the Institute and established contacts with new groups to define possible future collaborations.

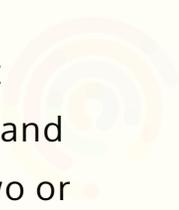
Regarding previous relationships, the work with "El Otro Cuerpo" [The Other Body] was strengthened, thus developing a Fondart project that sought to describe the poetics that emerge from difference and how care appears across them (objective 1). Moreover, collaboration with the "Núcleo de Accesibilidad e Inclusión" [Group of Accessibility and Inclusion] of the Pontificia Universidad Católica de Valparaíso was initiated for the development of the Living Lab, a proposed technology-based mobile laboratory for inclusive research in natural environments of social phenomena (objectives 2 and 3).

In relation to internal collaborations with other lines of the Institute, the work with line 3 in aspects related to the social participation of people with intellectual and developmental disabilities is highlighted. Furthermore, we highlight the joint work in the design and development of the pilot instrument for the MICARE Longitudinal Study, which is a general objective of the Institute.



SCIENTIFIC OUTPUT





The data analysis of the publications under MICARE shows that most scientific outreach pieces have been published in scientific SCOPUS and Web of Science (93%). More than 60% of the publications include two or more researchers from the Institute, with an important contribution from Postdoctoral Researchers in the scientific production of this first year.

In MICARE we believe that outreach and democratic access to information are objectives for which we must work actively. Because of this, it is important to work towards Open Access publications.

We also believe it is necessary to promote Easy Reading versions of those articles that report results of interest to our groups, especially people with intellectual and developmental disabilities, and elderly people with cognitive impairment. We hope to make progress fulfilling this need in the short term.

Finally, we highlight the collaborative work between lines 1 and 2 (the sociocultural aspects of care, in synergy with the care of dependent elderly people), and lines 3 and 4 (the study of intellectual and developmental disabilities, in synergy with technology and care).

The following diagram shows a summary of the scientific output of the Millennium Institute for Care Research:

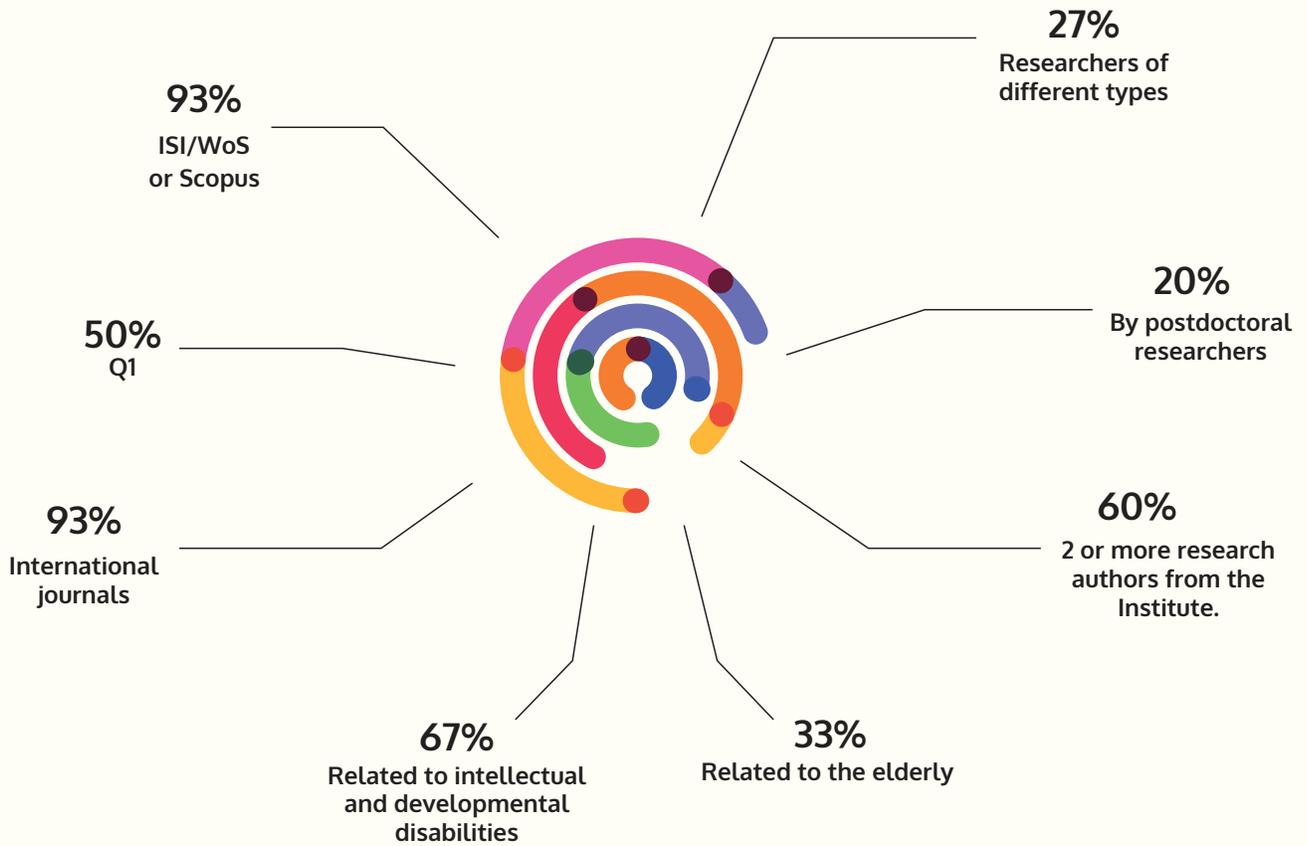


Figure 1. Summary of the MICARE output during 2021.



PRESENTATIONS AT CONGRESSES



In **line 1**, we highlight the participation in scientific activities in which results were presented on a study which explored the impact of the pandemics on elderly caregivers. These results were shared in a seminar held at the Pontificia Universidad Católica de Chile and at the XXV Congress of the Geriatrics and Gerontology Society of Chile 2021. Of notable relevance is the presentation of data about caregivers during the pandemic, a period in which they faced multiple challenges and difficulties that will likely continue to impact their quality of life.

In other relevant activities of this line, Beatriz Fernández (research associate at MICARE) gave a presentation on “Persistencia de la desigualdad de género entre mujeres y hombres cuidadores de personas mayores y en situación de discapacidad” [Persistence of Gender Inequality between Female and Male Caregivers of Elderly People and People with Disabilities] in the COES Conference: Work and Time Use. Differentiated uses and valuation of time.



The presentation also addressed topics related to the objectives of line 1 and 3 about the characteristics of caregivers of the elderly and people with disabilities, as well as the gender variable as a relevant factor in caregiving in Chile.

The postdoctoral researcher in line 1, Francisca Ortiz, also participated in academic outreach activities related to her research and the objectives of the line. We highlight her lectures at the University of Manchester about social networks of support in elder care and innovative methodologies to study them. This is a relevant topic for MICARE, as it is important to include new methodologies that allow a more accurate approach to care.

Regarding the participation in scientific activities of the researchers of **line 2**, we highlight the webinar “Caregivers Day: Challenges for caregivers in Latin America and the Caribbean,” an activity of the Social Protection and Health Division of the Inter-American Development Bank (IDB). This activity presented the current evidence and challenges regarding the situation of informal care in Latin America and the Caribbean, particularly in relation to the mental health of this group. A presentation on this topic was also given at the 8th Conference of Scientific Culture of the Universidad Andrés Bello.

The situation of informal caregivers in Chile was addressed in a conference given as part of the PhD in Psychology at the Universidad de la Frontera. We also highlight the participation in the conference “Religiosity and well-being of the elderly,” organized by the PhD in Nursing Science of the Universidad Andrés Bello.

From **line 3**, researchers participated in national and international academic activities. Marcela Tenorio (MICARE's alternate director) was invited by the Faculty of Law of the Pontificia Universidad Católica de Valparaíso to a discussion about maternity support for women with disabilities and presented the early work at MICARE on care and support for people with intellectual disabilities and the elderly at the seminar "From Universities to Chile", held at the Universidad de los Andes.

Research associate Vanessa Vega gave a lecture on the use of technologies for inclusion as part of the Explora program in Valparaíso. She was invited by the Interdisciplinary Communication and Accessibility Group of the Universidad de la República (Uruguay). Paulina Arango (research associate at MICARE) and Florencia Herrera (adjunct researcher at MICARE) also participated in the "Ciclo de Mujeres en la Investigación Social", which was arranged by the Dispar FONDECYT (National Fund for Scientific and Technological Development) project. These presentations discussed the challenges and possibilities involved in research with people with intellectual disabilities, their families and caregivers, as well as the personal experience of being a researcher with a disability.

It is worth noting the participation of the MICARE Spokesperson's Office in academic activities, such as the seminar "#FreeBritney: Legal capacity of women with intellectual disabilities and mental health disorders in Latin America", organized by the Hernán Correa de la Cerda Institute of Judicial Studies and the Human Rights and Gender Commission of the National Association of Magistrates of the Judiciary System of Chile.



In this activity, Carolina Lucero (MICARE's spokesperson) gave a lecture about her experience as a person with intellectual disabilities and her opinion regarding the challenges that Chile faces in this matter, especially concerning interdiction.

Researcher Andrés Aparicio, who leads **line 4**, participated in the "7º Encuentro Online de la Red de Cuidadoras y Cuidadores de Personas con Autismo o Necesidades Especiales" [7th Online Meeting of the Network of Caregivers of People with Autism or Special Needs], in which he gave a talk titled "Autism and care from academia." This activity addressed the importance of integrating, in a respectful manner, the autistic adult community in both research and care of autistic children. Participation in this meeting helped to establish contact with the community of caregivers of autistic people and to gather information on their position regarding needs and support.





EDUCATION



In 2021, MICARE developed its support and mentorship program for the Institute's undergraduate and graduate students. This plan considers that each student will be accompanied by a MICARE researcher which will act as a tutor or mentor.

The types of tutoring and support required are defined between each student and the Institute's researcher, and are set out in an Individual Training Plan detailed in each agreement.

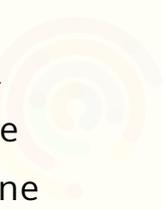
In this way, each student receives the necessary support in their training process, according to the experience of each MICARE researcher.





FORMAL COLLABORATION NETWORKS





In 2021, a collaboration agreement was formalized with the National Service for the Elderly (SENAMA), which has made possible to initiate joint work to achieve objectives that are fundamental for MICARE. One of them is research on the care of dependent elderly people. In this area, MICARE researchers are currently working on the analysis of data on formal caregivers in Long-stay Facilities from a SENAMA study. It is expected that this information will lead to a series of scientific publications in the next few years of the Institute's implementation.

We also promoted the Diploma in long-term care for the elderly: with emphasis on care in long-stay facilities, day centers and home care, with the Pontificia Universidad Católica de Chile. It is expected that this agreement will allow the development of other training and outreach activities in the future.

Concerning our contributions to public policy, in 2021, Claudia Miranda (Director of MICARE) participated in the creation of "Strategic Orientations on Aging 2021-2030" and was invited by the "Servicio Nacional del Adulto Mayor" [National Service for Older Adults] (SENAMA) together with academic and civil society organizations. Claudia Miranda also actively participates as an expert consultant in the Technical Committee on Mental Health of the Elderly, organized by SENAMA and the Ministry of Health, which will remain in operation for the next four years.

Other Collaborating Networks:

In a cross-line collaboration, Marcela Tenorio, Paulina Arango and Florencia Herrera (research associates and adjunct researcher of line 3) together with Andrés Aparicio (research associate of line 4) led the creation of "DiscaRed: Red de Investigadoras e Investigadores en Discapacidad" [Network of Researchers on Disability]. For the formation of this network, calls were made through social media to Chilean and foreign researchers, inside or outside the country, who research on disability.

In 2021, MICARE also supported the implementation of the Community Adjusted Vaccination in Puente Alto, as part of a joint initiative with the Ministry of Social Development and Family, the Undersecretary of Social Services, the National Secretariat for the Human Rights of Persons with Disabilities (SENADIS), the Municipality of Puente Alto, the Con Trabajo Foundation, Universidad de los Andes, and the Center for Advanced Studies on Educational Justice from the Pontificia Universidad Católica de Chile.

Another significant collaboration during 2021 was the design and execution of a certification course on care for the elderly, which is expected to be offered at least once a year.

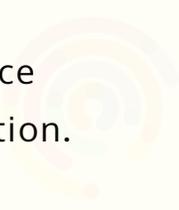
The Diploma in Comprehensive Approach for the Support and Care of Older People was created in an alliance and collaboration with the Pontificia Universidad Católica de Chile, through the Older Adult UC program, the UC Center of Old Age and Aging Studies (CEVE-UC), the National Service for Older Persons (SENAMA), the Ibero-American Social Security Organization (OISS), the Ibero-American General Secretariat (SEGIB), the Chilean Agency for International Cooperation for Development (AGCID), and the MICARE Institute.





CONNECTION WITH OTHER SECTORS





During 2021, MICARE participated in a series of meetings to influence the drafting of laws, public policies, and the Constitutional Convention. Marcela Tenorio (MICARE's alternate director) and Ricardo Pizarro (MICARE's spokesperson) gave presentations to the Communications and Human Rights commissions of the Constitutional Convention. In addition, Claudia Miranda (MICARE's director) gave a presentation at the Human Rights commission of the same organization. In these instances, a proposal of the availability of cognitively accessible versions in Easy Reading of the document to be voted on in the "exit referendum" of the Constitution, and of the new Constitution, if it is approved, was presented.

These proposals were accepted as indications in the regulations and MICARE will support the realization of this project from July to September 2022. We consider this a substantial step towards full political and social participation of the elderly and people with disabilities in Chile.

In addition, researchers Paulina Arango and Vanessa Vega participated in the Commission of Elderly People and Disability of the Chamber of Deputies, where they were invited to give their expert opinion on the Autism Bill.

MICARE, through their research associates, has affiliated with a number of advisory councils, advisory committees, technical committees, and working groups in the public and private sectors. Some of the highlights in the public sector are the Expert International Advisory Group in the Project Living Alone with Cognitive Impairment (LACI), the Advisory Council for the National System of Support and Care,

the COVID-19 Advisory Council for Groups, the Mental Health Technical Committee for the elderly, Advisory Committee on Dementia and the Regional Dementia Technical Committee.

In terms of participation with the private and non-governmental sector, the National Board of Directors of COANIL [Corporation for Aid to Disabled Children], the Board of Directors from "Corporación Talleres Adaptación y Desarrollo" [Adaptation and Development Workshops Corporation], the Advisory Committee from "Centro de Investigación de Envejecimiento Saludable" [Healthy Aging Research Center] of the Consortium of State Universities and the Advisory Council CUIDO60- "Observatorio sobre Envejecimiento, Cuidados y Derechos" [Observatory on Aging, Care and Rights] in Cuba stand out.

It is important to highlight that, since its first year of implementation, MICARE researchers have managed to position themselves as referents in topics related to their interest groups, which is recognized in the invitations and calls to participate in these instances.



PRESS AND SOCIAL MEDIA



At MICARE we seek to contribute with a coherent and cohesive communication that allows us to spread our research work efficiently and effectively. The main objective is to position ourselves as a reliable source on issues related to the care of elderly dependents and people with intellectual and developmental disabilities.

We have developed a Communication Plan focused on proactive and reactive scientific outreach, with presence in the media, social media and the implementation of general outreach activities.

Throughout 2021, a total of **67 articles and interviews were published in print media, websites, radio and television.** This number also includes opinion pieces written by our associate researchers and members of our executive team.

In addition to our media presence, our social media strategy has been one of the strongest outreach elements in our Communication Plan. We thereby intend to ensure that everything we do within the Institute can be effectively made visible through our digital channels. This is because we recognize the demands of the current times in the constant connection of organizations with their communities.

We currently have four active social media accounts whose audiences are in constant growing numbers. You can find us on Instagram, LinkedIn, Twitter, and Facebook.



We also launched our YouTube channel in 2021 as a complement to our social media and website.

As of December 31, 2021, we had a total of **3,491 followers, 107,018 interactions and 691,612 impressions** across all our platforms.





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