

ANNUAL REPORT 2024

Millennium Nucleus for Disability and Citizenship
Studies (DISCA)

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1. INTRODUCTION & EXECUTIVE SUMMARY



1. Introduction & Executive Summary

The Millennium Nucleus for Disability and Citizenship Studies (DISCA) is dedicated to the inter- and transdisciplinary study of the processes and mechanisms through which persons with disabilities become citizens. It has four lines of research: political participation, sexuality and reproduction, access to health, and inclusive and participatory disability research.

The short-term goals are to: a) produce associative and transdisciplinary research on disability, b) generate networks of collaboration and dialogue with other disability research centers worldwide, and c) develop human capital at various levels, promoting the inclusion of people with disabilities in all aspects of DISCA's work.

In the long term, the goal is to establish DISCA as a center of excellence in disability research in Latin America, fostering and articulating disability research across various disciplines and giving voice to new researchers with disabilities.

This center has come to fill a gap in disability studies, providing a space where researchers and students working on disability can meet and collaborate. This is evident from the requests we constantly receive to collaborate with researchers from different disciplines throughout Chile and other Latin American countries. Many of these requests come from people with disabilities. To accommodate these requests and foster the growth and development of new researchers, we created the role of Collaborators, which is focused on people who are not currently studying and do not hold the doctorate required to be considered researchers.

DISCA upholds the disability movement's motto: "Nothing about us without us." Accordingly, we conduct research with people with disabilities, not about them. DISCA is led by a researcher with a disability and has a Board of Experts by Experience comprising seven individuals with various disabilities (visual, hearing, psychosocial, intellectual, developmental, and physical) who advise DISCA on its research and participate directly in scientific output. Furthermore, we prioritize the mainstream inclusion of people with disabilities, whether as researchers, students, collaborators, or administrative staff. Currently, 30% of the team identifies as people with disabilities.

In the scientific development of DISCA's lines of research, we identify methods and techniques that promote the participation of people with disabilities, respecting their voices, diversity, and the value of their experiences. During the first year, progress was made in each research line on the specific objectives focused on the analysis of legislation, existing public policies, and the identification of barriers. During this second year, progress has continued on the objectives of analyzing the resistance strategies developed by people with disabilities in the exercise of their citizenship, mainly through a quantitative research that implemented a national online survey of over a thousand people. Other complementary qualitative research projects have been developed in each line to address specific topics.

The objectives of each line were established in a staggered manner, so having completed the literature reviews and implemented the national survey, we are now in a position to advance in the final specific objective of each line, focused on providing recommendations with theoretical and empirical support that can have an impact on the lives of people with disabilities.

The work on each line is carried out collaboratively with researchers and students from different disciplines. To this end, the team of principal researchers met bi-weekly to stay abreast of the progress of the different lines. This horizontal and highly participatory approach has characterized DISCA's development.

During this second year, the number of scientific publications increased, with publications in all lines of research. 61% of the publications had more than one DISCA author, and there were significant collaborations between researchers, students, and even 3 publications with authors from the Board of Experts by Experience.

The team participated in 71 presentations at conferences relevant to disability studies, and 42% of these were international. Of those in Chile, 44% were in regions other than the Metropolitan Region.

Nine scientific activities were organized, which were directly related to the lines of research and allowed for the creation of new networks. We especially highlight the 1st DISCA Congress: Disability and Citizenship, which brought together more than 40 speakers and 130 attendees over two days, marking a milestone for the development of disability studies in Chile.

DISCA researchers participated in six editorial committees, and two researchers were honored with different awards due to the significant contribution of their research.

Regarding human capital development, the number of undergraduate, master's, and doctoral students supported increased from 13 to 23 during 2024. Of these, 26% identify as people with disabilities. Support continued to be provided to students from external universities who requested tutoring from DISCA due to the lack of expertise in these subjects at their universities. During 2024, five students completed their studies: two undergraduate, one master's, and two doctoral. All of them remain linked to DISCA as collaborators or young researchers.

We implemented the second version of the undergraduate course "Introduction to Disability Studies" in collaboration with the School of Sociology at Diego Portales University. 71 students participated, of whom 42% identified as people with disabilities. Of the 23 guest lecturers, 57% identified as people with disabilities.

In 2024, the design of a Diploma in Social Studies in Disability was also achieved, which will be taught in 2025 at Diego Portales University. This program is led by Jaime Ramírez, a doctoral student with a disability at DISCA and a member of our Board.

Regarding networking, DISCA significantly increased its articulation, reaching eight formal and 14 informal collaboration networks. Various members of the team participated in these networks, and all of them have made it possible to advance and contribute to the development of the lines of research.

To disseminate DISCA's work and the experience of its team, face-to-face and online activities were organized, ensuring the presence of people with disabilities in the speaking roles. In addition, we executed an External Outreach Fund to publish the book "Discapacidad en Chile: Una Introducción" ("Disability in Chile: An Introduction" in English). This book featured the participation of 24 authors, 16 of whom are part of DISCA and 12 of whom identify as people with disabilities. This book provides a general overview of disability in Chile, mentioning the barriers experienced by this group of people and the challenges, advances, and proposals that seek their inclusion and equality.

Financially, 100% of the budget allocated for 2024 was executed, 100% of the 2023 External Outreach Fund was executed, and we were awarded a second External Outreach Fund that will be executed during 2025.

Finally, as a cross-cutting aspect, the incorporation of accessibility measures in all DISCA activities stands out. This included ensuring that venues were accessible for attendees and speakers, providing sign language interpretation, simultaneous captioning, personal assistance for people with disabilities, and financial support for speakers with disabilities. Incorporating these measures is an ethical commitment, as it allows the

knowledge we produce about disability to be accessible to people with disabilities. However, we believe that accessibility should be an essential part of all research centers, because people with disabilities have the right to participate in and access knowledge in all areas. If basic accessibility measures are not incorporated, research centers are excluding a very significant part of society, which is estimated to correspond to more than 2,700,000 adults in Chile (SENADIS, 2023).

1.1. Resumen Ejecutivo

El Núcleo Milenio Estudios en Discapacidad y Ciudadanía (DISCA) está dedicado al estudio inter y transdisciplinario de los procesos y mecanismos a través de los cuales las personas con discapacidad se transforman en ciudadanas. Tiene cuatro líneas de investigación: participación política, sexualidad y reproducción, acceso a la salud e investigación en discapacidad inclusiva y participativa.

Las metas a corto plazo son: a) producir investigación asociativa y transdisciplinaria sobre discapacidad, b) generar redes de colaboración y diálogo con otros centros de investigación en discapacidad a nivel mundial, y c) desarrollar capital humano en varios niveles, promoviendo la inclusión de personas con discapacidad en todos los aspectos del trabajo de DISCA.

A largo plazo, la meta es establecer a DISCA como un centro de excelencia en la investigación sobre discapacidad en América Latina, fomentando y articulando la investigación sobre discapacidad a través de diversas disciplinas y dando voz a nuevos investigadores con discapacidad.

Este centro ha venido a llenar un vacío en los estudios en discapacidad, proporcionando un espacio donde investigadores y estudiantes que trabajan en discapacidad puedan reunirse y colaborar. Esto se ha hecho evidente por las solicitudes que recibimos de manera constante para colaborar con investigadores de diferentes disciplinas en todo Chile y en otros países de América Latina. Muchas de estas solicitudes provienen de personas con discapacidad. Para dar cabida a estas solicitudes y fomentar el crecimiento y desarrollo de nuevos investigadores, creamos el rol de Colaboradores, que está enfocado a personas que no están estudiando y tampoco tienen el grado de doctor requerido para ser considerados como investigadores.

DISCA respeta el lema del movimiento de discapacidad "Nada sobre nosotros sin nosotros". Por ello, realizamos investigaciones *con* personas con discapacidad, no *sobre* ellas. DISCA está dirigido por una investigadora con discapacidad y cuenta con un Consejo de expertos por experiencia formado por siete personas con distintas discapacidades (visual, auditiva, psicosocial, intelectual, del desarrollo y física) quienes asesoran a DISCA en sus investigaciones y participan en la producción científica de manera directa. Además, priorizamos la inclusión de personas con discapacidad de manera transversal, ya sea como investigadores, estudiantes, colaboradores y equipo administrativo. Actualmente un 30% del equipo se identifica como personas con discapacidad.

En el desarrollo científico de las líneas de investigación de DISCA, identificamos métodos y técnicas que promueven la participación de personas con discapacidad, respetando sus voces, diversidad y el valor de sus experiencias. Durante el primer año se avanzó en cada línea de investigación en los objetivos específicos enfocados al análisis de la legislación, políticas públicas existentes e identificación de barreras. Durante este segundo año, se ha seguido avanzando en los objetivos de análisis de las estrategias de resistencia desarrolladas por las personas con discapacidad en el ejercicio de su ciudadanía, principalmente a través de una investigación cuantitativa que ejecutó una encuesta en línea a nivel nacional a más de mil personas. Otras investigaciones cualitativas complementarias se han ido desarrollando en cada línea, para abordar temáticas específicas.

Los objetivos de cada línea se plantearon de manera escalonada por lo que habiendo terminado las revisiones de literatura y aplicado la encuesta nacional, nos encontramos en posición para avanzar en el último objetivo específico de cada línea enfocado en entregar

recomendaciones que tengan sustento teórico y empírico para que puedan impactar en la vida de las personas con discapacidad.

El trabajo en cada línea se realiza de manera colaborativa con investigadores y estudiantes de distintas disciplinas. Para ello, el equipo de investigadores principales se reunió de manera quincenal, para mantener al tanto de los avances de las distintas líneas. Este trabajo horizontal y con alta participación ha caracterizado el desarrollo de DISCA.

Durante este segundo año, se aumentó el número de publicaciones científicas y se contó con publicaciones en todas las líneas de investigación. Un 61% de las publicaciones contaron con más de un autor parte de DISCA y hubo colaboraciones significativas entre investigadores, estudiantes e incluso 3 publicaciones contaron con autores del Consejo de expertos por experiencia.

El equipo participó en 71 presentaciones en congresos relevantes para los estudios en discapacidad, y un 42% de ellas fueron internacionales. De las que fueron en Chile, un 44% fueron en regiones distintas a la Metropolitana.

Se organizaron nueve actividades científicas, las que estuvieron en directa relación con las líneas de investigación y permitieron generar nuevas redes. Destacamos de manera especial el Primer Congreso DISCA: Discapacidad y Ciudadanía que convocó a más de 40 expositores y 130 asistentes durante dos días, marcando un hito para el desarrollo de los estudios en discapacidad en Chile.

Investigadores de DISCA participaron en seis comités editoriales y dos investigadores fueron galardonados con distintos premios debido al significativo aporte de sus investigaciones.

En cuanto a la formación de capital humano, aumentó el número de estudiantes de pregrado, magíster y doctorado acompañados de 13 a 23 durante 2024. De ellos, un 26% se identifica como persona con discapacidad. Se siguió acompañando a estudiantes de universidades externas quienes solicitaron tutoría a DISCA debido a la falta de expertise en estas temáticas en sus universidades. Durante 2024, cinco estudiantes terminaron sus estudios: dos de pregrado, uno de master y dos doctorales. Todos ellos siguen vinculados a DISCA como colaboradores o investigadores jóvenes.

Implementamos la segunda versión del curso de pregrado “Introducción a los Estudios en Discapacidad” en colaboración con la Escuela de Sociología de la Universidad Diego Portales. Participaron 71 estudiantes, de los cuales un 42% se identificó como persona con discapacidad. De los 23 docentes invitados, un 57% se identificó como persona con discapacidad.

En 2024 también se logró el diseño de un Diplomado en Estudios Sociales en Discapacidad, que se impartirá en 2025 en la Universidad Diego Portales. Este programa está dirigido por Jaime Ramírez, estudiante doctoral con discapacidad de DISCA y miembro de nuestro Consejo.

En cuanto al trabajo en red, DISCA aumentó su articulación de manera significativa, llegando a ocho redes de colaboración formales y 14 informales. En estas redes participaron diversas personas del equipo y todas han permitido avanzar y aportar al desarrollo de las líneas de investigación.

Para divulgar el trabajo de DISCA y la experiencia de su equipo, se organizaron actividades presenciales y en línea, donde se aseguró que hubiese personas con discapacidad en los espacios de exposición. Además, ejecutamos un fondo de Proyección al Medio Externo para publicar el libro “Discapacidad en Chile: Una Introducción”. Este libro contó con la participación de 24 autores, de los cuales 16 son parte de DISCA y 12 se identifican como personas con discapacidad. Este libro entrega un panorama general sobre

la discapacidad en Chile mencionando las barreras que experimenta este grupo de personas y los desafíos, avances y propuestas que buscan su inclusión e igualdad.

Financieramente, se ejecutó un 100% del presupuesto asignado para 2024, se ejecutó un 100% del Fondo de Proyección al Medio Externo del 2023, y nos adjudicamos un segundo Fondo de Proyección al Medio Externo que será ejecutado durante el 2025.

Por último, como aspecto transversal, destaca la incorporación de medidas de accesibilidad en todas las actividades de DISCA. Esto incluyó asegurar que los lugares fueran accesibles para asistentes y expositores, proporcionar interpretación en lengua de señas, subtítulo simultáneo, asistencia personal para personas con discapacidad y apoyo financiero para expositores con discapacidad. Incorporar estas medidas es un compromiso ético, ya que permite que el conocimiento que producimos sobre discapacidad sea accesible para las personas con discapacidad. Sin embargo, creemos que la accesibilidad debiese ser parte esencial de todos los centros de investigación, porque las personas con discapacidad tienen derecho a participar y acceder al conocimiento en todas las áreas. Si no se incorporan medidas básicas de accesibilidad, los centros de investigación están excluyendo a una parte muy relevante de la sociedad, que se estima corresponde a más de 2.700.000 adultos en Chile (SENADIS, 2023).

1.2. Outstanding Achievements

A primary achievement during DISCA's second year has been the continued consolidation and increased inclusion of people with disabilities within the team. Currently, 30% of the 76 persons formally affiliated with DISCA, including researchers, students, collaborators, and administrative staff, identify as persons with disabilities.

Additionally, significant progress was made in solidifying our Board of Experts by Experience, comprising seven individuals with disabilities who provide guidance on DISCA's research development. To enhance the Board's functioning, a facilitator was hired in 2024 to support the two board members with intellectual disabilities in reviewing documentation prior to consultations. All consultations provided by the board were remunerated, formalizing this service. Furthermore, board members participated in two scientific publications, one conference presentation, and two members are currently pursuing doctoral studies, a process facilitated by DISCA principal researchers' support and sponsorship.

Throughout the year, our team continued to expand, with a steady influx of individuals seeking formal affiliation or to establish networks with the team for future initiatives, research projects, and internships.

In 2024, DISCA once again offered a Support Fund to finance members' scientific endeavors, providing financial assistance for research projects, conference participation, and publication expenses. The fund's coverage was also broadened in 2024 to include undergraduate and master's students, collaborators, and members of the Board of Experts by Experience, in addition to the doctoral students and researchers supported in 2023.

Among our scientific accomplishments, the design, validation, and implementation of an online survey on disability and citizenship, specifically tailored for individuals with disabilities, was completed. This process was conducted with the full involvement of our principal researchers and the Board of Experts by Experience. The survey reached over a thousand people with disabilities nationwide.

Regarding the organization of scientific activities, a key highlight was the 1st DISCA Congress: Disability and Citizenship, which brought together over 40 presenters and 130 attendees for various panels and sessions on politics, health, education, intellectual disability, guidelines, work inclusion, and childhood. This Congress marked a milestone for DISCA, and we plan to replicate it annually.

In terms of human capital development, we offered the undergraduate course "Introduction to Disability Studies" for the second consecutive year, in collaboration with the School of Sociology at Diego Portales University. The course was created with and for people with disabilities and featured 23 guest lecturers, 57% of whom identified as people with disabilities. Furthermore, 42% of the 71 students identified as people with disabilities.

Concerning collaborative networks, we emphasize our strong connection with the public sector through formal participation in the "Technical Commission on the Autism Law" and the "Technical Roundtable for the Promotion of Inclusion and Participation of People with Disabilities in Higher Education". Additionally, DISCA is participating in the "Intersectoral Roundtable on Disability and Social Inclusion O'Higgins Region" and has maintained continuous collaboration with the Department of Studies of the National Disability Service.

In adherence to our principles, accessibility measures were incorporated into all our in-person and online activities. This included ensuring accessible venues for attendees and speakers, providing sign language interpretation, real-time captioning, assistance in auditoriums, and financial support for speakers with disabilities.

2. SCIENTIFIC AND TECHNOLOGICAL RESEARCH



2. Scientific and technological research

2.1. Methodological and technical procedures

The center's most relevant study is the National Survey on Disability and Citizenship. This study addresses the four lines of research of DISCA and aims to analyze the barriers and facilitators that people with disabilities face in accessing political participation, exercising sexuality and reproduction, and accessing healthcare.

This is a quantitative study based on online surveys, with a non-probabilistic sample design. The sampling unit consisted of individuals over 18 years of age, who identify as having some type of disability and reside in Chile.

During DISCA's second year, the entire team of principal researchers, along with our postdoctoral researcher, completed its design, and a sociologist was hired to coordinate the fieldwork for the final stage of survey validation and implementation.

Notably, the instrument construction process was participatory and inclusive. In 2023, it was validated by our Board of Experts by Experience, and subsequently by a group of 22 expert evaluators using the Content Validity Index (CVI), through the calculation of Lawshe's Content Validity Ratio (CVR). Subsequently, in early 2024, the survey was sent to an association of people with intellectual disabilities who adapted it to "clear language", which is a way of adapting information to make it easier to read and understand. They also provided suggestions for its application to people with intellectual disabilities.

From the outset, we planned to have the survey in two formats, one regular and one in clear language for people with intellectual disabilities or low educational levels. However, when we received the version adapted to clear language, we realized that its wording greatly improved and would favor comprehension for everyone, so the clear language wording was applied to both formats.

The survey addresses the four DISCA's lines of research through 65 variables in five modules:

- Module 1 – Sociodemographic Characterization
- Module 2 – Disability
- Module 3 – Political Participation
- Module 4 – Access to Healthcare
- Module 5 – Sexuality and Reproduction

Once the instrument was validated, all research background information was sent to and approved by the Ethics Committee of Universidad Diego Portales.

Subsequently, the survey was uploaded to REDCap (Research Electronic Data Capture), a web platform that allows the creation of secure and robust online surveys. For this process, a document of recommendations was developed for the programming and presentation of the survey on the platform, which considered measures to ensure accessibility in its design and navigation, as well as compatibility with screen readers.

Then, a pilot test was conducted with 46 people with different disabilities, and new adjustments were required, including its adaptation to different devices, so that it could be properly viewed on computers, tablets, and cell phones.

The final version of the survey began with a video presenting the study. This video (and all subsequent ones) was spoken, subtitled, and interpreted into sign language. In addition, the entire text of the video could be read continuously.

Then, the person was asked how they preferred to answer the survey. There were three options: 1) self-administration of the survey, 2) request a sign language interpreter, 3) request support from a team member to review and answer the survey.

If the person requested support through options 2) or 3), the team contacted them to coordinate the administration of the survey with an interpreter or support staff, according to their needs.

Following the support request, the informed consent was displayed on the same platform. This could be reviewed in writing or in the video that was spoken, subtitled, and interpreted into sign language.

Once the consent was given, the person could decide in which format to answer the survey. First version: written in clear language, second version: written in clear language, with additional explanations of concepts, validated by a group of people with intellectual disabilities.

Its application began in August 2024 and ended in November 2024. The survey was disseminated through email, the website, and social networks of DISCA. In addition, sponsorship was requested from the National Disability Service, who supported the dissemination, and organizations of people with disabilities and municipal disability offices were also contacted directly by DISCA team.

As mentioned above, the survey could be self-administered online or administered with support (sign language interpreter or a team member). To provide this support, sign language interpreters were contacted in advance to review the survey together, clarify their doubts, and thus they could support deaf people who requested this service. In parallel, a team of three sociology students, who had been interns at DISCA, and had taken the course “Introduction to Disability Studies”, was formed. In addition to having professional training for the application of surveys, they were given tools to provide support to people with disabilities.

Support could be provided in two ways: remotely or in person. Remotely, it was done through a video call with an interpreter or support person, who read the survey and entered their answers on the platform. In person, the DISCA support team traveled to five communes in the country to administer the survey. Additionally, some more distant municipal teams were trained directly by a municipal staff member with experience in providing support to people with disabilities. This allowed for field application operations where the trained municipal staff convened groups of people with disabilities and provided support to those who required it, or took the printed survey to homes or remote locations and then uploaded the answers to the platform. All the people who provided support signed an ethical commitment to guarantee the facilitation of the understanding of the survey without influencing the will of the people to answer.

The number of responses and general characteristics of the sample (disability, gender, age, and geographical area) were monitored weekly. With this, prioritization criteria were generated to reach the most heterogeneous sample possible.

The sample reached 1,074 people. The first descriptive results at the national level are as follows:

- 60.5% women and 39.5% men
- Average age of 41 years.
- 82.7% live in an urban area, while 17.3% live in a rural area.
- 25.2% identify with more than one disability, followed by 24.4% who identify with a physical disability, 13.2% with a developmental disability, and 11.2% with a visual disability.

We are currently analyzing the results with the Stata MP 15.1 software to publish the findings during 2025.

In addition, regional reports will be prepared in those areas where collaboration was received from the municipal teams, which was part of the commitments acquired during the application.

In any case, the process experienced so far with the survey has given us enormous learning on how to incorporate accessibility measures throughout an investigation, so that people with disabilities can participate from its design, piloting, and application in equal conditions.

1. POLITICAL PARTICIPATION

The general objective of the line is to critically examine how persons with disability construct and negotiate citizenship in the field of political participation in Chile. The specific objectives are:

- A) Analyze legislation and public policies on the political participation of persons with disability.
- B) Identify the barriers to participation faced by persons with disability as voters and political authorities.
- C) Analyze the adaptation and resistance strategies developed by persons with disability for political participation.
- D) Draw up recommendations to improve the participation of persons with disability in politics.

In relation to Objective A, an analysis was conducted of the legislation and public policies on the political participation of persons with disabilities. This included a review of relevant laws and judicial decisions, with a particular focus on assisted voting for persons with disabilities.

Regarding Objective B, a literature review was undertaken on the political participation of persons with disabilities.

Both analyses have served as the foundation for scientific publications and conference presentations by the research team.

Objectives C and D are being addressed through the Political Participation module of the disability and citizenship survey. As mentioned above, the resulting data is currently under analysis, and initial publications are expected in 2025.

Additionally, three other investigations have been developed within this line of research.

Firstly, our director, Florencia Herrera, and young researcher Daniel Muñoz, are conducting research to identify and analyze the barriers and facilitators that persons with disabilities face when exercising their right to vote. Fieldwork was conducted in 2023, and data analysis took place throughout 2024. As the fieldwork involved recording go-along interviews, the analysis of the audiovisual material has taken longer than anticipated. The results and subsequent recommendations are expected in 2025.

Secondly, our directors, in collaboration with students and DISCA's administrative team, carried out a historical research project that sought to reconstruct the experiences of persons with disabilities who were victims of political violence during the dictatorship in Chile. This project was initiated due to the lack of available information in Chile regarding the impact of the dictatorship on persons with disabilities. As has been historically the case, disability was rendered invisible during the dictatorship and in subsequent transitional justice, reparation, and memory processes. To address this gap, a keyword search was conducted within human rights reports produced post-dictatorship. This meticulous work allowed for the identification of additional terms used to refer to disability, such as "invalid,"

“handicapped,” and “mentally deficient”. These terms led to names, and these names led to individual stories. The findings were published in a report titled “Doubly Disappeared” and was donated to the Museum of Memory and Human Rights, with whom we will continue exploring these findings in 2025, with the goal of identifying additional individuals and expanding this record.

Lastly, our director, with a member of the advisory Board (an autistic person), in collaboration with DISCA students, developed the research project “You can sit with us”: Building bridges and co-creating knowledge between autistic and non-autistic peers in the implementation of the “Autism Act” in Chile. This research involved conducting interviews with autistic and non-autistic individuals who participated in the initial processes of the Technical Agency for the implementation of Law No. 21.545. The initial results were presented by our Board representative at an international conference, and a related article and set of recommendations are expected to be published in 2025.

2. SEXUALITY AND REPRODUCTION

The general objective of the line is to critically examine how persons with disability construct and negotiate citizenship in the field of sexuality and reproduction in Chile. The specific objectives are:

- A) Analyze legislation and public policies related to the sexual and reproductive rights of persons with disability.
- B) Identify the barriers faced by persons with disability as regards sexuality and reproduction.
- C) Analyze the adaptation and resistance strategies developed by persons with disability in the exercise of sexuality and reproduction.
- D) Draw up recommendations to improve the access of persons with disability to sexuality and reproduction.

In relation to Objective A, an analysis was conducted of the legislation and public policies on the exercise of sexuality and reproduction of persons with disabilities. This included a review of relevant laws and judicial precedents related to the topic, with a focus on parenthood and reproduction.

Regarding Objective B, a literature review was undertaken of existing publications regarding the sexuality and reproduction of persons with disabilities.

Both analyses have served as the foundation for scientific publications and conference presentations by the research team.

Objectives C and D, are being addressed through the Sexuality and Reproduction module of the disability and citizenship survey. As mentioned above, the resulting data is currently under analysis, and initial publications are expected in 2025.

As a fundamental part of this line of research, the Fondecyt project "Reproductive Processes and Parental Experiences of Persons with Disabilities in Chile: Discrimination, Adaptation, and Resistance" (1210575), led by director Florencia Herrera, continues to be developed. Nearing completion, the fieldwork phase comprised over 80 in-depth and narrative interviews, including approximately 40 interviews with parents with disabilities, eight interviews with children of parents with disabilities, over 20 interviews with individuals with disabilities without children, and more than 10 interviews with key informants. The sample is diverse in terms of gender, disability type, educational level, and geographic area. The majority of interviews were conducted by researchers with disabilities, which facilitated the establishment of an atmosphere of trust, as many of the experiences narrated were

shared between the interviewee and interviewer. When necessary, interviews incorporated the support of a sign language interpreter or a trusted assistant of the interviewee. Informed consent protocols were designed in multiple formats to ensure accessibility for individuals with visual, auditory, and intellectual disabilities. The interview transcripts are being analyzed using thematic content analysis and narrative analysis. Initial findings have already resulted in scholarly publications and presentations at national and international conferences.

3. ACCESS TO HEALTH CARE

The general objective of the line is to critically examine how persons with disability construct and negotiate citizenship in the field of health care. The specific objectives are:

- A) Analyze legislation and public policies related to the access of persons with disability to health care.
- B) Identify the barriers in access to health care by persons with disability.
- C) Analyze the adaptation and resistance strategies of persons with disability in their encounters with health institutions.
- D) Draw up recommendations to improve the experiences of persons with disability in their encounters with health institutions.

In relation to Objective A, an analysis was conducted of the legislation and public policies on the access to health care. This analysis has served as the foundation for scholarly publications and conference presentations by the research team.

Regarding Objective B, a systematic review of existing publications regarding the access to healthcare for persons with disabilities was conducted. Due to the broad nature of the topic, the line coordinator, Elena Rotarou, formed a team of eight people, including researchers and PhD students of DISCA. This systematic review has been submitted for publication and is currently under review.

Objectives C and D are being addressed through the Access to Healthcare module of the disability and citizenship survey. As mentioned above, the resulting data is currently under analysis, and initial publications are expected in 2025.

Of significant relevance to the development of this line of research is the awarding to our alternate director, Pablo Marshall, of the Fondecyt project “Non-Consensual Measures in Mental Health in Chile: Institutional Analysis and Alignment with Human Rights Standards”. The project's general objective is to critically examine the regulation of non-consensual measures in mental health in Chile, in accordance with human rights standards, and considering the difficulties of reconciling medical discretion in determining therapeutic objectives with the intervention of law to regulate, safeguard rights, and resolve conflicts. The project will employ a combination of doctrinal legal methodologies and socio-legal methodologies. It also includes research visits, conference attendance, fieldwork for the collection of qualitative information, supervision of graduate students, the organization of seminars, and a workshop for the dissemination of results.

4. INCLUSIVE AND PARTICIPATORY DISABILITY RESEARCH

The general objective of the line is to analyze methodologies developed in inclusive and participatory disability research. The specific objectives are:

- A) Review methodologies developed in inclusive and participatory disability research and evaluate their viability in the Chilean context.
- B) Analyze the ethical implications of research with persons with disability.

- C) Adapt and/or design instruments and specific techniques for inclusive and participatory disability research.
- D) Develop practical recommendations on how to conduct disability research in Latin America.

Regarding Objective A, a review was conducted on methodologies and qualitative methods used in inclusive, participatory, and emancipatory research with people with disabilities.

In relation to Objective B, a new investigation was initiated with the objective of understanding the experiences of disability researchers when submitting projects for evaluation by a Scientific Ethics Committee in Chile. To address this, an exploratory qualitative study is being conducted through semi-structured interviews with researchers in Chile, in addition to a literature review of Chilean regulations related to the operation of Ethics Committees and an analysis of existing publications on ethical barriers in disability research. This study is being led by the alternate director of DISCA, Pablo Marshall, and involves the participation of nine individuals from DISCA, including researchers, students, and collaborators. The initial results of this research are expected in 2025.

Concerning Objective D, another investigation was initiated, entitled “How is Disability Studied? Exploring the Research Practices of the DISCA Core”. The objective is to analyze, from the perspective of Critical Disability Studies, the experiences of researchers associated with the DISCA Core in research with people with disabilities, considering ethical, methodological, and subjective aspects. This study employs an exploratory qualitative approach through a case study and includes the use of focus groups and semi-structured interviews. This research is being coordinated by one of the principal researchers, Juan Pino, with the participation of other DISCA students, and the results of this study are expected during 2025.

Lastly, regarding Objective C, the aforementioned survey design and validation process, which involved our Board of experts by experience and also included adaptation to clear language by a group of people with intellectual disabilities, forms part of the practical applications in designing instruments inclusively and participatively. These same strategies have been employed in all the investigations mentioned across the different lines of research, where it is ensured that consent forms, data collection instruments, and feedback documents are available in various formats to guarantee access for all individuals under equal conditions.

2.2. Associative & collaborative work

DISCA research lines are directly interconnected. For example, there are barriers that equally affect political participation and access to healthcare for people with disabilities. Similarly, the exercise of sexuality and reproduction is often linked to the healthcare access available to people with disabilities. The line of Inclusive and Participatory Disability Research, is particularly integrated with the other lines, as it seeks to analyze the most relevant methodologies for disability studies in general. With this level of theoretical articulation between the lines, the scientific publications, conference presentations and media appearances of the researchers in general address more than one line of research.

To organize the development of the research lines, each line is overseen by a principal researcher coordinator, and researchers may participate in more than one line simultaneously, as stated below.

1. **Political Participation.** Coordinator: Pablo Marshall. Principal researchers: Florencia Herrera, Juan Pino, Marcela Tenorio. Other researchers: Andrés Aparicio & Carolina Becerra (adjunct), Diego Solsona, Daniel Muñoz, Viviana Ponce de León & Eduardo Marchant (young), Eilionóir Flynn & Carolina Ferrante (senior).
2. **Sexuality and Reproduction.** Coordinator: Florencia Herrera. Principal researchers: Pablo Marshall, Elena Rotarou. Other researchers: Pamela Gutiérrez (adjunct), Andrea Yupanqui, Pía Rodríguez & Constanza López (young), Agustina Palacios, Eilionóir Flynn & Carolina Ferrante (senior).
3. **Access to Healthcare.** Coordinator: Elena Rotarou. Principal researchers: Pablo Marshall, Florencia Herrera, Marcela Tenorio. Other researchers: Rafael Pizarro & Pamela Gutiérrez (adjunct), Andrea Yupanqui, Diego Solsona, Viviana Ponce de León, Michelle Lapierre & Edison Calahorrano (young), Dikaïos Sakellariou, Narelle Warren, María Pía Venturiello & Carolina Ferrante (senior).
4. **Inclusive and Participatory Disability Research.** Coordinator: Juan Pino. Principal researchers: Florencia Herrera, Marcela Tenorio. Other researchers: Carlos Araneda (postdoc), Rafael Pizarro & Carolina Becerra (adjunct), Daniel Muñoz & Constanza López (young), Eilionoir Flynn, Dikaïos Sakellariou, Narelle Warren, María Pía Venturiello, Carolina Ferrante & Thomas Shakespeare (senior).

However, all researchers can participate in projects they are interested in regardless of the line they belong to. To facilitate this, the principal researchers meet remotely every two weeks for a 60-minute session to update the progress of each line. As specific projects develop within the lines, the availability and interest of the team for particular tasks are updated accordingly.

For example, the new research project on Ethics Committees in Chile, within the line of inclusive and participatory disability research, was coordinated by Pablo Marshall. An open invitation was extended to all researchers, students, and collaborators to participate, resulting in the formation of a nine-person team currently conducting the study. Progress updates are provided to the line coordinator, and the entire team is kept informed through bi-weekly meetings.

Additionally, DISCA's online survey on disability and citizenship spans all lines of research and involves the direct participation of all principal researchers. Elena Rotarou serves as the study coordinator, reporting progress bi-weekly and collaborating with the principal research team on necessary decisions.

Lastly, during 2024 we significantly expanded our network collaborations, increasing formal networks from three in 2023 to eight in 2024, and informal networks from five to 13 in the same period. Details of these collaborations are outlined in the Collaborative networks section below.

2.3. Results and impact

In 2024, 23 publications were produced (increase of ten compared to 2023). Of these, six were published in ISI/WoS indexed journals, three in Scopus and 14 publications were book or books chapters. Of the total articles published in WoS and Scopus, 55% were in the first quartile.

The publications contributed to the various lines of research of DISCA: nine were related to the Political Participation line, seven to the Sexuality and Reproduction line, nine to the Access to Healthcare line, and seven to the Inclusive and Participatory Disability Research line.

Furthermore, it is noteworthy that 61% of the publications included more than one DISCA researcher or student among the authors, reflecting the collaborative work developed within the team to date. This also represents a substantial increase from 2023, when only 38% of publications had more than one DISCA author.

Among the publications from 2024, we highlight the articles "Accessing Sexual and Reproductive Health Services in Chile: Women with Disabilities and Their Experience with Gynaecological and Obstetric Violence" published in *Sexuality Research and Social Policy*, and the article "‘Five rungs down’: encounters between disabled parents and the medical institution", published in *Disability & Society*. Both articles reflect collaborative work among team DISCA members and were published in Q1 journals, making significant contributions to disability studies in Chile, specifically within the research lines of access to health and sexuality and reproduction.

Another relevant 2024 article for DISCA is "Women with disabilities and the loss of custody of their children: 'Carers, but not mothers'", published in *Feminism & Psychology*. This article resulted from collaborative work within the formal network with Social Inclusion and Rights Protection Network, REPRODIS and integrated findings from three previous investigations by DISCA researchers. This article is related to research lines of sexuality and reproduction, and political participation.

We especially emphasize the book "Discapacidad en Chile: Una Introducción" ("Disability in Chile: An Introduction" in English), a product of the External Projection Fund 2023 (detailed in the Outreach section below). We highlight not only its scientific value in providing a comprehensive overview of the disability landscape in Chile but also the significant participation of 24 contributing authors. Sixteen of these authors are part of the DISCA team, encompassing researchers, students, collaborators, Board members, and administrative staff, and 12 identify as persons with disabilities. Furthermore, the Millennium Institute for Care Research MICARE spokespersons group, a group of people with intellectual disabilities that advises that Millennium Institute, contribute a chapter. The book addresses DISCA's four lines of research, with particular emphasis on inclusive and participatory disability research, reflecting the aforementioned collaboration among authors and the incorporation of accessibility measures in its publication. These measures included big font size and non-serif font type, 18-point line spacing, left alignment, and the provision of physical, digital and audiobook versions. The digital version is compatible with screen readers. Finally, the chapter developed in collaboration with the MICARE spokespersons group is available in Easy-to-read on our website.

Lastly, we underscore the scientific contribution made by the members of our Board of Experts by Experience. In 2024, two publications included Board members as co-authors. First, "Activismo de las personas con discapacidad. ¿Por qué es fundamental?" a chapter in our book *Discapacidad en Chile: Una Introducción*, featured a principal researcher, a doctoral student, and two Board members. Second, "Insumos y recomendaciones para políticas públicas e intervención social en torno a las luchas de las personas con discapacidad en América Latina," published in *Colección Convocatorias de Investigación*, included a principal researcher, a doctoral student, a Board member, and two additional authors external to DISCA. These collaborations are fundamental to DISCA, as we aim to support and enhance the academic development of people with disabilities. Furthermore, DISCA's support has been instrumental in the professional and academic development of its Board members. Currently, two of them are pursuing doctoral studies, a process facilitated by the support and sponsorship of DISCA's principal researchers.

We are committed to the principles of Open Access in academic publishing. We believe that making research freely accessible to the public is essential for the advancement of knowledge, particularly in this area, where people with disabilities face greater barriers to accessing information. To support this commitment, we allocate resources to our researchers to cover Open Access publication fees, ensuring that their work is available to a widest and most diverse audience.

We especially value the positive feedback received from the disability community, specifically National Disability Collective, CONADIS, as well as from other organizations of people with disabilities and deaf people, who have approached us during our activities to express their appreciation for the work we do in enriching disability studies in Chile, and for providing leading roles for people with disabilities in our activities, where they have spaces for presentation and moderation. This has been of particular importance to us because our activities have become a safe space where people with disabilities can attend knowing that they will have the necessary accommodations, and that they will be treated as equals and that the research is done *with* people with disabilities and not only *about* them.

2.4. Summary table of publications

Table 1: Summary table of publications

<u>Category of Publication</u> ¹	<u>MSI Center Members</u>	<u>Number of Publications co-authored by students</u>	<u>Total Number of Publications</u>
ISI/WOS Publications or Similar to ISI/WOS Standard	Principal Researchers	1	3
	Other Researchers	1	4
SCOPUS Publications or Similar to SCOPUS Standard	Principal Researchers	0	2
	Other Researchers	0	3
SCIELO Publications or Similar to SCIELO Standard	Principal Researchers	0	0
	Other Researchers	0	0
Scientific Books and chapters	Principal Researchers	3	12
	Other Researchers	0	4
Other Scientific Publications	Principal Researchers	0	0
	Other Researchers	0	0
Total of Publications		5	28

Note: The information was extracted from the Annual Reports of the Millennium Management System. There are a total of 23 publications; however, some of them include both principal researchers and other researchers as authors. Therefore, the "Total Number of Publications" column duplicates publications. This is why the sum of the last column exceeds 23.

2.5. Other relevant scientific achievements

In 2024, the team's researchers participated in 71 conference presentations, 42% of which were international. Of those held in Chile, 44% took place in regions outside the Metropolitan Region. We also emphasize that a member of our Board of Experts by Experience made a presentation. Although this individual presentation was not included in the report, DISCA considers the involvement of Board members in these spaces to be significant.

Eight of these congress presentations featured our researchers as keynote speakers, reflecting their distinguished careers and continued relevance in the field of disability studies.

Furthermore, 13 conferences and seminars (four of them international) featured presentations by more than one DISCA researcher. This highlights DISCA's growing role as a hub for disability researchers, bringing together leading figures in the field.

In addition, we highlight the participation of the Director, Florencia Herrera, and the doctoral student, Constanza López, in the Leeds Disability Studies Conference, held in England. This conference holds significant importance within disability studies worldwide, attracting prominent disability studies centers and researchers from around the globe.

We also underscore the participation of the principal researcher, Marcela Tenorio, and the adjunct researcher, Andrés Aparicio, in the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Congress, held in Chicago, USA. This Congress is highly relevant to the field, as it is the primary global organization dedicated to the scientific study of intellectual disability.

Regarding the organization of scientific activities in 2024, DISCA held its first Summer School in January, aimed at the entire DISCA team, including researchers, students, collaborators, and members of the Board of Experts by Experience. This event featured two highly relevant scientific training sessions: the "Creating Accessibility Training Workshop," led by a journalist with disability expert in accessibility, and the "National Disability Survey III Methodology Training Workshop and Database Usage," conducted by the National Disability Service's research department.

Pursuing our efforts to conduct scientific activities outside the Metropolitan Region, the seminar "Exploring the Intersection Between Disability, Territory and Local Politics" was held in Rancagua in July. Hosted by the University of O'Higgins, this seminar featured a keynote lecture by Dr. Anahí Guedes de Mello, titled "Ableism from a Latin American Perspective," followed by a panel discussion on "Disability Studies, Gender, and Rurality," and a concluding panel on "Local Disability Policies". This event provided a multifaceted analysis of local policies, ableism, and the intersectionalities affecting the lives of people with disabilities.

Furthermore, DISCA held its 1st DISCA Congress: Disability and Citizenship in November at the Universidad Diego Portales in Santiago. Over two days, academics, researchers, public agencies, and civil society organizations from across the country gathered to share experiences and research findings on disability. With over 130 attendees, four central panels, and parallel sessions, the congress addressed topics such as politics, health, education, intellectual disability, guidelines, work inclusion, and childhood. A call for papers for this congress yielded a high volume of submissions, with over 40 presenters ultimately participating. The event consolidated and reaffirmed the interdisciplinary approach of the Millennium Nucleus DISCA, bringing together diverse disciplines and experiences from various parts of the country, and fostering collaboration between the state, academia, and civil society, a collaboration we recognize as a constant challenge in knowledge

production. The high attendance at this event underscored the existing gap in Chile for specific scientific forums on disability. Notably, the congress was moderated by a deaf person using sign language, with an interpreter voicing their communication for the audience. This was an important gesture, giving voice to the deaf community in their native language and providing representation for a diverse range of individuals throughout our activities.

In all the aforementioned activities, necessary measures were taken to ensure venue accessibility for attendees and speakers. Sign language interpretation, real-time captioning, and accessibility guidelines for presenters were provided. Trained students assisted people with disabilities with tasks such as navigating the venue, accessing facilities, and asking questions. This support was highly valued and often crucial for the full participation of attendees with disabilities. Additionally, financial support was provided to all speakers with disabilities requiring travel, as a means of ensuring equal access.

Three additional scientific activities were organized during the year, in collaboration with other institutions: 1) In June, DISCA researchers collaborated with the University of O'Higgins to organize the First Interdisciplinary Congress in Health Sciences, aimed at promoting positive changes in public health policies and programs; 2) In October, a meeting was held with the Director of the Lurie Institute at Brandeis University, USA, and authorities from Universidad Diego Portales to discuss the formation and evolution of the Lurie Institute, its relationship with the community, and lessons learned; 3) In December, DISCA and MICARE jointly organized the International Seminar "Towards a New Comprehensive Regime to Regulate and Facilitate the Exercise of Legal Capacity in Chile," which was addressed from an interdisciplinary perspective.

Finally, DISCA participated in the organization of two other scientific activities in 2024. These were the workshop New Perspectives on Disability Law, held in October in collaboration with Universidad Central, and the Disability and Human Rights Seminar, held that same month in partnership with Universidad Austral de Chile.

DISCA's researchers participated in six distinct editorial boards. Principal researcher Marcela Tenorio is part of the editorial board of the "Journal of Mental Health Research in Intellectual Disabilities", an international, peer-reviewed, interdisciplinary journal indexed in WoS with a Q2 impact factor. Principal researcher Elena Rotarou and adjunct researcher Rafael Pizarro are members of the editorial board of the "International Journal of Environmental Research and Public Health", an open-access, peer-reviewed journal indexed in PubMed Central. Young researcher Pía Rodríguez-Garrido contributes to the editorial boards of two significant Spanish-language publications, "MUSAS: Revista de Investigación en Mujer, Salud y Sociedad" and the dossier "Género y ruralidad en Iberoamérica" of the journal Palimpsesto, a journal of Ibero-American social studies. Additionally, adjunct researcher Andrea Yupanqui participated in the editing of the "Colección de Libros Estudios de Violencia de Género de la Universitat de Les Illes Balears" in Mallorca, Spain. Finally, directors Florencia Herrera and Pablo Marshall served as editors of the DISCA-published book, "Discapacidad en Chile: Una Introducción". The team's diverse participation in editorial boards, particularly in non-disability-specific venues, is highly relevant, as DISCA researchers ensure that the experiences of people with disabilities are appropriately represented in these publications.

In 2024, young researcher Pía Rodríguez-Garrido received the Award for Best Presentation at the 1st Chilean Congress of Qualitative Health Research, from Universidad de Las Américas, in recognition of the quality and impact of the work presented. Additionally, director Florencia Herrera was recognized with the Research Contribution Award by the Vice-

Rectory for Research and Innovation of Universidad Diego Portales for her contribution to innovative research development.

DISCA and its researchers did not apply for any patents nor intellectual property registration during 2024.

3. EDUCATION AND CAPACITY BUILDING



3. Education and Capacity Building

Table 2: Mentored students

MSI RESEARCHER	NUMBER									TOTAL NUMBER PER MSI RESEARCHER
	Undergraduate students			Graduate students						
				Masters			Doctoral			
	F	M	ND	F	M	ND	F	M	ND	TOTAL
Florencia Herrera	2	6	1	1	1	0	2	1	0	14
Pablo Marshall	0	0	0	0	0	0	2	1	0	3
Juan Pino	1	0	0	0	1	0	1	2	0	5
(Researcher 1, Researcher 2, ...)										
Elena Rotarou	0	0	0	0	0	0	1	0	0	1
TOTAL	3	6	1	1	2	0	6	4	0	

In 2024, four of the five principal researchers actively mentored 23 students, an increase of ten compared to 2023. This mentorship occurred through two primary channels. Firstly, via their own affiliations with universities, where their roles within academic teams allowed students to seek their guidance. Secondly, and consistently throughout our project, seven students from diverse programs, including those from universities not affiliated to DISCA, proactively sought mentorship from our team members due to their recognized expertise in disability studies. This trend underscores a potential gap in existing training programs, where academic staff may lack sufficient experience in disability studies, necessitating students to seek external mentorship. Moreover, two doctoral students and one master's student, while not formally integrated into DISCA due to pre-existing supervisory committees, actively participate as collaborators and have benefited from the research support provided by our team. To illustrate this impact further, one of these students, Valquiria Ramos, completed an internship at DISCA with the Alternate Director to investigate the academic publishing practices of DISCA researchers.

The criteria for student mentorship, whether through internal or external programs is determined by the researchers' availability and the alignment of the thesis topics with DISCA's research lines. As a research center, we provide supplementary financial support to two undergraduate and two master's students annually, while the remaining mentees do not receive direct financial assistance from us.

Our student body represents a diverse array of disciplines, including sociology, law, methodology, psychology, anthropology, occupational therapy, speech therapy, and journalism. Notably, two of our students are currently pursuing doctoral programs internationally, in Spain and the United Kingdom.

Furthermore, we wish to underscore that among the 23 students mentored in 2024, six of them identify as persons with disabilities, comprising three undergraduate, one master's, and two doctoral students. This is particularly significant for DISCA, as students with disabilities often encounter greater barriers in accessing, continuing, and completing their academic pursuits. To exemplify this point, we can cite the case of a doctoral student with a physical disability who utilizes an electric wheelchair and commenced their studies at Universidad Diego Portales. Even during the application process, adjustments were necessary to ensure their participation. Subsequently, with their enrollment, the program's faculty and administrative staff have developed a heightened awareness of physical barriers

within buildings, identified more accessible spaces, and implemented measures to ensure the student can participate in all aspects of the program on an equal basis. Indeed, this experience underscores how the very barriers and obstacles we study often remain deeply ingrained and invisible within community and institutional cultures until the lived experience of a student with a disability brings them to the forefront. Consequently, the enrollment of students with disabilities provides a valuable opportunity to instigate necessary changes, paving the way for greater participation of future students with disabilities.

In terms of academic progression, in 2024 DISCA celebrated the graduation of five students: two doctoral, one master's, and two undergraduates. The doctoral graduates have transitioned to the Young Researcher category and continue to contribute to DISCA's research lines. The graduated master's and undergraduate students have become Collaborators, maintaining their connection with DISCA through participation in scientific and dissemination activities as attendees and presenters of their thesis findings.

Regarding the activities undertaken by DISCA students, doctoral candidate Víctor Romero completed an internship in the Department of Critical Disability Studies at the 17 Institute for Critical Studies in Mexico, under the supervision of Dr. Beatriz Miranda, to advance his project "Dissident Bodies in Action: Situated Ethnographies of Disca Activism in Public Spaces". Recognizing his innovative work, he also received the "Premio Edulab UC: Distinción en el Día de la Transferencia y la Propiedad Intelectual UC" for his project "ConectEMOs: Usando imanes para conectar el pensamiento y la emoción" (ConectEMOs: Using magnets to connect thought and emotion).

Building upon our research output, a notable advancement from 2023, where collaborative work did not yet translate into publications, 2024 saw the publication of five DISCA articles co-authored by DISCA students, as previously detailed.

Furthermore, the active engagement of our students in the broader academic community is evidenced by their participation in 12 conferences presentations, predominantly international, on topics aligned with their theses. While these individual presentations are not formally included in this report, they underscore the progress of their research and represent a substantial contribution to the development of DISCA's research lines. Supporting this engagement, at least three students received financial support from DISCA to facilitate their travel to these presentations.

Supporting this engagement, we highlight four scientific publications by doctoral students that, regrettably, could not be reported to the system due to the absence of co-authorship by DISCA researchers. Nevertheless, these publications are highly relevant to our students' research and significantly contribute to DISCA's research lines:

- Rodríguez Gatta, D., Rotenberg, S., Allel, K., Reichenberger, V., Banks L.M., & Kuper, H. (2024). Access to general health care among people with disabilities in Latin America and the Caribbean: a systematic review of quantitative research. *The Lancet Regional Health Americas*. 32, 100701. Recuperado el 11 de abril de 2025, de [https://www.thelancet.com/journals/lanam/article/PIIS2667-193X\(24\)00028-0/fulltext](https://www.thelancet.com/journals/lanam/article/PIIS2667-193X(24)00028-0/fulltext)
- Romero-Rojas, V. & Montaña- Castro, N. (2024). Memorias invisibilizadas: conmemoración del golpe de Estado desde la perspectiva de personas con discapacidad. *Psicoperspectivas: individuo y sociedad*. 23(3). Recuperado el 11 de abril de 2025, de <https://www.psicoperspectivas.cl/index.php/psicoperspectivas/article/view/3281>
- Romero- Rojas, V. y Lizama, M. (2024). *La Emoción de Crear: artes, aprendizaje socioemocional y discapacidad*. Santiago, Chile: Ediciones UC.

- Marchant, E. (2024). Trabajo y personas con discapacidad en Chile: barreras, normativa y brechas de implementación. En Herrera, F. & Marshall, F. (Ed.) *Discapacidad en Chile: Una Introducción* (pp. 115-139). Santiago, Chile: Ediciones Universidad Diego Portales.

A further key achievement in the realm of human capital formation is the successful co-design and implementation of the undergraduate course "Introduction to Disability Studies," in collaboration with the School of Sociology at Universidad Diego Portales. Significantly, this course was explicitly designed for and with the participation of people with disabilities. While an elective for undergraduate students, specific slots were allocated for students with disabilities, and external students were welcome to attend and access all course content without formal evaluation. The 2024 iteration enrolled 71 students, with 30 (42%) identifying as people with disabilities. Moreover, the course featured 23 guest lecturers, 57% of whom identified as people with disabilities. Adding to this rich learning environment, three of the instructors were DISCA doctoral students, and two were DISCA collaborators students.

Integral to the course's design was a strong commitment to accessibility. It was held in a spacious, second-floor room with two elevators and level street access, with an accessible restroom adjacent to the classroom. The hybrid classroom facilitated remote connection for both students and lecturers as needed. Classes offered simultaneous captioning and sign language interpretation when deaf people were present. Furthermore, it was also a learning space for the lecturers. It is not always possible to teach alongside and for people with disabilities. To facilitate this, recommendations were provided to lecturers in advance to make presentations accessible, and having a large number of guest lecturers allowed for the creation of new networks among the lecturers.

The course was appreciated for its flexibility, allowing students to choose the topics and format for their evaluations. They could even present in person or show a recording, whichever was more convenient. This flexibility poses a challenge for those who require more structure and clarity in evaluations, which we aim to improve in future iterations of the course. Other positive aspects of the course included high participation interest and some students became involved in other areas of interest for DISCA, such as submitting undergraduate thesis proposals aligned with the course content, applying for professional internships, forming networks among students with common interests and several students working as personal assistants in DISCA's on-site activities.

Underpinning the entire learning experience, the shared experience of disability among students and lecturers provided both a theoretical and embodied framework for understanding disability, making it less distant and unknown.

Another highly significant milestone for DISCA in 2024 was the collaborative design of the Diploma in Social Disability Studies, scheduled to commence in 2025 within the Faculty of Social Sciences and History at Universidad Diego Portales. This initiative involved the formation of a collaborative network of DISCA students and researchers for its design. Jaime Ramírez, a doctoral student with disability and member of our Board, was appointed as the Program Director. The entire academic faculty comprises DISCA students, researchers, and collaborators, positioning this diploma as an excellent avenue for expanding training in DISCA's research lines to a wider audience.

In conclusion, DISCA offers a positive assessment of its engagement with students, acknowledging the substantial impact on both our research lines and the advancement of our scientific and outreach activities. Moreover, students have consistently reported that DISCA's mentorship and sponsorship have been instrumental in their academic and

professional growth, with particular significance for students with disabilities, who often navigate more complex pathways to educational and career success.

4. COLLABORATIVE NETWORKS



4. Collaborative networks

During 2024, DISCA prioritized strengthening its collaborative networks through three key strategies: deepening established formal collaborations from 2023, formalizing previously informal connections, and engaging diverse stakeholders to cultivate new partnerships.

These efforts resulted in a significant expansion of our collaborations, increasing formal networks from three in 2023 to eight in 2024, and informal networks from five to 13 in the same period. Details of these collaborations are outlined below.

1. **MICARE Millennium Institute Collaboration.** Initiated in 2023, this collaboration continued its objective to foster scientific synergy for joint research projects in care and disability. Key activities included promoting joint affiliations and acknowledgments in publications, facilitating dissemination and activity coordination, enabling joint initiatives on shared research interests, and maximizing information exchange regarding scientific and technical work. Notably, an international seminar with researchers from both centers was organized, a chapter in our first book was co-authored by researchers and MICARE spokespeople with intellectual disability, and the number of participating researchers in this network expanded.
2. **Technical Commission on the Autism Law.** DISCA maintained its active participation in this Ministry of Health-convened technical commission (established in 2023). The commission aimed to identify barriers hindering the development of more inclusive educational communities across all levels and modalities of the national educational system. This engagement facilitated collaboration with expert professionals, civil society organizations, autistic individuals, and caregivers. Director Florencia Herrera is formally represented by Mauricio López, an autistic activist and expert-by-experience Board member.
3. The collaborative design and execution of the elective **undergraduate course "Introduction to Disability Studies"**, ongoing since 2023, saw increased involvement of researchers and students in its 2024 version. This required collaborative content delivery and fostered networks extending beyond the course itself.
4. Building upon the network established for the undergraduate course, a collaboration was formed in 2024 for the design of the 2025 **Diploma in Social Disability Studies** at Diego Portales University. This initiative was led by a person with a disability, who, alongside the network, designed a competitive diploma program slated for launch in 2025.
5. The collaboration with **REPRODIS** was formalized in 2024. This facilitated sustained collaborative work, resulting in participation in new joint research projects, the co-organization of an online seminar and enhanced connections with the University of Magallanes.
6. **Assistive Technology Support Unit.** Through the participation of Associate Researcher Carolina Becerra, Chile's only deaf PhD holder, DISCA contributes to this multidisciplinary network of female researchers conducting applied research for the development of communication assistive technologies.
7. **Technical Roundtable for the Promotion of Inclusion and Participation of People with Disabilities in Higher Education.** Director Florencia Herrera was invited to participate in this roundtable by the Undersecretariat of Higher Education and the National Disability Service (SENADIS). The roundtable aims to review and propose

public policies promoting the inclusion and participation of people with disabilities in higher education and convenes monthly.

8. **Intersectoral Roundtable on Disability and Social Inclusion O'Higgins Region.** Principal Researcher Juan Pino was convened to this roundtable, bringing together numerous regional public agencies to coordinate, promote, and publicize actions and programs related to disability and social inclusion.

Informally, DISCA engaged in an additional 14 collaborative networks.

1. In 2024, the collaboration with the **Department of Studies of the National Disability Service (SENADIS)** continued. Notably, SENADIS conducted a training workshop for the DISCA team on the methodology and results of the 2023 national disability survey and supported the dissemination of our DISCA survey, which reached over thousand individuals with disabilities.
2. The Director of DISCA was invited by the **Universidad Diego Portales Research Ethics Committee** to present research with, for, and by people with disabilities. The Director extended the invitation to the "Agrupación Líderes con mil Capacidades," who also shared their experiences as individuals with intellectual disabilities participating in research.
3. The Director of DISCA visited the **Universidad de Magallanes** for ethics committee training sessions, a disability research methodologies workshop for academics, and a public seminar for students and academics on "researching with, from, and for people with disabilities."
4. DISCA maintained its collaboration with the **Lurie Institute for Disability Policy at Brandeis University, USA**. A key highlight was Director Florencia Herrera's presentation at the Carrie Buck Distinguished Fellowship in Boston, where she also explored new collaborations.
5. Collaboration with the **Faculty of Social Sciences at the University of Buenos Aires** persisted, with three DISCA researchers participating in the XVI National Conference of Interdisciplinary Debate on Health and Population, where a disability-focused session was organized. Subsequent meetings have been held to publish a dossier of selected presentations, anticipated in 2025.
6. The Director of DISCA continued her participation in the **International Consortium of Research on Parents and Parenting with Disabilities**, which supports researchers examining parental disability. The consortium holds regular meetings and provides access to the International Compendium of Data Sources for Parents with Disabilities.
7. Two DISCA researchers and two doctoral students participate in the critical Disability Studies **Working Group of the Latin American Council of Social Sciences (CLACSO)**, which aims to prioritize on legislative actions, human rights approaches, public policies, adversity and cultural fortification, and disability productions in academia.
8. The Director and two students participate in the **National Disability Collective (CONADIS)**, founded in 2019 to defend and vindicate the rights of people with disabilities. Its current president is our doctoral student and expert-by-experience Board member, Jaime Ramírez.
9. DISCA participates in the **Chilean Society for Social Network Science** through the affiliation of one of our students.
10. Young Researcher Pía Rodríguez is part of the **Laboratory for Social Studies of Birth** at the University Institute of Lisbon. Its objectives include promoting knowledge about

birth conditions and characteristics in Portugal and developing synergies between multidisciplinary structures and approaches in birth studies, nationally and internationally.

11. Pía Rodríguez is also part of the **Study Group: Women, Health, and Ethics** of the University of Barcelona, which promotes research on all aspects of women's health from a gender perspective and delves into ethical and social dimensions linked to women's health.
12. Through a DISCA doctoral researcher involved in the **UC Down Center**, a connection was established, leading to working meetings to share activities, the organization of an online seminar, and engagement with people with intellectual disabilities participating in the center.
13. Our Alternate Director, a Principal Researcher, a Young Researcher, and a doctoral student participated in "**Expo consentido(s): a walk towards empathy**", a seminar on inclusion and the ethical and methodological challenges of researching disability funded by the Ministry of Science, Public Science, and the San Sebastián University.
14. Through our Director, a connection was established, leading to working meetings to share activities and the organization of an online seminar with **the Chilean Guide Dog School**.

5. OUTREACH AND CONNECTIONS WITH OTHER SECTORS



5. Outreach and connections with other sectors

a) Outreach and Projection to the External Environment

During 2024, we placed an emphasis on **the broad dissemination of DISCA's work and the expertise of its team to people with disabilities who are interested in these topics**. In this regard, we continued to integrate accessibility measures across all our activities, thereby enabling the equitable participation of people with disabilities. Furthermore, we prioritized the strategic outreach of activities through diverse formats tailored to specific audiences. For instance, we incorporated promotion via Chilean Sign Language videos for the deaf community, recognizing that literacy is not universally prevalent. Additionally, we implemented invitations through WhatsApp and audio messages for individuals with intellectual disabilities, who indicated this as a more commonly utilized and accessible mode of communication. These proactive initiatives directly resulted in a notable increase in the participation of people with disabilities in our activities.

A core objective of DISCA is to **foster robust networks of collaboration and dialogue with other key stakeholders within the disability community**. Consequently, our outreach endeavors in 2024 included a second series of four online seminars that incorporated collaborations with disability advocacy groups and institutions. This synergistic approach facilitated engagement with more diverse audiences and catalyzed the development of collaborative work plans that extended beyond the immediate scope of these seminars. The thematic focus of these seminars directly aligned with DISCA's lines of research. Moreover, consistent with the preceding year, **these seminars ensured the substantive inclusion of people with disabilities within the presentation spaces**.

Expanding our external engagement initiatives, in 2023 we executed an External Projection Fund, culminating in the editorial production of a dissemination-oriented book on disability. In November 2024, we launched "Discapacidad en Chile: Una Introducción" ("Disability in Chile: An Introduction" in English). This publication provides an overview of the landscape of disability in Chile, elucidating the barriers encountered by this population group alongside the challenges, advancements, and proposed solutions aimed at achieving their full inclusion and equality. Grounded in current knowledge and empirical evidence, this book is strategically targeted towards people with disabilities, their families, students, professionals, and all interested parties. This work was co-edited by the Directors of DISCA and 24 authors contributed. Sixteen of these authors are part of the DISCA team, encompassing researchers, students, collaborators, Board members, and administrative staff, and 12 identify as persons with disabilities. Furthermore, the MICARE spokespersons group, a group of people with intellectual disabilities that advises that Millennium Institute, contribute a chapter. During November and December, we successfully hosted one in-person and one online book launch event. Copies of the publication have been distributed to disability advocacy organizations, institutions serving individuals with disabilities and representatives of national administrations holding portfolios relevant to diverse inclusion policies.

Furthermore, we wish to highlight the participation of Director Florencia Herrera in an **open conversation about impediments, disability and the university as knowledge infrastructure at Leiden University College in September 2024**. During this engagement, Florencia Herrera presented DISCA's work and its impact, emphasizing the crucial role of disability studies in shaping alternative understandings of knowledge. We underscore this activity as it reflects the positive outcomes of DISCA's efforts to advance its international collaborative network.

Another impactful initiative was the presentation of the **"Doubly Disappeared" Report to the Museum of Memory and Human Rights in Chile (MMDH)**. This report represents a pivotal historical research project undertaken by DISCA, designed to reconstruct the untold stories of people with disabilities who were victims of political violence during the dictatorship in Chile. Both the development of the report and its subsequent delivery to MMDH are of fundamental significance, as prior to this endeavor, comprehensive information regarding the specific impact of the Chilean dictatorship on people with disabilities was absent. This constitutes a crucial initial milestone, which we intend to further develop in collaboration with the MMDH, with the anticipation of engaging the broader community to gather additional cases and enrich the existing historical records in this area.

Finally, during the second year of the DISCA, consistent progress was made towards the strategic objective of **positioning the critical topic of disability within various academic and public debates in our country**. This achievement was reflected in different press appearances, featuring several opinion columns addressing pertinent national issues. In this context, we also highlight the interview granted to our Director, Florencia Herrera, within the framework of the Carrie Buck Distinguished Fellowship keynote event, organized by The Lurie Institute for Disability Policy at Brandeis University in Boston, United States.

b) Connections with other sectors

During 2024, we enhanced our connections with external stakeholders at DISCA. Notably, in 2024, DISCA researchers collaboratively engaged in the following connections with other sectors:

- Director Florencia Herrera and Alternate Director Pablo Marshall participated in the development of our historical research project "Doubly Disappeared."
- Director Florencia Herrera and Young Researcher Daniel Muñoz participated in the National Urban Development Policy Experts Workshop providing expert consultancy.
- Principal Researcher Marcela Tenorio and Associate Researcher Andrés Aparicio provided training to national professionals of the Victim and Witness Assistance Division of the Public Prosecutor's Office.

All principal researchers, individually engaged in a total of 12 initiatives with external stakeholders, encompassing training sessions and expert consultancy with national and international organizations. We particularly highlight the following:

- Director Florencia Herrera continued her participation in the Social Justice and Human Rights Principles for Global Deliberations on Heritable Human Genome Editing, where she provides expert consultancy.
- Alternate Director Pablo Marshall serves as a Member of the Advisory Committee for the Implementation of a Mental Health Policy at the Universidad Austral de Chile, funded by an AUS project of the Ministry of Education.
- Principal Researcher Marcela Tenorio is a member of the Board of Directors of COANIL and provided numerous training sessions on access to justice for people with disabilities to judges, the Judicial Assistance Corporation and the Public Prosecutor's Office in Chile.
- Principal Researcher Elena Rotarou is a member of three working groups of the Regional Office for Europe of the World Health Organization providing expert consultancy.
- Principal Researcher Juan Pino is part of the working team for the "Transition to Independent Living" Project in the O'Higgins Region.

Lastly, Young Researchers Pía Rodríguez and Daniel Muñoz, along with Associate Researcher Andrés Aparicio, participate in various activities, providing expert consultancy to public institutions and recognized international associations.

6. ADMINISTRATION, GOVERNANCE AND FINANCIAL STATUS



6. Administration, Governance and Financial Status

a) Organization and administration

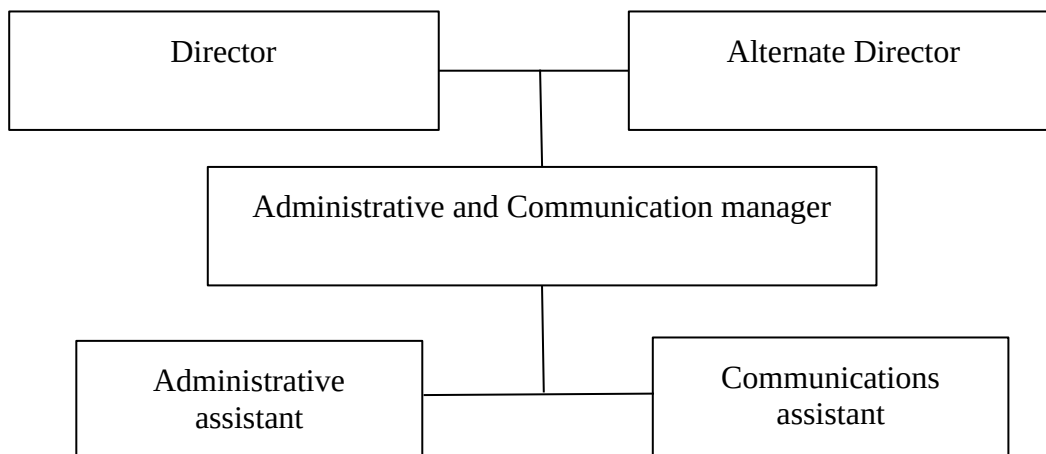
DISCA began its operations on December 12, 2022. From that moment, the administrative team organized itself with the director and the alternate director in charge, working collaboratively in management.

On January 2, 2023, the administrative manager began their duties, overseeing compliance in scientific, financial, and administrative matters. They have held this position to date.

Effective January 1, 2024, the administrative manager also assumed coordination of communications. To support this expanded role, two assistants were hired reporting directly to the administrative manager, as depicted in Figure 1. In line with DISCA's commitment to prioritizing persons with disabilities, an autistic person and a member of the Board of Experts by Experience, commenced his role as communications assistant in January. In March a deaf business administration technician with prior experience collaborating with members of the team on other projects, joined as administrative assistant.

As previously mentioned, the organizational structure of the administrative staff was modified in 2024 and is illustrated in the following figure.

Figure 1: Organizational chart



DISCA comprises five host institutions, corresponding to the universities affiliated with the director (Universidad Diego Portales), the alternate director (Universidad Austral de Chile), and the other three principal researchers (Universidad San Sebastián, Universidad de los Andes, and Universidad de O'Higgins).

Communication with the host institutions is conducted through the affiliated principal researcher. Universidad Diego Portales has provided an office equipped with four workstations for DISCA's operations. This office is located in the Faculty of Social Sciences and History, very close to the office of DISCA Director.

In 2024, in-person activities were held at four of the five host institutions. These universities facilitated suitable spaces for the activities and ensured the necessary coordination to guarantee the accessibility of both the spaces and the activities conducted there.

Additionally, through the communications assistant, a direct relationship was maintained with the communications departments of each host institution. These departments supported

the dissemination of activities and managed press coverage for articles and columns by the researchers affiliated with their institution.

b) Financial Status

In 2024, DISCA's operations were entirely supported by ANID funding, totaling US\$162,562. Additional funding was received from the External Outreach Fund, with US\$6,397 allocated in 2023 and US\$10,661 in 2024; the latter sum is projected to be fully expended by 2025.

Total Funding:¹

During 2024, 100% of the MSI budget allocated for DISCA was utilized. For the 2024 fiscal year, 100% of the MSI budget allocated to DISCA was utilized. The 2023 External Outreach Fund was fully expended within 2024, and the 2024 External Outreach Fund is projected for full utilization by 2025.

It is important to note that approximately 10% of the MSI Budget is spent on the implementation of accessibility measures that ensure the participation of people with disabilities in a cross-cutting manner in DISCA's tasks and activities.

Table 4: 2024 Sources of Funding

Funds	2024 Sources of Funding	
	Amount [CLP\$]	Percentage of resources used by the Center [%]
MSI	152.483.636	100%
PME 2023	6.000.000	100%
PME 2024	10.000.000	0%
TOTAL	168.483.636	

¹ Para aquellas fuentes de financiamiento con el mismo origen, se debe realizar sólo un ingreso con el valor total de la fuente de financiamiento y no ingresar uno a uno estos montos.

The following table presents the detailed expenditure structure. It should be noted that the Research Support Fund provided by DISCA in 2024 is part of the center's core resources. Its execution is distributed according to the categories of each expense; for example, if a person requested support to present at a conference, it will be considered in operational expenses, while if someone requested the hiring of a research assistant, it will be reported within the corresponding staff expenses. In 2024, the Support Fund awarded a total of CLP\$15,650,000 to 16 different members of the team.

Table 5: Expenditure structure

Type of Expense	Total Amount [CLP\$]
Scientific Staff Personal Científica	50.205.940
Technical Staff Personal Técnico	800.000
Administrative Staff Personal Administrativo	28.393.100
Communications Staff Personal de Comunicaciones	11.800.000
Investments Inversiones	0
Infrastructure Infraestructura	0
Consulting Consultorías	31.697.604
Operacionales	32.586.993
Institución albergante	12.999.999

7. OTHER ACHIEVEMENTS



7. Other achievements

As mentioned at the beginning of the document, among the main achievements of the first year of implementation, the inclusion of people with disabilities in the team as researchers, students, research assistants, and administrative staff stands out. This is extremely important for DISCA, which aims to ensure that research is always conducted with people with disabilities. This is especially crucial in disability studies, where first-hand experience is essential to understand different contexts, barriers, and supports that can be provided.

Additionally, we want to emphasize to promote accessibility as a means to ensure the equitable involvement of persons with disabilities as participants and key contributors in all aspects of DISCA's work. This included:

- Conduct regular meetings with the Board of Experts by Experience
- Audit DISCA event venues to ensure physical accessibility for seminars, meetings, survey implementation, conducting interviews, etc. (including ramps, accessible restrooms, step-free pathways from street to venues, accessible layouts for restrooms and coffee breaks, adjustable fixed microphones and freehand microphones, among others)
- Provide communication accessibility for DISCA activities (seminars, meetings, survey implementation, conducting interviews, etc), by securing sign language interpretation, captioning, Easy Read supplementary materials, image descriptions, sans-serif typography, adequate color contrast in images, extended time for people with speech impairments or deaf people, among others.
- Implement a pre-event needs form for all DISCA activities to identify and address participants' additional support needs (e.g., dietary restrictions, sensory sensitivities, etc.)
- Develop and maintain accessible DISCA digital resources (e.g., accessible website, screen reader-compatible documents, audio guides for key publications, etc.)
- Develop and deliver attitudinal accessibility training for DISCA staff and external participants, including guidelines on inclusive language and human rights approach.
- Allocate and administer a budget for people with disabilities assistance to ensure accessibility for in-person DISCA activities, including funding for accessible transportation and travel for people with disabilities from other regions.
- Provide personal assistance to people with disabilities at DISCA events, including training DISCA staff to provide support and allocating funds for travel expenses for personal assistants accompanying people with disabilities from other regions.
- Implement inclusive hiring and selection procedures across all DISCA activities (hiring, activity participation, internships, thesis supervision, etc.).

These measures are essential because knowledge must be accessible to people with disabilities. If a venue has access barriers or there is no sign language interpreter, people with disabilities will be excluded. And this is not only important in disability studies; knowledge in general must be accessible to everyone. All research centers should have minimum accessibility measures.

8. Annexes



Annex 1.- Research Lines

Nº	Research Line	Research Line Objectives	Description of Research Line	Researcher	Research Discipline
1	Political participation	Critically examine how persons with disability construct and negotiate citizenship in the field of political participation in Chile.	Analyze legislation and public policies on the political participation of persons with disability. Identify the barriers to participation faced by persons with disability as voters and political authorities. Analyze the adaptation and resistance strategies developed by persons with disability for political participation. Draw up recommendations to improve the participation of persons with disability in politics.	Pablo Marshall, Florencia Herrera, Juan Pino, Marcela Tenorio, Andrés Aparicio, Carolina Becerra, Diego Solsona, Daniel Muñoz, Viviana Ponce de León, Eduardo Marchant, Eilionóir Flynn & Carolina Ferrante.	Political Science. Law. Sociology. Educational and Cognitive Psychology. Other Medical Specialties. Social Psychology. Other Sociologies.
2	Inclusive and participatory disability research	Analyze methodologies developed in inclusive and participatory disability research	Review methodologies developed in inclusive and participatory disability research and evaluate their viability in the Chilean context. Analyze the ethical implications of research with persons with disability. Adapt and/or design instruments and specific techniques for inclusive and participatory disability research. Develop practical recommendations on how to conduct disability research in Latin America.	Juan Pino, Florencia Herrera, Marcela Tenorio, Carlos Araneda, Rafael Pizarro, Carolina Becerra, Daniel Muñoz, Constanza López, Eilionoir Flynn, Dikaos Sakellariou, Narelle Warren, María Pía Venturiello, Carolina Ferrante & Thomas Shakespeare.	Cultural and Social Anthropology. Law. Sociology. Educational and Cognitive Psychology. Other Medical Specialties. Methodology. Other sociologies
3	Sexuality and reproduction	Critically examine how persons with disability construct and negotiate citizenship in the field of sexuality and reproduction in Chile	Analyze legislation and public policies related to the sexual and reproductive rights of persons with disability. Identify the barriers faced by persons with disability as regards sexuality and reproduction. Analyze the adaptation and resistance strategies developed by persons with disability in the exercise of sexuality and reproduction. Draw up recommendations to improve the access of persons with disability to sexuality and reproduction.	Florencia Herrera, Pablo Marshall, Elena Rotarou, Pamela Gutiérrez, Andrea Yupanqui, Pía Rodríguez, Constanza López, Agustina Palacios, Eilionóir Flynn & Carolina Ferrante.	Law. Sociology. Educational and Cognitive Psychology. Other Medical Specialties. Other sociologies. Economy
4	Access to health care	Critically examine how persons with disability construct and negotiate citizenship in the field of health care	Analyze legislation and public policies related to the access of persons with disability to health care. Identify the barriers in access to health care by persons with disability. Analyze the adaptation and resistance strategies of persons with disability in their encounters with health institutions. Draw up recommendations to improve the experiences of persons with disability in their encounters with health institutions.	Elena Rotarou, Pablo Marshall, Florencia Herrera, Marcela Tenorio, Rafael Pizarro, Pamela Gutiérrez, Andrea Yupanqui, Diego Solsona, Viviana Ponce de León, Michelle Lapierre, Edison Calahorrano, Dikaos Sakellariou, Narelle Warren, María Pía Venturiello & Carolina Ferrante.	Law. Sociology. Educational and Cognitive Psychology. Other Medical Specialties. Other sociologies. Economy

Annex 2.- Institute / Nucleus Researchers

Category of researcher	Quantity	Average age	Nationality		Distribution Gender		
			National	International	Male	Female	Not stated
Director	1	51	1	-	-	1	-
Alternate Director	1	45	1	-	1	-	-
Principal Researcher	5	46	3	2	2	3	-
Senior Researcher	7	48	-	7	2	5	-
Young Researcher	9	39	8	1	4	5	-
Adjunct Researcher	5	48	4	1	2	3	-
Postdoctoral	1	43	1	-	1	-	-

Annex 3.- Publications (Total or partially financed by MSI)

3.1.- WOS Publications or Similar to WOS Standard:

3.1.1 Principal Researchers:

N°	Title	**Authors	DOI	Quartile*	Lines of Research	N° principal researchers of the center
1	Cervical Cancer Screening Uptake Among Women with Disabilities: Findings from a Cross-Sectional Study in Chile	Jara-Rosales, S., Rotarou, E.S.	10.3390/ijerph21121578	Q2	Access to health care.	1
2	Accessing Sexual and Reproductive Health Services in Chile: Women with Disabilities and Their Experience with Gynaecological and Obstetric Violence	Rotarou, E. S., Yupanqui-Concha, A., Rodríguez-Garrido, P., et al. (2024)	10.1007/s13178-024-00942-3	Q1	Sexuality and reproduction. Access to health care.	1
3	'Five rungs down': encounters between disabled parents and the medical institution	Herrera, F., Peralta, C. et al. (2024)	10.1080/09687599.2024.2379335	Q1	Sexuality and reproduction. Access to health care.	1

***Q4: Ingresar esta opción para aquellos artículos que no posean cuartil.**
Ingresar solamente los apellidos de investigadores del centro, para el resto de los autores, utilizar la expresión "et al." para indicar que hay más autores

3.2.- SCOPUS Publications or Similar to SCOPUS Standard:

3.2.1 Principal Researchers:

N°	Title	**Authors	DOI	Quartile*	Lines of Research	N° principal researchers of the center
1	Comprehensive Gerontological Assessment: An Update on the Concept and Its Evaluation Tools in Latin America and the Caribbean—A Literature Review	Rotarou ES., Pizarro-Mena R. et al.	10.3390/ijerph21121697	Q2	Access to health care.	1
2	Women with disabilities and the loss of custody of their children: "Carers, but not mothers"	Herrera, F., Rodríguez-Garrido, P., Yupanqui-Concha, A. et al.	10.1177/09593535241294149	Q1	Sexuality and reproduction. Access to health care.	1

3.3.- SCIELO Publications or Similar to SCIELO Standard

3.3.1 Principal Researchers:

Nº	Title	**Authors	DOI	Quartile*	Lines of Research	Nº principal researchers of the center
1	-	-	-	-	-	-
2	-	-	-	-	-	-
3	-	-	-	-	-	-

3.4.- Scientific Books and Chapters

3.4.1 Principals Researchers:

Nº	Title	Autor	URL/Link	ISBN	Lines of Research	Nº principal researchers of the center
1	Discapacidad en Chile: Una introducción	Herrera, F. & Marshall, P. (Eds.) (2024)	https://ediciones.udp.cl/libro/discapacidad-en-chile-una-introduccion/	978-956-314-608-0	Political participation, Sexuality and reproduction, Access to health care and Inclusive and participatory disability research.	5
2	Sexualidad, reproducción y parentalidad en personas con discapacidad	Herrera, F. & Rojas, A. (2024) in Herrera, F. & Marshall, P. (Eds.) (2024)	https://ediciones.udp.cl/libro/discapacidad-en-chile-una-introduccion/	978-956-314-608-0	Sexuality and reproduction.	1
3	Acceso a la justicia para las personas con discapacidad en Chile	Marshall, P. & Tenorio, M. (2024) in Herrera, F. & Marshall, P. (Eds.) (2024)	https://ediciones.udp.cl/libro/discapacidad-en-chile-una-introduccion/	978-956-314-608-0	Political participation	2
4	"Si nos enseñan, lo vamos a lograr": autonomía desde la voz de los Expertos por Experiencia hacia los conocimientos científicos	Tenorio, M., Aparicio, A. et al. (2024)	https://ediciones.udp.cl/libro/discapacidad-en-chile-una-introduccion/	978-956-314-608-0	Political participation and Inclusive and participatory disability research.	1
5	Health care reforms and policies from a disability-rights perspective	Rotarou, E.S. (2024)	https://www.taylorfrancis.com/chapters/edit/10.4324/9781003228059-12/health-care-reforms-policies-disability-rights-perspective-elena-rotarou	9781032131849	Access to health care.	1
6	'Who am I to write this?': An approach to the field of feminist disability studies in Latin America	López-Radrigán, C y Herrera, F (2024)	https://www.taylorfrancis.com/chapters/edit/10.4324/9781003310709-16/write-constanza-l%C3%B3pez-radrig%C3%A1n-florencia-herrera	9781032316499	Inclusive and participatory disability research.	1
7	Insumos y recomendaciones para	Pino-Morán, J.,	https://biblioteca-repositorio.clacso.edu.ar/bitstream/handle/handle/11362/64819/1/Insumos_y_recomendaciones_para_el_dise%C3%B1o_de_pol%C3%ADticas_de_inclusi%C3%B3n_de_personas_con_discapacidad.pdf	978-987-813-856-5	Political participation	1

	políticas públicas e intervención social en torno a las luchas de las personas con discapacidad en América Latina	Lopez-rodrigan, C; Ramirez, J. et al.	m/CLACSO/251172/1/Democraci a-DDHH-y-Paz-4.pdf			
8	Salud y personas con discapacidad: hacia un acceso equitativo	Rotarou, E., Pizarro, R. & Verdugo, W. (2024) in Herrera, F. & Marshall, P. (Eds.) (2024)	https://ediciones.udp.cl/libro/discapacidad-en-chile-una-introduccion/	978-956-314-608-0	Access to health care.	1
9	Participación política	Marshall, P. & Herrera, F. (2024) in Herrera, F. & Marshall, P. (Eds.) (2024)	https://ediciones.udp.cl/libro/discapacidad-en-chile-una-introduccion/	978-956-314-608-0	Political participation	2
10	Activismo de las personas con discapacidad. ¿Por qué es fundamental?	Pino-Morán, J., Vera, L., Ramírez-Fuentes, J. & Romero-Rojas, V. (2024) in Herrera, F. & Marshall, P. (Eds.) (2024)	https://ediciones.udp.cl/libro/discapacidad-en-chile-una-introduccion/	978-956-314-608-0	Political participation	1
11	La lectura fácil como herramienta para el acceso a la justicia de las personas con discapacidad intelectual y del desarrollo en América Latina	Tenorio, M. (2024)	https://www.sitios.scjn.gob.mx/cec/editorial/el-acceso-una-justicia-adaptada	978-84-1197-973-3	Political participation and Inclusive and participatory disability research.	1
12	Sin detección, sin denuncia y sin proceso: la vulneración de derechos de niñas y niños con discapacidad intelectual en Chile	Tenorio, M., & Fuentes, A. (2024) in P. Fuica, J. Maluenda, & F. Moraga (Eds.) (2024).	https://researchers.uss.cl/es/publications/inclusi%C3%B3n-de-personas-en-situaci%C3%B3n-de-discapacidad-una-aproximaci	978-9962-8517-4-5	Political participation	1

3.5.- Other Publications

3.5.1 Principals Researchers:

Nº	Title	Publication Category	Other Category	Authors	DOI	Quartile	Lines of Research	Nº principal researchers of the center
1	-	-	-	-	-	-	-	-
2	-	-	-	-	-	-	-	-
3	-	-	-	-	-	-	-	-

3.6.- Other researchers: “WOS Publications or Similar to WOS Standard”, “SCOPUS Publications or Similar to SCOPUS Standard” “SCIELO Publications or Similar to SCIELO Standard”, “Books and chapters in books” y “Other Publications”:

N°	Title	Publication Category	Other Category	Authors	DOI/URL	Quartile	Lines of Research	N° principal researchers of the center
1	De la urgencia de un enfoque anticapacitista en educación inclusiva	Libros y Capítulos de Libros		Araneda-Urrutia, C. & Eyzaguirre-Negrete, L.	https://ediciones.udp.cl/libro/discapacidad-en-chile-una-introduccion/	Q4	Inclusive and participatory disability research.	-
2	Derecho a la ciudad y a una vivienda adecuada: desafíos que enfrentan las personas con discapacidad en Chile en el ámbito de la accesibilidad	Libros y Capítulos de Libros		Gaete-Reyes, M. & Acevedo-López, J.	https://ediciones.udp.cl/libro/discapacidad-en-chile-una-introduccion/	Q4	Inclusive and participatory disability research.	-
3	Inclusion of people with disabilities in Chilean health policy: a policy analysis	ISI/WOS o Similar a ISI/WOS standard		Rodríguez Gatta, D., Gutiérrez Monclus, P., Wilbur, J., Hanefeld, J., Banks, L. M., & Kuper, H.	10.1186/s12939-024-02259-4	Q1	Access to health care.	-
4	Gyneco-obstetric violence and its impact on the mental health of women with disabilities: a case study in Chile	ISI/WOS o Similar a ISI/WOS standard		Rodríguez-Garrido, P., Yupanqui-Concha, A., & Valenzuela-Contreras, C.	10.1080/09589236.2024.2366960	Q1	Sexuality and reproduction. Access to health care.	-
5	Strategies to promote dignified and feminist academia: some collaborative reflections from Chile	ISI/WOS o Similar a ISI/WOS standard		Rodríguez-Garrido, et al.	10.1177/014177892312221748	Q2	Inclusive and participatory disability research.	-
6	Haitianization of Migration: The Lack of Attachment of Haitian Women in the Medical Discourse of the City of Rancagua, Chile	Scopus		Cociña-Cholaky, M., Rodríguez-Garrido, P.	10.19137/pys-2024-310104	Q4	Sexuality and reproduction. Access to health care.	-

3.7.- Collaborative publications:

Category of Publication	1 researcher		2 researchers		3 researchers		4 or more researchers	
	Nº	%	Nº	%	Nº	%	Nº	%
WOS Publications or Similar to WOS Standard	4	66%	1	17%	1	17%	-	-
SCOPUS Publications or Similar to SCOPUS Standard	1	33%	1	33%	1	33%	-	-
SCIELO Publications or Similar to SCIELO Standard	-	-	-	-	-	-	-	-
Books and chapters	9	64%	5	35%	-	-	-	-
Other Publications	-	-	-	-	-	-	-	-
<u>Total of publications</u>	14		7		2		-	-

Annex 4.- Products of Projection to the External Environment (PME)

Nº	Date	Product	Objective	Researchers	Target audience	Type	Scope
1	14-11-2024	Digital book "Discapacidad en Chile: una introducción"	Expand the scope of the publication to include individuals with physical and visual disabilities.	María Florencia Herrera Oesterhe, Pablo Marshall Barberán, Elena Rotarou, Juan Andrés Pino Morán, Marcela Tenorio Delgado, Thomas Shakespeare, Rafael Pizarro Mena, Carlos Araneda Urrutia & Mariela Gaete Reyes Andrés Aparicio.	Público general. Profesionales del área del centro. Estudiantes universitarios de pregrado. Estudiantes de postgrado. Docentes universitarios. Medios de comunicación.	Book	National
2	14-11-2024	Book "Discapacidad en Chile: una introducción"	Ensure broad dissemination, with a primary focus on individuals with disabilities and organizations led by or serving people with disabilities.	María Florencia Herrera Oesterhe, Pablo Marshall Barberán, Elena Rotarou, Juan Andrés Pino Morán, Marcela Tenorio Delgado, Thomas Shakespeare, Rafael Pizarro Mena, Carlos Araneda Urrutia & Mariela Gaete Reyes Andrés Aparicio.	Público general. Profesionales del área del centro. Estudiantes universitarios de pregrado. Estudiantes de postgrado. Docentes universitarios. Medios de comunicación.	Book	National