Access to healthcare among people with disabilities in Chile

DANAE HARMONIA RODRÍGUEZ GATTA

Thesis submitted in accordance with the requirements for the degree of

Doctor of Philosophy
of the
University of London

DECEMBER 2024

Department of Population Health

Faculty of Epidemiology and Population Health

LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE

Funded by the National Research and Development Agency of Chile

Research group affiliation: International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine, University of London, London, UK.

Declaration

I, Danae Harmonia Rodríguez Gatta, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

Globally, there are more than one billion people with disabilities. They often have increased health needs due to underlying impairments and secondary conditions, as well as societal exclusion. Thus, they more frequently require general healthcare and, in some cases, specialist services. Yet, people with disabilities often experience worse access to healthcare due to system level failures and consequent barriers encountered along the health journey that restrict their right to health.

This thesis aimed to assess the inclusion of persons with disabilities in the health system of Chile. I undertook a systematic review of healthcare access in Latin America and the Caribbean and found some evidence that people with disabilities have higher use of health services and may experience health inequities, calling for further evidence on coverage, affordability, and quality of care. Then, I analysed the Chilean National Socioeconomic Survey (n = 192,666) to address that data gap in Chile. The study showed that people with disabilities experience health inequities, particularly in terms of worse health status, lower coverage of health services, and increased barriers in accessing healthcare. Moreover, I performed a comprehensive health policy analysis by examining Chilean health policies and interviewing key informants. The study revealed considerable failures at system level, concluding that improvements are needed both in the formulation and implementation of health policies with disability inclusion in Chile. Finally, I conducted a health system assessment by collecting mixed methods data to complete a structured indicator framework in collaboration with the Ministry of Health of Chile and civil society organizations. The study found that overall progress towards disability inclusion was low. Therefore, it was recommended to formulate a national policy on disability-inclusive health, to strengthen the leadership of people with disabilities, and to train health workers on disability.

Collectively, these findings provided robust evidence on the lack of inclusion and participation of people with disabilities in the health system of Chile and the subsequent health inequities experienced. Prioritizing and mainstreaming disability in society, with meaningful participation of people with disabilities, will help building a disability-inclusive health system and achieving universal healthcare that *leaves no one behind*.

Table of contents

List of figures

List of tables

This thesis is dedicated to my beloved sister Maite Sol and my family

Acknowledgments

I would like to first express my deepest gratitude to Dominik and my parents – Cristián Rodríguez and Kareen Besoain – Maite Sol, and Vicente. Gracias infinitas, you filled this journey with inspiration, support, and unconditional love. Thank you for always encouraging me to seek my dreams! I extend my gratitude to all the rest of my family, both in Chile and Germany, and my friends back home and in other parts of the world, who were part of my professional and personal development.

I am profoundly thankful to my supervisors, who have helped me grow as a researcher. It has been an immense opportunity and honour working with you and learning from you the last four years. I am grateful for your time, insightful feedback, and invaluable guidance. Thank you, Professor Hannah Kuper, for your unwavering support, expertise, mentorship, generosity, and encouragement, always with a strong leadership. Thank you, Dr Morgon Banks, for your ongoing support, clarity, keen attention to details, and for helping me enhance my mixed methods skills. This work would have not been possible without you.

I would like to thank my Advisory Committee of powerful and inspiring women, including Professor Pamela Gutiérrez Monclus, Phyllis Heydt, Professor Johanna Hanefeld, Dr Jane Wilbur, and Dr Elena Rotarou. I also have been fortunate to collaborate with Constanza Piriz Tapia, Elvira Tagle Schmidt, and Cristobal Castro Acuña of the Ministry of Health of Chile, and civil society organizations represented by Jimena Luna Benavides, Judit Vilaró Cáceres, Rodrigo Moreno Celis, Gonzalo Tobar Carrizo, Daniel Vivar Jara, Miguel Rojas Varela, María Isabel Robles Meza, and Lía Muñoz Ramírez. Additionally, I would like to acknowledge the support of the group of student assistants at University of Chile, including Andrea Coloma, Bárbara Pabst, Maitte Carimán, María Elisa Berríos, Rosario Coloma, and Trinidad Gilabert. A very special thanks to my long-time mentors and friends, Professor Catterina Ferreccio Readi and Dr Sonia García Calzón, who have supported me since my initial steps in research.

I deeply appreciate sharing this path with my dear friends and colleagues, Dr Sara Rotenberg, Dr Kasim Allel, Dr Veronika Reichenberger, Luthfi Azizatunnisa', Queen Seketi, Dr

Nathaniel Scherer, and members of the International Centre for Evidence in Disability at LSHTM. I am also thankful to the LSHTM Berlin Office and our student group, including Tomoka Nakamura and Dr Jordan Klein. Thank you, Professor Beate Kampmann, Nora Anton, and colleagues of the Charité Center for Global Health for welcoming me during the thesis write-up. A special thanks to the Missing Billion team for their ongoing support throughout this time.

I would like to thank the National Agency for Research and Development of Chile for funding this PhD. Similarly, I extend my gratitude to the London School of Hygiene and Tropical Medicine and the Millennium Nucleus Studies on Disability and Citizenship of Chile for supporting my fieldwork, publications, and conference attendance. Finally, thank you to every participant who generously contributed to this research. I am privileged to have spent time with you.

List of abbreviations

AT	Assistive Technology
CI	Confidence Intervals
CHWs	Community Health Workers
COMPIN	National Commission of Preventive Medicine and Disability
ENENF	National Nursing Examination
EUNACOM	Single National Medical Knowledge Test
FONASA	National Health Fund (*Fondo Nacional de Salud*)
GDP	Gross-Domestic Product
GES	Explicit Health Guarantees *(Garantías Explícitas en Salud)*
GP	General Practitioner
ISAPRES	Private Health Insurances (*Instituciones de Salud Previsional*)
ICF	International Classification of Functioning, Disability, and Health
IVADEC-CIF	Community Assessment of Performance Evaluation
LAC	Latin America and the Caribbean
LMICs	Low- and middle-income countries
LSHTM	London School of Hygiene and Tropical Medicine
MoH	Ministry of Health
NDA	National Disability Agency (*SENADIS*)
NSES	National Socioeconomic Survey of Chile
OECD	Organization for Economic Cooperation and Development
OPDs	Organizations of People with Disabilities
OR	Odds Ratio
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO	Prospective Register of Systematic Reviews
SRH	Sexual and Reproductive Health
UHC	Universal Health Coverage
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WASH	Water, Sanitation, and Hygiene
WG	Washington Group
WHO	World Health Organization

Thesis structure

The format of this thesis is “Research Paper Style” and includes the following chapters:

Chapter 1 introduces an overview to disability and health globally and in Chile, setting the context for the studies conducted in this PhD.

Chapter 2 summarizes the aim, objectives, and methods of this PhD.

Chapter 3 presents a systematic review of access to general healthcare among people with disabilities in Latin America and the Caribbean.

Chapter 4 explores the patterns of healthcare use, coverage, and barriers to accessing health services among people with and without disabilities in Chile.

Chapter 5 displays a policy analysis on the inclusion of people with disabilities in Chilean national health policy.

Chapter 6 presents a national health system assessment study on inclusive health for people with disabilities in Chile conducted with the Ministry of Health and organizations of people with disabilities.

Chapter 7 compiles a discussion based on the evidence presented in previous chapters and summarises the main conclusions of this PhD.

Chapter 1

Introduction

1.1 | Background

The experience of disability is inherently human and common. About 16% of the world's population – 1 in 6 people – have long-lasting health conditions, which coupled with barriers of the environment, restrict their highest attainable standard of health, wellbeing, and participation in society.[1] This number represents an estimated 1.3 billion people with disabilities globally according to the World Health Organization (WHO).[1] The prevalence is projected to rapidly increase over time, driven by population ageing and increasing prevalence of chronic diseases.[1] People with disabilities, on average, have greater need for healthcare and use health services more often than the general population.[1–3] However, they face several barriers to healthcare, critical health inequities, and social exclusion.[1–3] Hence, disability constitutes a public health concern that needs to be addressed by health systems and society as a whole. This topic forms the central focus of the current thesis.

1.2 | Framing disability

The concept of disability has evolved over time and different understandings coexist across and within countries. Disability is understood as a synonym of a health condition or permanent impairment under the medical model of disability.[4] The focus of this model is on the individual and medical and rehabilitative interventions aim to treat the "body impairments". For example, a person diagnosed with muscular dystrophy, a progressive musculoskeletal disease characterized by wasting and weakness of the muscles [5], might be monitored by a neurologist or physiatrist and referred to physiotherapy for maintenance of body functions and structures. Although for many it is clinically relevant to address the needs of the underlying health condition to improve quality of life, other equally relevant aspects might be missed under a sole medical perspective. Disability rights and benefits, assistive technology and home adaptations, and community, support, or other health needs may be overlooked. Consequently, two people with the same health condition or impairment may experience very different impacts on their lifestyle, including levels of participation, due to their environmental and personal factors. Therefore, the still powerful medical paradigm in the health sector, could perpetuate a narrow understanding of disability.[6]

In contrast, the social model of disability outlines a different conceptualization, where disability is "separated" from health conditions or impairments.[4] This model points at the societal barriers (i.e. attitudinal, physical, etc.) as the main cause for the experience of disability and lack of equal participation in society. For instance, a person with bipolar disorder may not be able to sustain a stable job because of discriminatory practices in the work environment and lack of appropriate accommodations, rather than the person's health condition. Nevertheless, the social model of disability is also not without critique, as some consider it to neglect the impacts on life caused by health conditions or impairments that cannot be entirely ameliorated by societal change – such as the experience of chronic pain. Hence, an intermediate approach integrating the last two models is the biopsychosocial model established by the WHO's International Classification of Functioning, Disability, and Health (ICF) (Figure 1).[7]

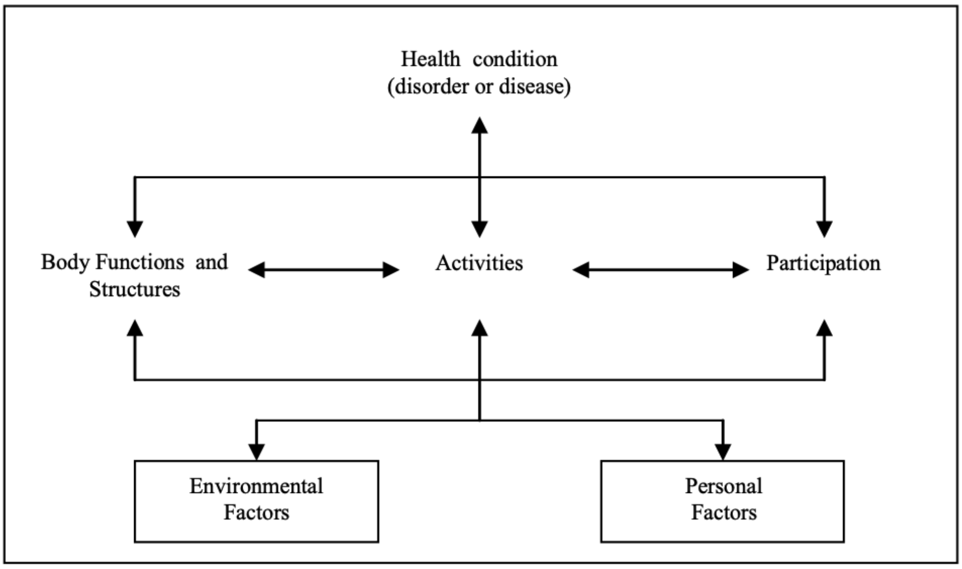


Figure 1. ICF model of disability: interactions between ICF components [7]

Under the ICF, disability is defined as an umbrella term for impairments, activity limitations, and participation restrictions, highlighting the negative interaction between health conditions and personal and environmental factors.[7] For example, a person diagnosed with ring chromosome 14 syndrome – a rare genetic disorder with neonatal onset – will commonly experience epilepsy and intellectual disability.[5] This person might have difficulties with basic daily activities such as getting dressed and participating in school due to lack of inclusive educational facilities. These experiences will be also mediated by additional environmental factors (e.g., access to health insurance, assistive technology, and caregiving support) and personal factors (e.g., age and sex).

In line with the ICF, the human rights approach to disability emerged as another widely agreed framework. The human rights model was coined by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). It describes that "*persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others*".[8] This model recognizes the inherent dignity of people with disabilities and ensures their complete enjoyment of all human rights. It promotes respect for difference and acceptance of diversity and focuses on equality of opportunity, non-discrimination, inclusion, accessibility, and participation in society. This thesis will be framed under the ICF and human rights model of disability.

1.3 | Epidemiology of disability

In 2021, there was an estimated 1.3 billion people with disabilities in the world; about 270 million more than in the previous decade.[1] Prevalence estimates were calculated based on the number of health conditions or impairments (lasting more than six months and associated with moderate to severe disability) of the 2021 Global Burden of Disease study, and are therefore largely in line with the medical model of disability.[1,9] Hence, the relationship with environmental factors are not considered and therefore, current global figures could overlook the true prevalence of disability. More comprehensive global estimates will be gathered as more data on disability considering the impact of the environment becomes available.[1]

The regions with the highest prevalence include Europe (20%) followed by the Americas (19%).[1] Disability prevalence is also greater in high-income countries (21%) than low-income countries (13%).[1] However, most people with disabilities (80%) live in low and middle-income settings. The differences between disability prevalence and country of residence relate to both the higher prevalence of some health conditions in high-income countries and lack of disability data in many low-income settings. Disability also increases with age, ranging from 6% in children and adolescents to 34% in older age groups above 60 years.[1] This association could be driven by the higher burden of health conditions among older age groups and is compounded by increased poverty, access to healthcare, ageism, and social exclusion.[9–11] Furthermore, disability is associated with female sex (18% versus 14% in men).[1] Higher disability prevalence among women could be explained by a complex set of factors. Globally, women live longer than men but experience a higher burden of health conditions associated with disability (e.g. musculoskeletal and mental health conditions).[12,13] The latter is coupled with gender inequalities. Women experience significant gaps in education and employment and are more likely to face poverty and gender-based discrimination.[14] Hence, they are more often exposed to environmental barriers to societal participation.

The experience of disability is often influenced by the “types of disabilities”, which are grouped by broad impairment types (i.e., physical, intellectual, etc.). Worldwide, the most prevalent health conditions deemed likely to result in moderate to severe disability include musculoskeletal, mental health, and neurological conditions, as well as hearing and vision loss.[1] Among musculoskeletal disorders, low back pain was the leading condition in 2019, with 568 million people globally.[13] Moreover, before the COVID-19 pandemic, there were 970 million people living with mental disorders, with depressive and anxiety disorders as the most common causes for years lived with disability.[15] In addition, migraine, diabetic neuropathy, stroke, Alzheimer’s disease and other dementias, and autism spectrum disorder were among the top neurological conditions contributing to years of life lived with disability.[16] Regarding sensory impairments, in 2019, about 400 million people had moderate to complete hearing loss.[17,18] In 2020, around 295 million had moderate or severe vision impairment and 43 million had blindness.[19] Furthermore, children and young people with neurodevelopmental conditions (health conditions affecting the developing nervous system and causing several impairments types) accounted for about 317 million people in 2019.[20] Of course, people may experience multiple types of impairment, particularly as they age. Nevertheless, disability is diverse, and health and support needs vary across people in different settings. Thus, having the same health condition or impairment type does not equal needs and experiences across groups, as these are mediated by their context and circumstances.[9]

1.4 | Pathways linking disability to poorer health

Although people with disabilities can have good health and live healthy lives, it is common that they have greater health needs and experience worse health than the general population (Figure 2).[1–3]

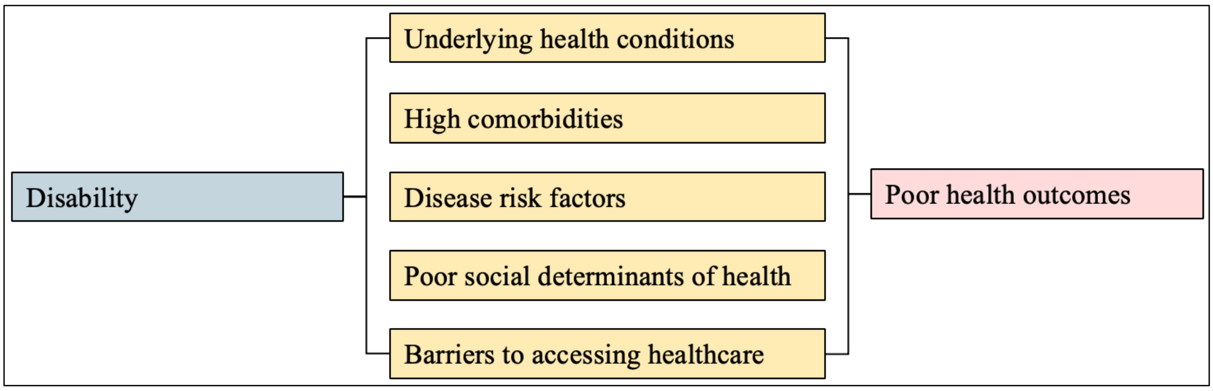


Figure 2. Pathways to poorer health outcomes among people with disabilities

First, they often have increased health needs due to underlying health conditions or impairments (e.g., rare genetic disorder with higher propensity to recurrent respiratory infections).[1,2,5,9] In addition, they usually have a higher prevalence of comorbidities.[1,2,9] For example, people with disabilities are more likely to have diabetes and cardiovascular disease.[21–23] Furthermore, people with disabilities are often exposed to disease risk factors, such as smoking and poor diet.[1,24] Additional pathways to poorer health are linked to social determinants of health.[25] People with disabilities are more likely to live in poverty and have additional costs related to disability (i.e., transportation, assistive technology, etc.), which restricts, among other things, access to timely and continuous healthcare.[1,26] They are also often excluded from education and employment,[1] which can be linked to poorer mental health and restricted access to public health interventions. For example, children with disabilities are more likely to never attend or drop out school due to a lack on inclusive education and appropriate accommodations.[20,27] Similarly, adults with disabilities are more likely to be unemployed than those without disabilities, especially among women with disabilities.[1,28] Furthermore, discrimination and stigma towards disability is strongly rooted in society across the world.[1,29] These cultural and societal aspects contribute to social exclusion and negatively impact health equity and wellbeing among people with disabilities. Hence, all these complex and interrelated pathways to poorer health explain the increased need for both general and, in some cases, specialist or rehabilitation services among people with disabilities.

1.5 | Conceptualizing access to healthcare

Access to healthcare relates to the ability of individuals to receive timely, affordable, and appropriate medical care when needed. It is therefore a complex and multi-dimensional concept, including components such as coverage of services, quality, and affordability. Moreover, it can be viewed from the perspective of societal level coverage and individual coverage.

Universal Health Coverage (UHC) implies "that all people have access to the full range of quality health services they need, when and where they need them, without financial hardship. It covers the full continuum of essential health services, from health promotion to prevention, treatment, rehabilitation, and palliative care".[30] UHC considers the dimensions of population coverage, service coverage, and financial protection (Figure 3).[31] This framework is useful to examine these key outcomes of healthcare access from the population or societal perspective, and it will be applied in this thesis.

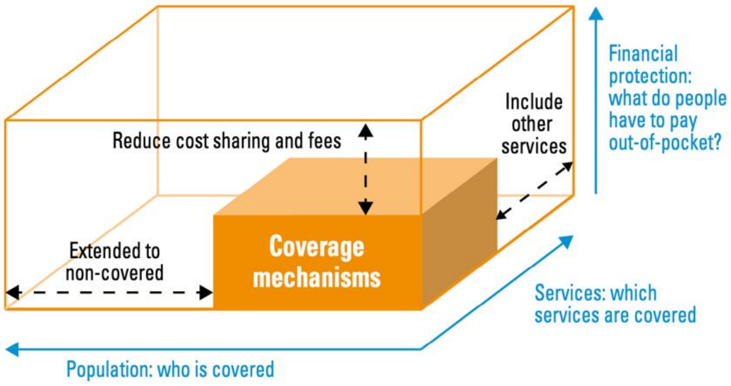


Figure 3. Dimensions of Universal Health Coverage [31]

Population coverage indicates who are entitled to healthcare according to law, which may depend on the fulfilment of certain eligibility criteria (e.g. employment status) and enrolment in insurance schemes.[32] Under UHC, it is expected that countries progress towards coverage of the whole population – every individual and community – irrespective of their circumstances. It also means that countries should *leave no one behind*, and first reach those who are furthest behind, such as women, children, young people and older persons, people living with HIV/AIDS, refugees, internally displaced persons, and migrants, people of African descent, Indigenous Peoples, people living in poverty and in inadequate housing conditions, and people with disabilities.[33]

Service coverage and financial protection are the two UHC dimensions globally monitored under the Sustainable Development Goals.[33] Coverage of essential health services is assessed based on 14 selected indicators on reproductive, maternal, newborn, and child health, communicable and noncommunicable diseases, and service capacity and access.[34] For instance, antenatal care is monitored as the proportion of women who attended at least four antenatal care visits in their last pregnancy. Yet, further understanding is needed on service coverage gaps regarding unmet need (i.e., persons with realized or unrealized health need that is not adequately met) and reasons for forgoing care (i.e., persons with realized health need unable to access healthcare due to a range of barriers).[34] Similarly, information about effective service coverage – health interventions of sufficient quality and quantity to achieve desired health outcomes – remains limited by lack of consensus on its measurement and availability of data.[34]

Finally, the financial protection dimension of UHC implies that people can demand for the health services that they need, without facing financial barriers, and in case of having out-of-pocket health payments when using services, these are neither catastrophic nor impoverishing. This UHC dimension is assessed, for instance, through financial hardship indicators such as catastrophic health spending (i.e., out-of-pocket spending above 10% of the household's income).[34]

To monitor UHC among sub-groups and *leave no one behind,* equity should then be examined by disaggregating indices and indicators by age, sex, disability, etc. Yet, global estimates on UHC inequities are rarely obtained due to lack of disaggregated data.[34] Nevertheless, extensive evidence suggests that people with disabilities face difficulties in the key dimensions of UHC.[1] They often have worse health coverage, unmet need for care, and experience financial hardship, poor quality, and follow-up treatments.[1,2,33,35,36] Hence, the global commitment of members states in reaching the Sustainable Development Goal 3 "Ensure healthy lives and promote well-being for all at all ages" by 2030 and the achievement of the target 3.8 on Universal Health Coverage are unlikely to be fulfilled, if the health needs of people with disabilities are not addressed (Figure 4).[1,33]

Figure 4. Sustainable Development Goal on good health and well-being [37]

Access to healthcare can also be considered at the individual level. Along the healthcare journey, several aspects are involved in ensuring access to healthcare for an individual and at the point of service delivery. Levesque's framework on healthcare access helps to depict the different dimensions involved in this process, and it will be applied in this thesis (Figure 5).[38] This framework conceptualizes access to healthcare "as the opportunity to identify healthcare needs, to seek healthcare services, to reach the healthcare resources, to obtain or use healthcare services, and to actually be offered services appropriate to the needs for care", and it takes the perspective of the individual rather than the population.[38] Both the demand and supply-side factors of access to healthcare are intertwined in the patient journey. The dimensions on the supply-side include the accessibility of health services (approachability, acceptability, availability and accommodation, affordability, and appropriateness) and the corresponding abilities of individuals – on the demand-side – to perceive, seek, reach, pay, and engage in healthcare.[38] The following simplified case would be a successful example on access to healthcare. For instance, a Deaf woman realizes the need for cervical cancer screening and manages to book an appointment in a primary healthcare centre nearby her home, which has sign language interpreters available. The test is fully covered by the health insurance and after the appointment she is scheduled for a follow-up. In this case, the health facility has successfully informed the community on the eligibility for screening, health workers are trained on disability, appropriate accommodations are available, and continuation of care is coordinated for its population. Thus, the person has effective coverage of a cancer screening service.

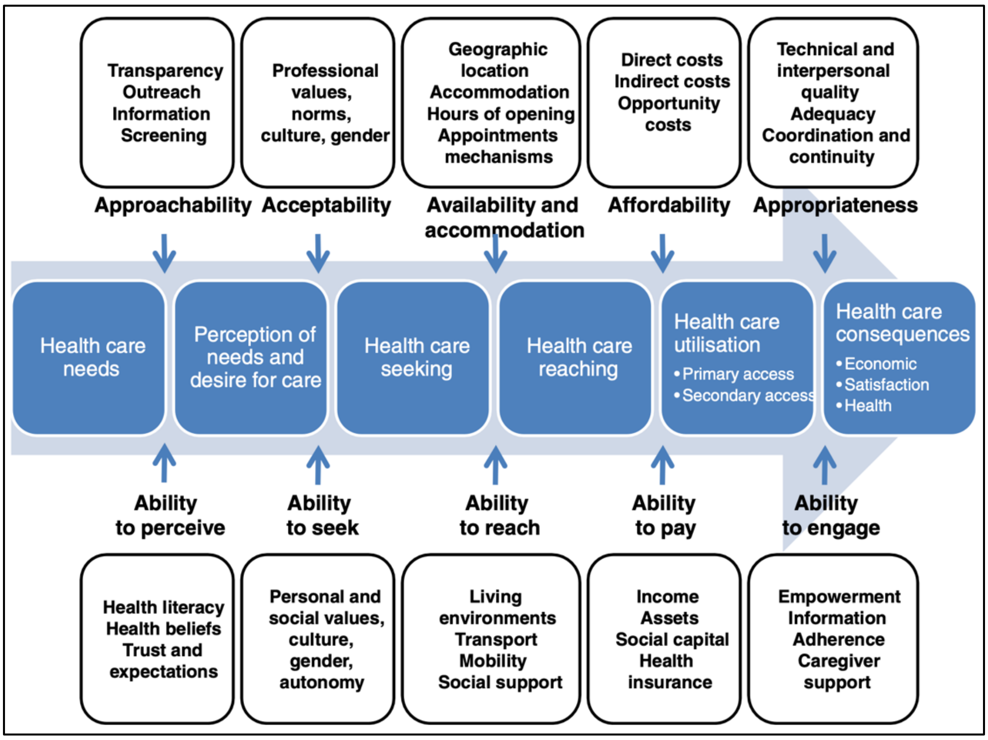


Figure 5. Levesque conceptual framework on access to healthcare [38]

1.6 | Barriers in accessing healthcare and health inequities among people with disabilities

Despite having greater healthcare needs, people with disabilities often experience multiple barriers in accessing health services along the healthcare seeking journey, in both the supply and demand-side factors described in the Levesque model. Quantitative and qualitative evidence suggests that people with disabilities frequently experience low health literacy, lack of awareness of health needs, as well as poor social support to access healthcare.[39–44] They also face attitudinal barriers such as stigma, discrimination and low respect of autonomy, and health workers with poor training, knowledge, and awareness about disability.[39–41,43–46] There is often a lack of accessible information and communication, inclusive infrastructure and equipment in health facilities, and inaccessible transportation services.[39–41,43–46] Additional barriers comprise the lack of reasonable accommodations and financial issues such as lack of access to health insurance.[39,41,44,45]

All these barriers hamper access to healthcare and contribute to worse health outcomes. Thus, people with disabilities face critical health inequities (i.e., differences in health that are unfair and largely avoidable and not inequalities explained by underlying health conditions).[1] A recent global study estimated that, on average, people with disabilities die about 14 years earlier than the general population, with even higher life expectancy gaps in low- and middle-income settings.[47] An elevated risk of mortality was associated with sensory, intellectual, and mixed impairments as well as psychosocial disabilities.[47] Further differences in health outcomes include higher morbidity and functioning limitations. For instance, people with disabilities have poorer oral health than those without disabilities (i.e., untreated dental disease, edentulous status, etc.) [48–50] and inaccessible health centres, transportation, and spaces for social participation act as environmental barriers that more often affect people with disabilities.[1] These issues, however, do not equally affect all people with disabilities. Different intersecting factors such as age, gender, socioeconomic status, impairment type, sexual orientation, race, indigenous populations, migration, and displacement may enhance or reduce vulnerabilities.[1,29]

1.7 | The call for inclusive health systems for people with disabilities

Barriers and health inequities among people with disabilities pose negative human rights implications. According to article 25 of the UNCRPD, people with disabilities have the right to health on an equal basis with others.[8] The ratification of this convention in most countries is a primary step towards disability inclusion, but further action is required for "the meaningful participation of people with disabilities in all their diversity and the promotion and mainstreaming of their rights into the work of the health sector".[51] Hence, in light of the persistent health inequities, the 2019 UHC political declaration called for the inclusion of people with disabilities.[52] Two years later, the 74th World Health Assembly adopted a resolution on the "highest attainable standard of health for persons with disabilities".[53] The resolution highlighted the commitment of member states and guides the role of Ministries of Health concerning disability inclusion in health systems. It also reinforces, among other things, the importance to develop a global research agenda on disability-inclusive health, including research on health policy and systems.

In this context, the Missing Billion Inclusive Health Systems Framework provides a structured approach to considering why health systems failures occur and how they can be addressed by highlighting key areas for assessment (Figure 6).[2,3] As observable barriers to healthcare arise from health system level failures, the framework does not only highlight relevant aspects at service delivery level, but also systemic factors crucial to ensure disability-inclusive health. The framework – applied in this thesis – emphasises the importance of governance, leadership, health financing, and data and evidence in determining health outputs and outcomes experienced by people with disabilities.[2,3] These structural system level components should comprise a minimum set of standards such as in-country laws and policies that protect the rights to health, representation of disability-related issues in the Ministries of Health, available budget for disability, and routine data to monitor the needs and health outcomes of people with disabilities.[2,3] Furthermore, key components comprise the demand and supply-side of service delivery. People with disabilities should have autonomy and awareness regarding their health and be able to afford health services. In addition, there should be accessible health facilities with health workers trained on disability and sufficient availability of rehabilitation services and assistive technology.[2,3] Progress across these components will help build health systems that "expect, accept, and connect" people with disabilities to access quality care and health services intentionally designed to include them.[3,54]

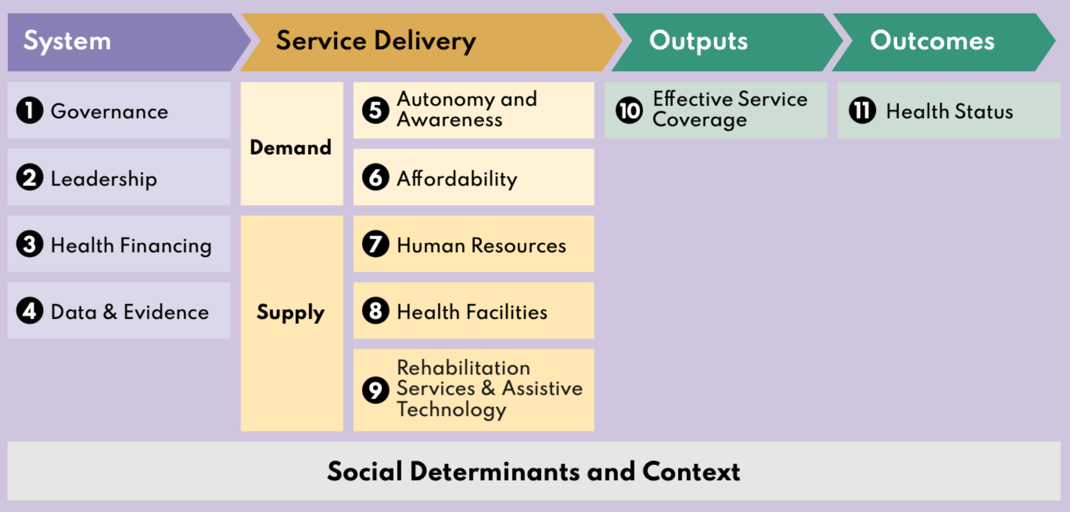


Figure 6. Missing Billion Inclusive Health Systems Framework [3]

1.7 | The case of Chile: disability and healthcare access

1.7.1 Chile's health system

Chile is a South American country with an increasingly aging population of nearly 20 million people.[55] The country extends about 4300 km from north to south and its climatic and geographical diversity (i.e., extremely arid region in the north and remote islands and fjords in the southern tip) pose unique challenges to the delivery of health services.[56] Chile's classification as a high-income country by the World Bank conceals high levels of income inequality (44 according to Gini Index) and a 7% poverty level by income according to the 2022 National Socioeconomic Survey.[57,58] Its nominal gross-domestic product (GDP) per capita was of US$17,000 in 2023.[57] Moreover, in 2022, the country's government health expenditure per capita was of US$755 and out-of-pocket expenditure – as a share of current health expenditure – was of 29%, compared to an average of 13% in Organization for Economic Cooperation and Development (OECD) countries.[57]

Chile has a dual health system including a public health insurance scheme provided by the National Health Fund (*Fondo Nacional de Salud, FONASA*) covering about 79% of the population and a private health insurance scheme (*Instituciones de Salud Previsional, ISAPRES*) covering around 16%.[59,60] Its dual structure originates from a health sector reform during the military regime between 1979 and 1986, under principles such as "individual freedom, justice, property rights, and subsidization".[61,62] Before the military coup, a National Health Service was in place, which was then transformed and decentralized to regions.[61] Nowadays, the Ministry of Health is structured by two Under-Secretariats. The Under-Secretariat of public health leads health policy while the Under-Secretariat of Healthcare Networks oversees healthcare provision in the public sector. The public health network is mostly state funded and is led by 29 Regional Health Services coordinating secondary and tertiary care (i.e., hospitals, specialist centres, etc.).[59,63] Primary healthcare is managed by municipalities (i.e., local governments) across the 346 communes in the country.[59] Furthermore, health service delivery is performed by both public and private healthcare providers. FONASA has a public-private partnership, whereby publicly insured beneficiaries can access care through private providers to bridge health service delivery gaps.[63]

In Chile, all workers must pay mandatory contributions – 7% of their income – to either the public or private health insurance scheme.[59] FONASA enrols any resident of the country as well as their legal dependents, regardless of their age, gender, income level, pre-existing health conditions, or nationality.[64] The health plan by the public health insurer is standard and beneficiaries are categorized by income level (groups A, B, C, or D; ranging from no resources in group A to a monthly gross income above USD ~752 in group D, as of December 2024).[60,64] All FONASA beneficiaries are entitled to zero copayments under the Institutional Care Scheme, whereby health services are free of charge under the public health network, according to a recent health reform in 2022 aiming to improve financial protection.[65] Furthermore, beneficiaries of groups B, C, and D are eligible to opt to private health services under the Free Choice Scheme by making copayments.[64] In contrast, those affiliated to private health insurers are offered individual health plans depending on their risk of illness and pay on average 10% of their income.[60] In this context, people with pre-existing health conditions had been subject to "skimming practices" of private insurers that aimed to drop out people with risky health profiles.[61,66,67] Several public health reforms have intended to eliminate such practices.[66] For instance, recent regulations have aimed to prohibit discrimination to enrol in private health schemes based on the existence of congenital health conditions and mental health conditions and psychosocial disabilities.[66,68,69] However, their impact is yet to be observed, since measures appear not to have been consistently implemented thus far.[66] Hence, people with higher health risks and lower income levels might still be more likely to be enrolled in the public health insurance scheme, without effective "choice" to opt out of the system.[60]

In 2005, Chile committed to Universal Health Coverage as part of a comprehensive national healthcare reform; to date 87 health conditions have guaranteed access through the Explicit Health Guarantees program (GES).[61,70] This program guarantees access, timeliness, quality, and financial protection for selected health conditions to those affiliated to the public or private health insurance scheme.[70] Evidence has shown that GES has increased the use and coverage of health services targeting selected health conditions, particularly among those from lowest-income levels.[62,71–73] Thus, the program appears to have influenced the efficiency of the health system and reduced unmet health needs.[62,73] However, differences in use and inequities persist across groups (e.g. by vulnerability, insurance type, etc.) and gaps remain in quality, barriers to care, and health conditions not covered by GES.[62,71–74]

Moreover, the 2019 OECD review of Chile’s public health system recommended to improve patient health literacy and participation, as patient groups reported that they lack information on their entitlements and the prioritization process for health conditions under GES.[59] Further actions for improvement of the overall health system included reducing the high burden of obesity and tobacco consumption and pushing private insurers to engage in health promotion activities.[59] The assessment also highlighted the need to strengthen epidemiological surveillance and public health genomics and increase cancer screening coverage.[59] In this context and addressing some of the OECD recommendations, Chile’s health system is currently undergoing a UHC reform with 14 pioneer primary care centres, to improve universal access to primary healthcare without discrimination by health insurance type.[75]

1.7.2 Epidemiology of disability in Chile

Estimates of the 2022 National Disability Survey indicate that 17% of the population in Chile (2 years and above) experiences disability (about three million people).[76] This survey with 35,536 participants, measures disability according to the WHO’s Model Disability Survey.[77] The majority of people with disabilities are women (20% versus 14% in men) and persons aged over 60 years.[76] About 6% have mild to moderate disabilities and 11% have severe disabilities.[76] The most frequently reported long-lasting conditions among adults with disabilities include physical impairments (38%) and psychosocial impairments (14%) among children and adolescents with disabilities.[77] Regarding dependence, 55% of people with disabilities report requiring assistance from another person.[77] Carers are usually women (spouses/partners, daughters) who assist their family member with disabilities within the household as a non-remunerated activity.[77]

1.7.3 Barriers in accessing healthcare and health inequities among people with disabilities in Chile

Even though Chile has taken steps towards UHC and disability-inclusion, there is emerging evidence that people with disabilities face health inequities and experience barriers that prevent them from equal access to healthcare. For instance, around 71% of adults with disabilities report to have comorbidities (i.e., three or more health conditions).[77] Moreover, women with disabilities have lower coverage of cancer screening,[78,79] and adults with disabilities more often have difficulties to pay for care, compared to those without disabilities.[80]

In 2008, Chile ratified the UNCRPD and in 2010 the National Disability Law (Nº20,422) was enacted, promoting equal opportunities and social inclusion of people with disabilities.[81,82] However, only a few people with disabilities are knowledgeable about this law (24%) and the UNCRPD (13%).[77] In addition, only 12% of adults with disabilities (8% of children) are registered in the National Disability Registry, even though certification provides social protection and additional benefits, such as preferential healthcare access and increase coverage of some rehabilitation services.[77,83,84] Therefore, people with disabilities may have limited awareness of their rights and health needs, although the latter is compounded by additional barriers. The low level of registered people with disabilities has also been explained by the difficult access to disability assessments and discrimination related to disability certification, particularly among people with psychosocial disabilities.[85]

Additional difficulties lie in the experiences of social exclusion and problems to afford, reach, and access appropriate health services. People with disabilities have lower average income levels and only 44% of adults with disabilities – in working age groups – are employed or searching for employment opportunities (versus a 68% among those without disabilities).[77] In 2022, about 22% of people with disabilities faced multidimensional poverty compared to 16% in those without disabilities.[58] Moreover, the public transportation system is perceived as the main environmental barrier (50%) by people with disabilities.[77] In addition, access to healthcare in Chile is highly provider dependent and the private sector appears to offer better availability and appropriateness of health services.[80] Since a high number of people with disabilities are affiliated to the public health insurance scheme (88%), they may often experience difficulties to access quality care.[77] For instance, people with disabilities in private insurance schemes are 3.6 times less likely to experience problems receiving healthcare at a health facility compared to those publicly insured.[80]

Further barriers to accessing healthcare by people with disabilities are related to poor knowledge about disability among health workers in Chile. A study including a sample of primary care centres across two regions indicated that most healthcare workers had not received disability-related training and that only 20% of respondents knew about the National Disability Law.[86] Lack of knowledgeable health workers and poor attitudes can result in discrimination. In fact, around 26% of people with disabilities reported to have felt generally discriminated due to their disability, especially among children between 10 to 17 years

(68%).[76,77] Hence, training of healthcare workers on the rights of people with disabilities was demanded by Organizations of People with Disabilities (OPDs) to the Committee on the Rights of People with Disabilities.[87]

Inaccessible health facilities are also regarded as a significant barrier of the environment by people with disabilities (40%).[88] One study showed that 59% of primary healthcare workers consider that the infrastructure of health facilities is inadequate for people with disabilities; there is often insufficient space for wheelchairs, a dearth of ramps, and accessible bathrooms.[86] Furthermore, OPDs have flagged the importance of clear protocols and accessibility of information (i.e. Braille, sign language, and easy-to-read formats).[87] In primary care a high number of health workers (77%) declared not having protocols in place to ensure appropriate services for people with disabilities and enough time to provide quality care (69%).[86] Therefore, these issues can likely result in inadequate provision of accommodations and accessible environments that could meet people's needs.

In summary, existing literature shows that disability is common around the world and that there is consistently higher prevalence of health needs and worse healthcare access among people with disabilities. Nevertheless, there are relevant knowledge gaps – particularly disability inclusion in universal health coverage and health policy and systems – including in Chile, which this thesis aims to address.

Chapter 2

Research aim, objectives, and methods

The aim of this doctoral thesis is to assess the inclusion of persons with disabilities in the health system of Chile and to provide evidence-based recommendations for improvement. To address this aim, this thesis uses quantitative and mixed methods research. The latter intentionally integrates quantitative and qualitative data sources to maximize the strengths of each method and triangulate information, addressing the complexity of health systems.[89] Mainly two methodological frameworks guide this thesis, including the Universal Health Coverage [31,34] and the Missing Billion Inclusive Health Systems Framework.[2,3] Moreover, this body of work is underpinned by a post-positivist/critical realist epistemological position – whereby phenomena exist independently of social actors, although acknowledging the influence of actors' interpretations of reality [90] – and pragmatism – whereby research questions guide the selection of feasible, mixed research methodologies that can usefully inform policy and practice, beyond the classical divide of research paradigms.[90,91]

Four sub-studies build the core of this "Research Paper Style" thesis: (1) a systematic review, (2) a secondary data analysis, (3) a health policy analysis, and (3) a health system assessment. The specific research objectives of each sub-study are presented below.

1. To systematically review the quantitative literature on access to general healthcare among people with disabilities, compared to those without disabilities, in Latin America and the Caribbean
2. To compare healthcare utilization, coverage, and barriers to accessing health services among people with and without disabilities in Chile.
3. To assess the inclusion of people with disabilities in Chilean general healthcare policy documents and to explore the perceptions of key national stakeholders regarding the policy context, policy processes, and actors involved.
4. To undertake a national assessment of the inclusion of people with disabilities in the health system of Chile and define recommendations for improvement based on the evidence.

The systematic review was the first sub-study conducted to obtain an overview of the evidence in Latin America and the Caribbean and identify key knowledge gaps. Subsequently, the health policy analysis was undertaken with in-depth research of governance and leadership on disability and health in Chile. Then, the overall assessment of disability inclusion in the Chilean health system was conducted, also using the preliminary evidence of the systematic review and health policy analysis. Finally, the secondary data analysis was the last sub-study conducted, providing the evidence of gaps in universal health coverage and health inequities among people with disabilities at the individual level in Chile. All sub-studies and their implications are linked together in Chapter 7 of this thesis. Table 1 below summarizes the methods and publication status of each research paper.

Table 1. Overview of research methods and publication status for each paper

Research objectives	Data source	Methods	Publication status, journal, and link	Thesis chapter
1	Published peer-reviewed literature	Systematic literature review of quantitative research articles.	• Published • Lancet Regional Health Americas • Link to paper	3
2	2022 National Socioeconomic Survey of Chile	Secondary cross-sectional analysis using multivariable logistic regressions.	• Under Review • Public Health	4
3	Health policy documents and interview transcripts	Policy content analysis using the EquiFrame and key informant interviews.	• Published • International Journal for Equity in Health • Link to paper	5
4	Policy documents, peer-reviewed and grey literature, and interview transcripts	Health system assessment using the Missing Billion System Level Assessment Toolkit, key informant interviews and workshops.	• In press • Health Research Policy and Systems • Link to preprint	6

Chapter 3

Access to general health care among people with disabilities in Latin America and the Caribbean: a systematic review of quantitative research

3.1 | Chapter preamble

Currently, there is a global call to document health inequities experienced by people with disabilities to advance disability-inclusive healthcare.[53] To address this call, the present chapter introduces a systematic review on access to healthcare among people with disabilities in Latin America and the Caribbean. At the time of this study, updated quantitative evidence, including non-English literature and studies from high-income countries, was lacking from the Latin America and the Caribbean region on disability and universal health coverage. The study aimed to systematically review the quantitative literature on access to general healthcare among people with disabilities, compared to those without disabilities, in the region. This quantitative research with a narrative synthesis defined disability according to the existing disability models presented in Chapter 1 and followed the UHC framework.[30,31]

Only 30 quantitative studies published between 2000 and 2023 were included in the review – three with medium risk of bias from Chile – showing the need for further evidence on health inequities experienced by people with disabilities. Namely, further evidence on coverage, affordability, and quality of care is required. This chapter provides an overview of the literature available in the region and helps identify key knowledge gaps. Consequently, it enabled the refinement of the research objective for the following Chapter 4 on healthcare access among people with disabilities in Chile. Additionally, the findings of the review have implications for UHC among people with disabilities as well as research implications regarding the framing of disability and the measurement of healthcare access, both presented in Chapter 7.

This systematic review was published in the journal *The Lancet Regional Health Americas* in March 2024 following peer-review. Appendices of this study can be found in Appendix A.

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

SECTION A – Student Details

Student ID Number	2004713	**Title**	Mrs
First Name(s)	Danae Harmonia		
Surname/Family Name	Rodríguez Gatta		
Thesis Title	Access to healthcare among people with disabilities in Chile		
Primary Supervisor	Hannah Kuper		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	The Lancet Regional Health - Americas		
When was the work published?	8 March 2024		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	**Yes**	Was the work subject to academic peer review?	**Yes**

*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	
Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I have conceptualized the study, developed the search strategy and conducted the search, screened and extracted data, drafted the paper, and compiled the final manuscript.

SECTION E

Student Signature	Danae Rodríguez Gatta
Date	4 September 2024

Supervisor Signature	Hannah Kuper
Date	4 September 2024

Access to general health care among people with disabilities in Latin America and the Caribbean: a systematic review of quantitative research

Danae Rodríguez Gatta,[a,b,] Sara Rotenberg,[c] Kasim Allel,[d,e] Veronika Reichenberger,[a] Lena Morgon Banks,[a] and Hannah Kuper[a]*

[a]International Centre of Evidence in Disability, Department of Population Health, Faculty of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, London, United Kingdom
[b]Millennium Nucleus Studies on Disability and Citizenship (DISCA), Chile
[c]Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, United Kingdom
[d]Department of Disease Control, Faculty of Infectious & Tropical Diseases, London School of Hygiene and Tropical Medicine, London, United Kingdom
[e]School of Government, Pontificia Universidad Católica de Chile, Santiago, Chile

The Lancet Regional Health - Americas
2024;32: 100701

https://doi.org/10.1016/j.lana.2024.100701

Summary

In Latin America and the Caribbean (LAC), there are 85 million people with disabilities (PwD). They often experience barriers accessing healthcare and die, on average, 10–20 years earlier than those without disabilities. This study aimed to systematically review the quantitative literature on access to general healthcare among PwD, compared to those without disabilities, in LAC. A systematic review and narrative synthesis was conducted. We searched in EMBASE, MEDLINE, LILACS, MedCarib, PsycINFO, SciELO, CINAHL, and Web of Science. Eligible articles were peer-reviewed, published between January 2000 and April 2023, and compared healthcare access (utilization, coverage, quality, affordability) between PwD and without disabilities in LAC. The search retrieved 16,538 records and 30 studies were included, most of which had a medium or high risk of bias (n = 23; 76%). Overall, the studies indicated that PwD use healthcare services more than those without disabilities. Some evidence indicated that women with disabilities were less likely to have received cancer screening. Limited evidence showed that health services affordability and quality were lower among PwD. In LAC, PwD appear to experience health inequities, although large gaps exist in the current evidence. Harmonization of disability and health access data collection is urgently needed to address this issue.

Keywords: **Systematic review; People with disabilities; Latin America; Caribbean; Access to healthcare; Health equity**

Introduction

Worldwide, there are 1.3 billion people with disabilities, a diverse group of persons with long lasting physical, mental, intellectual or sensory impairments who often face various barriers that restrict them from an equal participation in society.[1,2] This number is expected to increase further in the coming decades due to population ageing and the rise of chronic diseases.[1] People with disabilities often have greater health needs than the general population because of baseline health conditions and increased comorbidities.[1,3] However, they also frequently lack access to essential and high-quality health services due to several system- and individual-level barriers, which further increase health inequities.[3] Systemic barriers (ie, that arise at the level of the health system) include low availability of services, poor healthcare worker training, stigma and low physical and communicational accessibility along the healthcare journey.[1,3–5] While transport and substantial additional living costs, as well as low autonomy and awareness of access to healthcare, are some of the barriers people with disabilities face at the individual level.[1,4] Consequently, people with disabilities frequently have poorer health and on average die 10–20 years earlier than those without disabilities, even under circumstances that could have been avoided.[1,4,6] This life expectancy gap is even higher among low- and middle-income countries (LMICs).[6] This is why member states of the United Nations (UN) recently committed to disability inclusion in healthcare systems, including essential health services and public health interventions.[7]

Bright and Kuper (2018) explored English quantitative research on access to general healthcare services for people with disabilities in LMICs between 1995 and 2015.[8] General healthcare corresponded to essential health services (eg, antenatal care, immunization, etc.),

---

*Corresponding author. International Centre of Evidence and in Disability, Department of Population Health, Faculty of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, London, WC1E 7HT, United Kingdom.

E-mail address: danae.rodriguez@lshtm.ac.uk (D. Rodríguez Gatta).

excluding specialist health services. The included articles used a wide range of disability and healthcare access outcomes and 46% of included studies had medium or high risk of bias, restricting the possibility to draw robust conclusions.[8] Since this systematic review, further reviews have looked at the qualitative evidence,[9] barriers to access healthcare,[10] or access for specific types of disabilities.[11]

After Europe, the Americas have the highest prevalence of disability globally (19%)[1] and about 85 million (15%) people have disabilities in Latin America and the Caribbean (LAC).[12] The LAC region represents a diverse set of countries with important sub-regional socio-economic and health differences. In general, central America has the highest poverty rates, in contrast to the Southern Cone, although the entire region has consistently been characterized by inequality.[12] In most countries of LAC, primary healthcare is delivered by public health providers, although countries differ in their organization of basic health coverage.[13] For instance, some countries have national health systems (Belize, Brazil, Ecuador, El Salvador, Guyana, Honduras, Jamaica, Panama, Paraguay and Trinidad and Tobago), while others have contributory health coverage with multiple insurers (Bolivia, Chile, Colombia, Dominican Republic, Guatemala, Mexico, Peru, Suriname).[13] Furthermore, most countries protect populations with low-income against out-of-pocket payments and catastrophic health spending, but rarely other vulnerable groups.[13] Some well-known structural weaknesses in the health systems in LAC include fragmentation (both between public and private health systems, and within public healthcare), inequality in health access, financial constrains (eg, lowest health spending in Haiti, Venezuela, and Honduras), and lack of human resources and infrastructure.[14,15]

Disability can overlap with multiple vulnerabilities of other groups such as women, children, elderly, ethnic minorities, LGBTI+ people and migrants, whose representation varies widely across LAC.[12] Yet, analysis on healthcare access with disability lens remains scarce. This review will respond to the current call of UN member states to document health inequities experienced by all people with disabilities and further build evidence on healthcare access for LAC.[7] More than ten years have passed since the Pan American Health Organization established a regional strategy to improve disability data[5] and, despite the efforts to overcome this statistical invisibility, robust diagnostic analyses are still needed.[12] The COVID-19 pandemic revealed the still poor and unsystematic information about people with disabilities and healthcare.[16] Thus, an in depth and systematic analysis will help identify the evidence available and the remaining data gaps in healthcare access (utilization, coverage, quality, and affordability of health services).[17]

The research question addressed by this review is whether people with disabilities experience inequalities in access to healthcare in Latin America and the Caribbean. The aim of this study is to systematically review the quantitative literature on access to general healthcare among persons with disabilities, compared to those without disabilities, in LAC. This systematic review will improve upon the previous review of Bright and Kuper (2018) by capturing recent evidence and trends in access to general healthcare and including high-income countries of LAC and non-English studies, which have been previously excluded from systematic reviews.[8,9]

Methods

This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines[18] (Supplementary Material 1) and was registered in the Prospective Register of Systematic Reviews (PROSPERO) under the following number: CRD42021235797.

Search strategy and selection criteria

Studies were eligible if they were peer-reviewed articles of quantitative research with interventional or observational study designs (eg, cohorts, case–control, cross-sectional, etc.) carried out in Latin American and Caribbean countries, as defined by the World Bank in 2023.[19] They must have been published since 2000 onwards and written in English, Spanish, Portuguese, French, or Dutch. Quantitative sections from mixed methods studies were considered. Qualitative studies, studies conducted outside LAC or multi-country studies that did not provide disaggregation for a country in LAC were excluded as well as editorials, commentaries, letters to the editor, systematic reviews, case reports, study protocols, conference abstracts, and grey literature.

Participants were people with disabilities of any gender and age group, including those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.[2] Disability was defined in the study according to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the International Classification of Functioning, Disability and Health or the Social Model of Disability. It included people with specific conditions deemed likely to result in disability (eg, dementia, spina bifida, schizophrenia, etc., as listed in Iemmi et al., 2015)[20] as well as disability measured through functioning or activity limitations (eg, Washington Group questions, activities of daily living). We excluded people with mild disabilities (eg, symptoms of depression alone rather than clinical diagnosis or major depressive disorder, some difficulty in one activity of daily living/functioning domain or mild cognitive difficulties).

Eligible studies had to include one of the following measures of access to healthcare: coverage, utilization, quality, and affordability of health services. This conceptualization was based on the World Health Organization's definition of universal health coverage and its progress monitoring indicators of coverage of essential health services.[17,21] Among eligible studies, we also included the following secondary outcomes if available: adherence to health treatment or barriers to accessing healthcare. Outcomes could be measured within any type of general health services. The studies must have had a comparison group of people without disabilities and report measures of effect comparing people with and without disabilities.

Peer-reviewed published articles were searched on April 12th, 2023, through eight databases: EMBASE, MEDLINE, LILACS, MedCarib, PsycINFO, SciELO, CINAHL, and Web of Science. In addition, the reference lists of relevant systematic reviews were checked to identify potential articles. No language restrictions were applied; however, a date filter was applied to identify papers published after 2000. Comprehensive search strings were built with keywords and thesaurus and MeSH terms. Search terms were also identified in the full manuscript of other reviews of similar topics. The search was also conducted in Spanish and Portuguese, as these are the two main regional languages. An information specialist of London School of Hygiene and Tropical Medicine reviewed and approved the search strategy (Supplementary Material 2).

Two reviewers independently screened study titles, abstracts, and full text against the eligibility criteria. They then compared results and reached a consensus at each stage. A third reviewer resolved uncertainty or disagreement. Rayyan software was used for screening articles and recording decisions.[22]

Data analysis

Two reviewers independently extracted data of studies selected and agreed on results. A third reviewer resolved any disagreement between individual judgements. From each article the following information was extracted: citation details, study location, study design, participant characteristics (sex, age group, type of disability and method of assessment), outcome measures and method of assessment, results among participants with and without disabilities, summary of results (eg, measures of effect), type of health service used, barriers to healthcare and quality measures. Data extracted were recorded in a Microsoft Excel spreadsheet.

A narrative synthesis was conducted on each type of outcome of access to healthcare. Summary of results with measures of effect (eg, prevalence ratios with 95% confidence intervals [CI]) presented as unadjusted, age-sex adjusted and/or multivariable adjusted or mean with standard deviation were collected. Results were organised in subgroups according to outcome measurements and thereafter according to type of

1	Study design, sampling method is appropriate to the study question
2	Sample size calculations presented
3	Response rate reported and acceptable (>70%)
4	Disability measure clearly defined and reliable
5	Health access measure clearly defined and reliable
6	Confidence intervals or standard deviations are presented
7	Potential confounders taken into account in analysis
8	Case-Control: cases and controls are comparable (e.g., by sex and age group)
9	Case-Control: clear case control definitions
10	Cohort: groups being studied comparable at baseline in all respects other than the factor under investigation.
11	Cohort: Losses to follow up are presented and acceptable
Risk of bias	**LOW:** All or almost all of the above criteria were fulfilled, and those that were not fulfilled were thought unlikely to alter the conclusions of the study
	MEDIUM: Some of the above criteria were fulfilled, and those not fulfilled were thought unlikely to alter the conclusions of the study
	HIGH: Few or no criteria were fulfilled, and the conclusions of the study were thought likely or very likely to alter with their inclusion.

Table 1: Quality assessment criteria.

impairment (mental, physical, sensory, intellectual, or multiple impairments). Finally, a meta-analysis was intended for synthesis of results in case of sufficient homogeneity in healthcare access outcomes and across disability-specific groups.

Included studies were independently checked against quality criteria and then assessed for risk of bias by two reviewers using an adaptation of the SIGN50 guidelines.[23] Risk of bias was assessed through the study design, participants, outcomes and data analysis and additional criteria were available for case–control and cohort studies regarding the comparability of the groups and study design (Table 1). Any disagreement was discussed together with a third reviewer. Each study was graded as low, medium, or high risk of bias, depending on the criteria fulfilled and the possibility of altering the conclusions of the study. Studies with high risk of bias were excluded from the analysis of health outcomes.

Results

The initial search retrieved 16,534 records. Four additional studies were found through reference checking.[24–27] After deduplication, the titles and abstracts of 10,927 articles were independently screened. Then, 191 articles were fully screened and finally, 30 studies were included in this systematic review (Fig. 1); of which 8 had been also previously included in Bright and Kuper's (2018) review.[8]

Table 2 shows the main characteristics of the articles included. Most studies had a cross-sectional design (n = 24; 80%), were conducted in Brazil (n = 19; 63%) and in urban areas (n = 19; 63%). Articles were most frequently published in English language (n = 23; 77%) and from 2010 onwards (n = 27; 90%). Most participants were adults (n = 14; 47%) or of mixed age groups (n = 13; 43%). Participants often had any type of self-reported disability (n = 8; 26%) or functioning limitations (n = 8; 26%). Utilisation of healthcare was the most

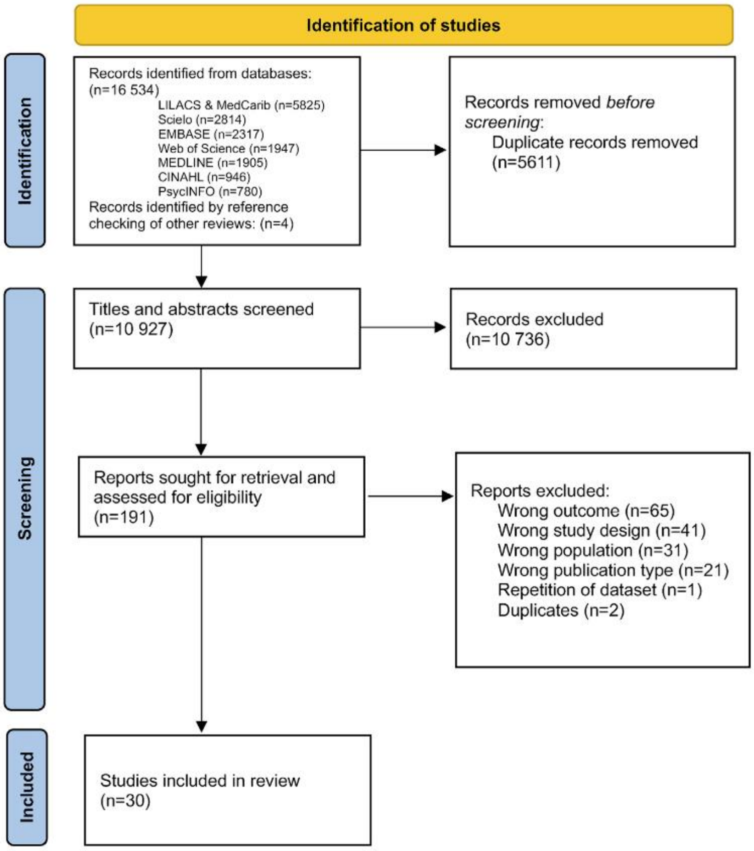


Fig. 1: **PRISMA flow diagram of study selection and identification.**

frequent outcome reported (n = 20; 63%) (Fig. 2). Health services often were outpatient visits (n = 16; 31%) and health treatment or medication (n = 12; 24%). The quality assessment revealed that most studies had a medium risk of bias (n = 16; 53%). Studies with high risk of bias (n = 7) were excluded from the synthesis analysis of health outcomes presented below.[24,28–33]

A meta-analysis could not be performed since there was not sufficient homogeneity in the measurement of disability and healthcare access outcomes. Disability was self-reported, measured through questionnaires, clinical assessments or identified in medical or school records (Table 3). Most studies collected data under a biomedical model of disability (ie, categorised disability according to the presence of impairments or medical conditions) (n = 22; 73%). Most healthcare outcomes were collected through questionnaires and were applied during in-person interviews; only two studies collected data from patient's records within the last 12 months.[46,52] However, healthcare outcomes were measured by different types of services and period (Table 4).

Table 4 shows the summary of outcomes measured, where 17 studies examined differences in healthcare utilization between people with and without disabilities. Nine studies (53%)–eight cross sectional studies and one cohort study–reported strong evidence of a higher utilization among people with disabilities (outpatient visits or hospitalizations).[39,45–52] However, two studies indicated that people with disabilities utilized oral health services less often than people without disabilities.[37,53] Three studies (18%) found some evidence of mixed utilization levels.[34,35,38] The studies focussed on people with hearing impairment or psychosocial disabilities all showed that they utilized health services more often than the comparison groups without disabilities.[45–51] Studies without significant results showed a trend towards either higher (n = 2) or mixed (n = 1) utilization levels among people with disabilities.[40,41,43]

Coverage of key services was examined in five studies, and three found statistically significant differences by disability status among women. For example, women with disabilities had lower coverage of preventive health services such as cancer screening, gynaecological check-ups and antenatal care than those without disabilities.[27,42,51] The rest of the studies indicated either no differences or lower coverage levels.[25,26] Furthermore, the two cross-sectional studies reporting on affordability revealed that people with disabilities had more difficulties affording health services or had catastrophic health expenditures than persons or households without disabilities.[36,44] Finally, a case–control study in Guatemala reported that the quality of healthcare services was lower among people with functional limitations than those without. They found that people with disabilities felt disrespected or found it difficult to understand the information given during a health treatment than people without disabilities.[42]

Variable	Category	N	%
Decade of publication	2000	3	10%
	2010	20	67%
	2020	7	23%
Country	Brazil	19	63%
	Chile	5	17%
	Colombia	1	3%
	Guatemala	1	3%
	Haiti	1	3%
	Mexico	1	3%
	Peru	1	3%
	Multiple	1	3%
Country income level	High income	5	17%
	Upper-middle income[a]	24	80%
	Lower-middle income	1	3%
Study location	Urban[b]	19	63%
	Urban and rural	11	37%
Study language[c]	English	23	77%
	Portuguese	4	13%
	Spanish	3	10%
Study design	Cross-sectional	24	80%
	Case-control	5	17%
	Cohort	1	3%
Disability group[d]	Any self-reported disability	8	26%
	Functional/activity limitations	8	26%
	Psychosocial disabilities	6	19%
	Hearing impairments	4	13%
	Intellectual/learning disabilities	3	10%
	Physical disabilities	2	6%
Age group	Mixed/all ages	13	43%
	Older adults (≥ 60 years) only	7	23%
	Adults (≥ 18 years) only	7	23%
	Children/adolescents only	3	10%
Outcome measured[e]	Utilization	20	63%
	Coverage	7	22%
	Affordability	3	9%
	Quality	2	6%
Type of service accessed[f]	Outpatient visits[g]	16	31%
	Health treatment/medication	12	24%
	Preventive care visits[h]	10	20%
	Hospitalization	8	16%
	Oral health services	5	10%
Risk of bias	Low	7	23%
	Medium	16	53%
	High	7	23%

[a] Albanese, 2011: all upper middle-income countries; expect Puerto Rico (high income) and Venezuela currently unknown (previously upper middle income). [b] Albanese, 2011: four countries urban and two both urban and rural; Bernabe-Ortiz, 2016: Semi-urban. [c] None of the eligible studies were found in French or Dutch language. [d] There is more than one type of disability reported in Albanese, 2011. [e] More than one outcome was reported in Kuper, 2018 and Fuentes-López, 2020. [f] More than one type of service reported in some papers. [g] Including: medical consultations, physician visits, GP appointments, home visits, emergency consultations. [h] Including: antenatal care, immunization, routine check-up, PAP test, mammogram, HIV/AIDS test, prostate cancer screening.

***Table 2:* Characteristics of included studies (n = 23).**

Two cross-sectional studies reported additional disaggregation by age, gender, and level of severity. Fuentes-López & Fuente (2020) found that older adults with

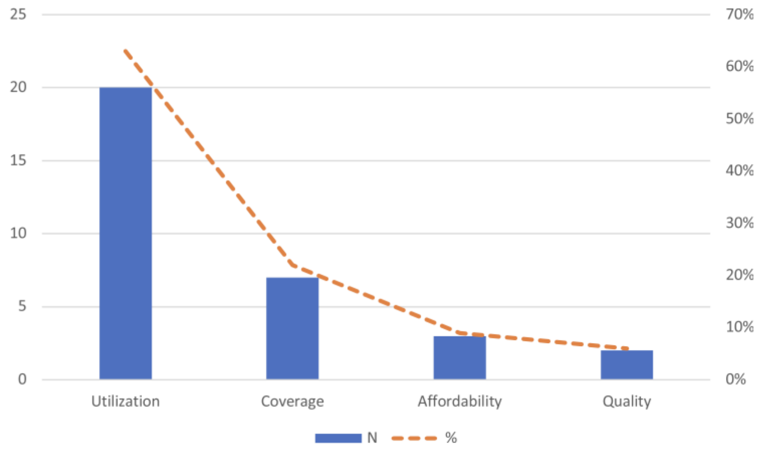


Fig. 2: **Health access outcomes measured across included studies (n = 23).**

hearing impairments were more likely to have a routine health checkup than older adults without disabilities and that women with hearing impairments visited GPs more often than those without disabilities.[51] Macarevich Condessa et al. (2021) found people with severe disabilities utilized oral health services less often than those with milder disabilities.[37] Only Albanese et al. (2011) disaggregated results by study location, however no clear differences were observed in the utilization of community health services among people with disabilities in urban versus rural Peru and Mexico.[38] Finally, although some studies adjusted their analyses by ethnicity, disaggregated results by indigenous people or afro-descendants were not found among included studies.

Four studies–two case-controls[41,42] and two cross-sectional studies[27,36]–reported barriers to access healthcare services. People with disabilities faced about 2–4 times more difficulties with the availability of health services[41,42] and access to health facilities (age-sex-adjusted odds ratio [OR] (95% CI) = 4.4 (1.9–10.2)), than those without disabilities.[41] They also reported difficulties in arriving at health facilities (aOR 2.95 (2.72–3.20)), being attended (aOR 1.72 (1.61–1.84)), or obtaining a doctor's appointment (aOR = 1.83 (1.72–1.94)).[36] Women with disabilities also believed that cancer screening tests did not apply to them (26–34%) or that they did not need them (around 26%).[27]

Fig. 3 presents the risk of bias assessment for each study. Studies had low (n = 7; 23%), medium (n = 16; 53%) and high (n = 7; 23%) risk of bias (Fig. 3). Almost all studies (n = 28; 90%) presented a health access measure clearly defined in the methods section and confidence intervals or standard deviations in the results (n = 26; 87%). However, sample size calculations were often not reported in the paper or incomplete (n = 25; 83%). Similarly, response rates were often not reported (n = 14; 47%). Generally, case–control studies (n = 5) had comparable and clearly defined cases and controls.

Discussion

This systematic review included 30 studies of quantitative evidence on general healthcare access among people with and without disabilities in Latin America and the Caribbean. Many studies indicated that people with disabilities use healthcare services more than those without disabilities. The few studies reporting on healthcare coverage had inconsistent results, although, there was some evidence that women with disabilities were less likely to have received cancer screening than those without disabilities. Both the affordability and quality of health services were reported to be lower among people with disabilities than those without. Overall, the evidence suggests that people with disabilities may experience health inequities in LAC.

Our results are consistent with other systematic reviews that found that people with disabilities more frequently use primary care services, outpatient care or are admitted to the hospital than those without disabilities.[8,11] However, the two studies reporting on oral health services found a lower use among people with disabilities, especially among those with severe limitations, and people with rare genetic diseases.[37,53] Furthermore, health coverage appeared to be limited for some services. Two studies found that women with disabilities have lower coverage of cancer screening than those without disabilities.[27,51] Similar findings were reported in a meta-analysis within high-income settings, where women with disabilities were less likely to have breast (22%) or cervical (33%) cancer screening than

First author, year	Country	Study design	Source of participants	Type of disability	Description and method to assess disability	Participants		Age range	Health access measure	Risk of bias
						With disabilities, n (%)	Without disabilities, n			
Amorim, 2011[34]	Brazil	Cross-sectional	Population	Hearing or visual	Self-reported hearing or visual impairment	Hearing 141 (14%); Visual 188 (19%)	619	>50 years	Utilization	Medium
Castro, 2013[35]	Brazil	Cross-sectional	Population	Any type of disability	Self-reported disability (physical or sensory impairment; multiple disability)	492 (18%)	2198	>11 years	Utilization	Medium
Araya Vallespir, 2014[28]	Chile	Cross-sectional	Primary care clinic	Any type of disability	Self-reported disability (physical, mental, or sensory impairment)	20 households	405 households	>14 years	Quality	High
Sato, 2015[25]	Brazil	Cross-sectional	Population	Any type of disability	Self-reported health status as bedridden	36 (3%)	1305	≥60 years	Coverage	Medium
Rotarou, 2017[36]	Chile	Cross-sectional	Population	Any type of disability	Self-reported disability (physical, mental, or sensory impairment)	7459 (10%)	68,695	≥18 years	Affordability	Medium
Sakellariou, 2017[27]	Chile	Cross-sectional	Population	Any type of disability	Self-reported disability (physical, mental, or sensory impairment)	5766 (9%); 5718 (16%)	60,515; 29,576	25–65 years; 50–75 years	Coverage	Medium
Granados-Martinez, 2019[29]	Mexico	Cross-sectional	Population	Any type of disability	Self-reported disability in household (physical, mental, or sensory impairment)	Median (SD) = 7 (0.196)	Median (SD) = 93 (0.419)	≥65 years	Affordability	High
Macarevich Condessa, 2021[37]	Brazil	Cross-sectional	Population	Any type of disability	Self-reported disability (physical, intellectual, or sensory impairment)	5445 (10%)	51,756	≥18 years	Utilization	Low
Albanese, 2011[38]	Multiple[a]	Cross-sectional	Population	Functional limitation	Self-reported severe or extreme difficulty in mobility	2237 (5–30%)[b]	n/a	≥65 years	Utilization	Low
Nascimiento, 2012[39]	Brazil	Cross-sectional	Registry	Activity limitation	Activities of daily living (Katz; Lawton and Brody)	100 (16%)	519	≥60 years	Utilization	Low
Dellaroza, 2013[40]	Brazil	Cross-sectional	Population	Activity limitation	Activities of daily living (Basic and instrumental)	BADL 566 (45%); IADL 567 (45%)	705; 704	≥60 years	Utilization	Medium
Danquah, 2015[41]	Haiti	Case-control	Population	Functional limitation	Washington Group Short Set of Questions	178	178	≥5 years	Utilization	Low
Bernabe-Ortiz, 2016[26]	Peru	Case-control	Population	Functional limitation	Washington Group Short Set of Questions	161	161	≥5 years	Coverage	Medium
Kuper, 2018[42]	Guatemala	Case-control	Population	Functional limitation	Washington Group Extended Set of Questions	707	465	>2 years	Coverage, quality	Low
Montoro Pazzini Watfe, 2020[43]	Brazil	Cross-sectional	Primary care clinic	Functional limitation	World Health Organization Disability Assessment Schedule; short version	Manaus 446 (66%); Sao Paulo 396 (56%)	533	≥60 years	Utilization	Low
León-Giraldo, 2021[44]	Colombia	Cross-sectional	Population	Functional limitation	World Health Organization Disability Assessment Schedule	Mean = 4.735	n/a	All ages	Affordability	Medium
Gonçalves, 2008[45]	Brazil	Cross-sectional	Primary care clinic	Psychosocial	Psychotic, mood, substance abuse, anxiety, eating and somatoform disorders; Structured Clinical Interview	385 (51%)	369	>14 years	Utilization	Medium
Castelo, 2012[46]	Brazil	Cross-sectional	Primary care clinics	Psychosocial	Lifetime bipolar disorder with moderate/severe functional impairment; Mood Disorder Questionnaire	55 (8%)	665	18–70 years	Utilization	Low
Fujii, 2012[47]	Brazil	Cross-sectional	Population	Psychosocial	Major Depressive Disorder (PHQ-9), self-reported depression, and depression diagnosed by physician	1105 (10%)	8684	≥18 years	Utilization	Medium
García-Huidobro,2012[30]	Chile	Case-control	Registry	Psychosocial	Major Depressive Disorder; electronic clinical register	206	412	>18 years	Utilization	High
Huang, 2014[48]	Brazil	Cross-sectional	Population	Psychosocial	Major Depressive Disorder; International Classification of Diseases, Geriatric Mental State, and Neuropsychiatric Inventory	99 (5%)	1973	≥65 years	Utilization	Medium
Chiavegatto Filho, 2015[49]	Brazil	Cross-sectional	Population	Psychosocial	Major Depressive Disorder and Anxiety Disorders[c]; WMH-CIDI questionnaire	n/a	n/a	≥18 years	Utilization	Medium
Bisol, 2008[24]	Brazil	Cross-sectional	Schools	Hearing	Hearing loss; registry special school for the Deaf	42 (46%)	50	15–21 years	Coverage	High
Freire, 2009[50]	Brazil	Cross-sectional	Population	Hearing	Permanent hearing loss; audiometry	126 (10%)	1184	≥15 years	Utilization	Medium
Fuentes-López, 2020[51]	Chile	Cross-sectional	Population	Hearing	Self-reported bilateral severe-to-profound hearing loss	745	n/a	≥21 years	Utilization, coverage	Medium

(Table 3 continues on next page)

First author, year	Country	Study design	Source of participants	Type of disability	Description and method to assess disability	Participants		Age range	Health access measure	Risk of bias
						With disabilities, n (%)	Without disabilities, n			
(Continued from previous page)										
Miranda, 2022[31]	Brazil	Cross-sectional	Referral centre, hospital	Hearing	Deaf children; registry care referral institution for the deaf	16	48	3–14 years	Utilization	High
Albanese,2011[38]	Multiple	Cross-sectional	Population	Intellectual	Dementia; 10/66 algorithm or DSM-IV dementia	1299 (7–12%)[d]	n/a	≥65 years	Utilization	Low
Oliveira, 2013[32]	Brazil	Case-control	Special needs centres	Intellectual	Down syndrome, cerebral palsy, autism, or intellectual disability; registry special needs school	103	103	>12 years	Utilization	High
da Silva, 2019[52]	Brazil	Cohort	Hospital	Intellectual	Severe-moderate intellectual disability; Baseline Pediatric Overall Performance Category	148 (20%)	610	1 month–16 years	Utilization	Medium
Debossan, 2022[53]	Brazil	Cross-sectional	Hospital	Physical	Rare genetic disease (Mucopolysaccharidoses and Osteogenesis Imperfecta); medical records	70	70	3–27 years	Utilization	Medium
Kessler, 2022[33]	Brazil	Cross-sectional	Population	Physical	Self-reported physical disability within household	10,878 (8%)	128,342	≥18 years	Coverage	High

Note: We reported number and percentage of participants whenever possible and calculated the total number of participants per group (ie, with or without disability) whenever studies only reported percentage. Decimals were rounded off. Abbreviations: BADL, basic activities of daily living; IADL, instrumental activities of daily living; n/a, not available; PHQ-9, Patient Health Questionnaire 9; WMH-CIDI, World Mental Health–Composite International Diagnostic Interview. [a]Mexico, Peru, Cuba Dominican Republic, Puerto Rico, Venezuela. [b]Cuba 546 (19%), Dominican Republic 439 (22%), Puerto Rico 603 (30%), Peru urban 143 (10%), Peru rural 30 (5%), Venezuela 204 (11%), Mexico urban 126 (13%), Mexico rural 146 (15%). [c]Including: panic disorder, agoraphobia, simple phobia, social phobia, generalized anxiety disorder, obsessive compulsive disorder, post-traumatic stress disorder, and separation anxiety. [d]Cuba 333 (11%), Dominican Republic 242 (12%), Puerto Rico 233 (12%), Peru urban 130 (9%), Peru rural 36 (7%), Venezuela 145 (7%), Mexico urban 93 (9%), Mexico rural 87 (9%).

***Table 3*: Summary information of included studies by disability type (n = 30).**

those without disabilities.[54] People with disabilities face barriers in accessing sexual and reproductive health services; for instance, in sub-Saharan Africa they face inaccessible physical health infrastructure, stigma and discrimination across different levels.[10] However, only limited interventions exist to promote sexual and reproductive health among this population in LMICs.[55] Further analyses on healthcare coverage are needed, including a wider range of preventive services (eg, family planning, HIV, immunization, chronic diseases, etc.).

Despite the finding of higher utilisation, people with disabilities might not have access to affordable or quality healthcare. Only two studies reported on affordability of healthcare. In comparison to those without disabilities, our findings suggest that people with disabilities find it difficult to afford services or face catastrophic health expenditures.[36,44] Previous systematic reviews, also found some evidence of higher health expenditures for people with disabilities[8,56] and a strong association between disability and poverty in LMICs.[57] Catastrophic health expenditures and additional living costs among people with disabilities and their families might be particularly problematic in LAC, where household wages remain limited.[1,5,12,56] Very little evidence was available on quality of healthcare. One study found that people with disabilities felt disrespected or reported that health information was difficult to understand.[42] A meta-synthesis of qualitative evidence in LMICs highlighted that health worker attitudes and health information are common barriers faced by people with disabilities when accessing primary healthcare.[9] Similarly, a global synthesis of qualitative evidence found that women with disabilities encounter lack of communication tools in health centres and lack of appropriate skills and training among health providers.[58] Training of health workers is essential to improve the healthcare experience[1] and according to a recent review, sustained learning with multiple teaching methods and participation of people with disabilities could be a successful disability training model.[59] Additional evidence on affordability of health services is key to inform policy required on financial protection measures tailored to the LAC region. Similarly, evidence on the quality of healthcare is essential to monitor the effectiveness of the interventions, which should respond to the specific needs of people with disabilities to improve wellbeing, quality of life and participation in society.

This systematic review has some limitations that should be considered. Most studies were conducted in Brazil (n = 19; 63%); thus, findings may reflect to a large extend Brazil's context and limit the generalizability to other countries in the LAC region. Furthermore, most studies had a cross-sectional design which restricts the possibility to analyse causal paths between disability and healthcare access. Moreover, many studies (n = 25; 83%) partially presented or did not report sample size calculations and therefore, we could not assess their power

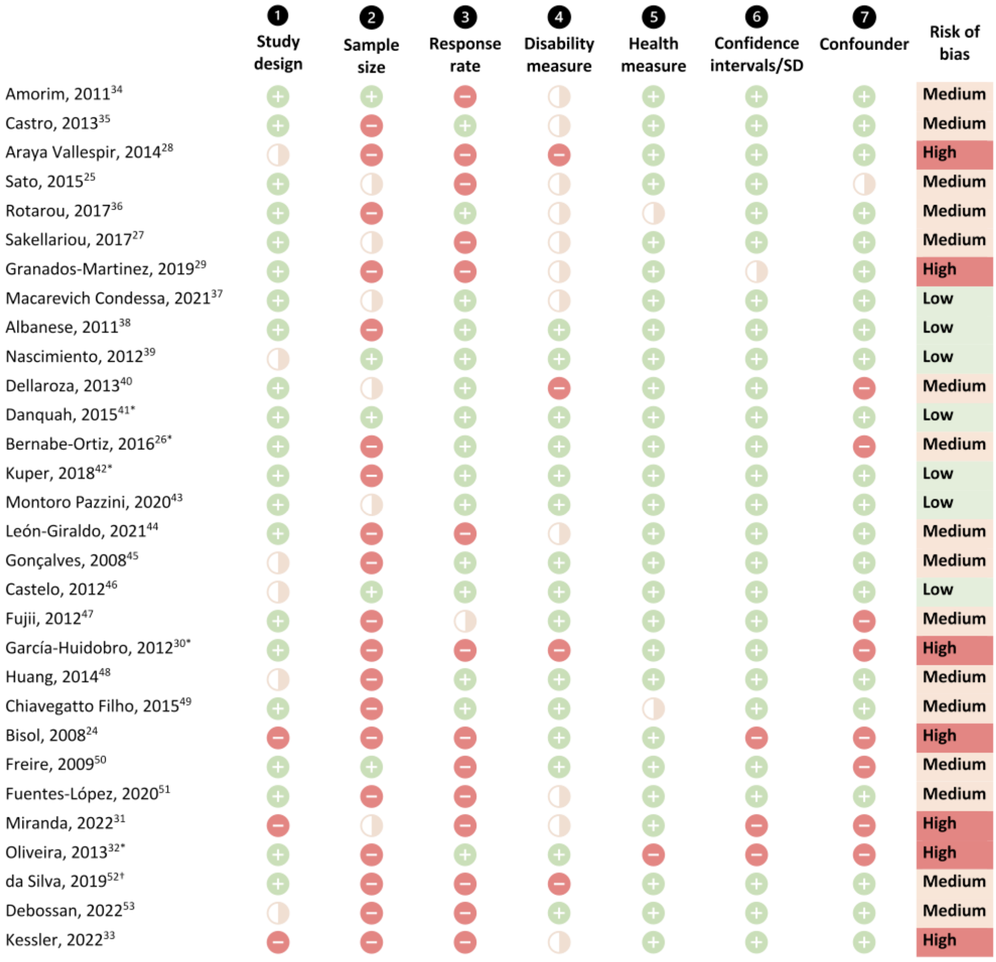
First author, year	Type of disability	Description of health access measure	Health access measure among participants		Measure of effect (95% CI)/p-value	Summary direction of effect	Risk of bias
			With disabilities	Without disabilities			
I. Utilization							
Amorim, 2011[34]	Hearing or visual impairment	Prostate cancer screening; lifetime	Hearing impairment 30%; visual impairment 58%	43%	aPR hearing impairment = 0.93 (0.81–1.08); visual impairment = 1.10 (1.01–1.20)	Mixed[a]	Medium
Castro, 2013[35]	Any type of disability	Hospitalization; last 12 months	Visual 7%; hearing 13%; physical 33% impairment; Multiple disability 23%	6%	aPR visual = 0.85 (0.45–1.60); hearing = 1.59 (0.88–2.86); physical impairment = 3.77 (2.00–7.11); Multiple disability = 3.26 (1.62–6.55)	Mixed[a]	Medium
Macarevich Condessa, 2021[37]	Any type of disability	Dental visits; last 12 months	34%	45%	aOR = 0.74 (0.83–0.66)	Lower[a]	Low
Albanese, 2011[38]	Functional limitation	Use of community healthcare services; last 3 months	n/a	n/a	Pooled aPR 1.02 (0.96–1.09) [aPR Cuba = 0.83 (0.74–0.92); Peru urban = 1.21 (1.03–1.41)][b]	Mixed[a]	Low
Nascimiento, 2012[39]	Activity limitation	Physician visits; last 12 months	None = 3 (7%); 1–5 = 58 (13%); ≥6 = 39 (31%)	None = 42 (93%); 1–5 = 390 (87%); ≥6 = 86 (69%)	$p < 0.0001$	Higher[a]	Low
		Hospitalization; last 12 months	None = 63 (12%); ≥1 = 37 (39%)	None = 461 (88%); ≥1 = 57 (61%)	$p < 0.0001$	Higher[a]	
Dellaroza, 2013[40]	Activity limitation	Hospitalization and >4 consultations; last 12 months	BADL 45%; IADL 45%	44%; 43%	PR BADL = 1.02 (0.76–1.36); IADL = 1.04 (0.81–1.33)	Higher	Medium
Danquah, 2015[41]	Functional limitation	Health centre visits (≥16 years); last year	0 = 34 (33%); 1–2 = 27 (26%); ≥3 = 42 (41%)	0 = 44 (42%); 1–2 = 35 (33%); ≥3 = 26 (25%)	aOR 1–2 versus 0 = 1.0 (0.5–2.0); ≥3 versus 0 = 2.1 (1.0–4.3)	Mixed	Low
		Health centre visits (<16 years); last year	0 = 40 (53%); 1–2 = 14 (19%); ≥3 = 21 (28%)	0 = 33 (45%); 1–2 = 26 (36%); ≥3 = 13 (18%)	aOR 1–2 versus 0 = 0.4 (0.2–0.9); ≥3 versus 0 = 1.3 (0.5–2.9)	Mixed	
Montoro Pazzini Watfe, 2020[43]	Functional limitation	Family physician visits; last 3 months	Sao Paulo yes = 60%, no = 53%; Manaus yes = 71%, no = 63%	Sao Paulo yes = 48%, no = 52%; Manaus yes = 42%, no = 58%	$p = 0.18$	Higher	Low
Gonçalves, 2008[45]	Psychosocial	GP visits; last 12 months	None = 60 (16%); 1 = 51 (13%); 2–5 = 132 (35%); 5–10 = 82 (22%); >10 = 57 (15%)	None = 104 (28%); 1 = 81 (22%); 2–5 = 111 (30%); 5–10 = 44 (12%); >10 = 26 (7%)	$p = 0.02$, when controlled for chronic disease	Higher[a]	Medium
		Emergency visits; last 12 months	None = 113 (30%); 1 = 90 (24%); 2–5 = 107 (28%); >5 = 67 (18%)	None = 194 (54%), 1 = 94 (26%), 2–5 = 56 (16%), >5 = 15 (4%)	$p < 0.0001$, when controlled for chronic disease	Higher[a]	
		Examinations	None = 86 (23%); 1 = 97 (26%); 2–5 = 132 (35%); >5 = 64 (17%)	None = 154 (40%); 1 = 111 (30%); 2–5 = 78 (21%); >5 = 32 (9%)	$p = 0.002$, when controlled for chronic disease	Higher[a]	
Castelo, 2012[46]	Psychosocial	≥4 GP visits; last 12 months	23 (42%)	165 (25%)	aRR = 1.92 (1.11–3.41)	Higher[a]	Low
Fujii, 2012[47]	Psychosocial	Physician visits; last 6 months	Mean (SD) = 8.4 (10.5)	Mean (SD) = 3.3 (5.6)	$p < 0.05$	Higher[a]	Medium
		Emergency visits; last 6 months	43%	17%	$p < 0.05$	Higher[a]	
		Hospitalization; last 6 months	18%	8%	$p < 0.05$	Higher[a]	
Huang, 2014[48]	Psychosocial	≥3 outpatient visits; last 3 months	41%	26%	adjusted Ratio of means = 1.50 (1.23–1.84)	Higher[a]	Medium
		Hospitalization; last 3 months	15%	4%	aPR = 2.87 (1.64–5.00)	Higher[a]	
Chiavegatto Filho, 2015[49]	Psychosocial	Health professional visit; last 12 months	n/a	n/a	aOR depression = 1.63 (1.14–2.33); anxiety = 1.85 (1.40–2.45)	Higher[a]	Medium
Freire, 2009[50]	Hearing impairment	Physician visits; last 2 months	55%	43%	PR = 1.3 (1.10–1.51)	Higher[a]	Medium
		Hospitalization; last 12 months	17%	8%	PR = 2.1 (1.42–3.14)	Higher[a]	
Fuentes-López, 2020[51]	Hearing impairment	GP visits	n/a	n/a	aOR = 1.78 (1.18–2.66)	Higher[a]	Medium
Albanese, 2011[38]	Intellectual	Use of community healthcare services; last 3 months	n/a	n/a	Pooled aPR 0.93 (0.90–0.97) [aPR Cuba = 0.87 (0.76–0.98); Peru rural = 1.12 (0.72–1.75)][c]	Mixed[a]	Low

(Table 4 continues on next page)

First author, year	Type of disability	Description of health access measure	Health access measure among participants		Measure of effect (95% CI)/p-value	Summary direction of effect	Risk of bias
			With disabilities	Without disabilities			
(Continued from previous page)							
Silva, 2019[52]	Intellectual	Hospital readmissions; last 12 months	Yes = 33 (29%); No = 79 (71%)	Yes = 36 (6%); No = 574 (94%)	aOR = 1.08 (1.05–1.29)	Higher[a]	Medium
Debossan, 2022[53]	Physical	Dental visits ever	Yes = 27 (39%), No = 43 (61%)	Yes = 49 (70%), No = 21 (30%)	aOR = 0.19 (0.43–0.08)	Lower[a]	Medium
II. Coverage							
Sato, 2015[25]	Any type of disability	Receipt of influenza vaccination	75%	74%	PR = 1.01 (0.81–1.26)	Null	Medium
Sakellariou, 2017[27]	Any type of disability	Receipt of a Pap test (25–65 years); last 3 years	48%	63%	aOR = 0.698 (0.65–0.75)	Lower[a]	Medium
		Receipt of mammogram (50–75 years); last 3 years	46%	61%	aOR = 0.771 (0.72–0.82)	Lower[a]	
Bernabe-Ortiz, 2016[26]	Functional limitation	Sought healthcare for health problem	Always = 61%; sometimes = 26%; never = 13%	Always = 64%; sometimes = 30%; never = 6%	p = 0.20	Lower	Medium
Kuper, 2018[42]	Functional limitation	Received treatment, if have any general health condition	357 (61%)	149 (53%)	aOR = 1.4 (1.0–1.9)	Higher[a]	Low
		Sought treatment for health problem; last 12 months	254 (76%)	78 (72%)	aOR = 1.2 (0.7–2.1)	Higher	
		Sought antenatal care (15–49 years); last 5 years	n/a	n/a	aOR = 0.4 (0.1–1.0)	Lower[a]	
		Children vaccinated (5–9 years)	94%	88%	aOR = 2.6 (0.3–20.2)	Higher	
Fuentes-López, 2020[51]	Hearing impairment	No receipt of gynecological check-up; last 3 years	97%;	84%	PR = 1.2 (1.1–1.2)	Lower[a]	Medium
		No receipt of Pap test; last 3 years	65%	42%	PR = 1.6 (1.3–1.8)	Lower[a]	
		No receipt of mammogram test; last 3 years	43%	37%	PR = 1.2 (0.7–1.6)	Lower	
III. Affordability							
Rotarou, 2017[36]	Any type of disability	Difficulty paying for treatment due to cost	11%	5%	aOR = 1.91 (1.74–2.09)	Lower[a]	Medium
León-Giraldo, 2021[44]	Functional limitation	Catastrophic health expenditure	n/a	n/a	aOR = 1.04 (1.01–1.06)	Higher catastrophic health expenditure[a]	Medium
IV. Quality							
Kuper, 2018[42]	Functional limitation	General feeling of being completely disrespected	47 (9%)	13 (4%)	aOR versus “completely respected” = 1.9 (1.0–3.7)	Lower[a]	Low
		Difficult to understand information given	121 (22%)	42 (14%)	aOR versus “easy” = 1.6 (1.1–1.4)	Lower[a]	
		Difficult to be understood by health provider	106 (20%)	43 (14%)	aOR versus “easy” = 1.3 (0.8–1.9)	Lower	

Abbreviations: BADL, basic activities of daily living; GP, general practitioner; IADL, instrumental activities of daily living; n/a, not available; PAP test, Papanicolaou test. [a]Strong or some evidence against a null association. [b]Dominican Republic = 0.94 (0.84–1.05); Puerto Rico = 1.04 (0.99–1.09); Peru rural = 1.38 (0.97–1.96); Venezuela = 0.98 (0.89–1.09); Mexico urban = 1.10 (0.89–1.13); Mexico rural = 1.01 (0.89–1.09). [c]Dominican Republic = 0.97 (0.83–1.12); Puerto Rico = 0.95 (0.89–1.02); Peru urban = 0.89 (0.72–1.09); Venezuela = 0.86 (0.73–1.00); Mexico urban = 0.92 (0.80–1.06); Mexico rural = 0.93 (0.78–1.12).

Table 4: **Summary of health access outcomes (n = 23).**



	❶ Study design	❷ Sample size	❸ Response rate	❹ Disability measure	❺ Health measure	❻ Confidence intervals/SD	❼ Confounder	Risk of bias
Amorim, 2011[34]	⊕	⊕	⊖	◐	⊕	⊕	⊕	Medium
Castro, 2013[35]	⊕	⊖	⊕	◐	⊕	⊕	⊕	Medium
Araya Vallespir, 2014[28]	◐	⊖	⊖	⊖	⊕	⊕	⊕	High
Sato, 2015[25]	⊕	◐	⊖	◐	⊕	⊕	◐	Medium
Rotarou, 2017[36]	⊕	⊖	⊕	◐	◐	⊕	⊕	Medium
Sakellariou, 2017[27]	⊕	◐	⊖	◐	⊕	⊕	⊕	Medium
Granados-Martinez, 2019[29]	⊕	⊖	⊖	◐	⊕	◐	⊕	High
Macarevich Condessa, 2021[37]	⊕	◐	⊕	◐	⊕	⊕	⊕	Low
Albanese, 2011[38]	⊕	⊖	⊕	⊕	⊕	⊕	⊕	Low
Nascimiento, 2012[39]	◐	⊕	⊕	⊕	⊕	⊕	⊕	Low
Dellaroza, 2013[40]	⊕	◐	⊕	⊖	⊕	⊕	⊖	Medium
Danquah, 2015[41*]	⊕	⊕	⊕	⊕	⊕	⊕	⊕	Low
Bernabe-Ortiz, 2016[26*]	⊕	⊖	⊕	⊕	⊕	⊕	⊖	Medium
Kuper, 2018[42*]	⊕	⊖	⊕	⊕	⊕	⊕	⊕	Low
Montoro Pazzini, 2020[43]	⊕	◐	⊕	⊕	⊕	⊕	⊕	Low
León-Giraldo, 2021[44]	⊕	⊖	⊖	◐	⊕	⊕	⊕	Medium
Gonçalves, 2008[45]	◐	⊖	⊕	⊕	⊕	⊕	⊕	Medium
Castelo, 2012[46]	◐	⊕	⊕	⊕	⊕	⊕	⊕	Low
Fujii, 2012[47]	⊕	⊖	◐	⊕	⊕	⊕	⊖	Medium
García-Huidobro, 2012[30*]	⊕	⊖	⊖	⊖	⊕	⊕	⊖	High
Huang, 2014[48]	◐	⊖	⊕	⊕	⊕	⊕	⊕	Medium
Chiavegatto Filho, 2015[49]	⊕	⊖	⊕	⊕	◐	⊕	⊕	Medium
Bisol, 2008[24]	⊖	⊖	⊖	⊕	⊕	⊖	⊖	High
Freire, 2009[50]	⊕	⊕	⊖	⊕	⊕	⊕	⊖	Medium
Fuentes-López, 2020[51]	⊕	⊖	⊖	◐	⊕	⊕	⊕	Medium
Miranda, 2022[31]	⊖	◐	⊖	◐	⊕	⊖	⊖	High
Oliveira, 2013[32*]	⊕	⊖	⊕	⊕	⊖	⊖	⊖	High
da Silva, 2019[52†]	⊕	⊖	⊖	⊖	⊕	⊕	⊕	Medium
Debossan, 2022[53]	◐	⊖	⊖	⊕	⊕	⊕	⊕	Medium
Kessler, 2022[33]	⊖	⊖	⊖	◐	⊕	⊕	⊕	High

Legend: SD, standard deviations. Full description of quality assessment criteria in Table 1. *Criterion 8 (cases and controls are comparable) was ⊕ except from Oliveira, 2013 ◐ and criterion 9 (clear case control definitions) was ⊕ for all. †Criterion 10 (groups comparable at baseline) was ◐ and criterion 11 (losses to follow up presented and acceptable) was .⊕

Fig. 3: Quality assessment and risk of bias across studies (n = 30).

and likelihood of reporting extreme results. There was a high level of heterogeneity in the measurement of disability and healthcare access, which made comparison across studies difficult. Although countries included in this review ratified the UNCRPD, most data were collected under a biomedical model of disability, despite the call for supporting both the individual and social dimension of disability.[60] Additionally, both disability and healthcare access outcomes were often self-reported. This could imply a risk of reporting bias among participants and further limit the robustness of the evidence. We also excluded participants with mild disabilities (eg, depressive symptoms alone) and despite these being systematically excluded, we could have introduced some selection bias by trying to differentiate mild from severe disabilities. Moreover, our review did not include grey literature and might have some level of publication bias.

Although the joint analysis of all people with disabilities reinforces the issue of health equity faced by this group, disability is diverse. Health needs vary by several factors (eg, health conditions, impairment type, age, gender, environment, residence, etc.) and even throughout the lifecourse.[1] Healthcare access among people with intellectual or learning disabilities was likely under-represented in this review. This finding supports the urgent call to improve data collection on people with intellectual and psychosocial disabilities, including in the LAC region.[12] Similarly, other groups of people with disabilities are not represented in this analysis. For instance, people living in large institutional settings such as care homes, prisons, etc., which have been found to be often excluded from censuses and household surveys in Latin America and the Caribbean.[12] Furthermore, disability could overlap with vulnerabilities of other minority groups (eg, indigenous people, afro-descendants, migrants, etc.) and due to lack of data, an intersectional analysis could not be conducted.[12] Future studies should report on healthcare access among people with disabilities by gender, impairment type, residence, and intersecting identities.

Despite these limitations, we present the most comprehensive literature and analysis from a region with limited evidence available. This systematic review has important strengths. We registered a study protocol and conducted the search strategy in several languages (English, Spanish and Portuguese). We also searched for studies in multiple databases and independently assessed information. In contrast with Bright and Kuper's and other previous reviews,[8,9] our analysis included 23% of studies in non-English language (n = 7) and 17% from high-income countries (n = 5), which would have not been included in other reviews.

In conclusion, people with disabilities appear to experience health inequities related to general healthcare access in Latin America and the Caribbean. Our findings provide some evidence that confirms the higher utilization of healthcare among people with disabilities in LAC, than those without disabilities. But important data and quality gaps exist in current research, especially in coverage, affordability, and quality of healthcare. Further harmonization of disability and health access data collection is urgently needed to assess health equity among populations with and without disability, including those with invisible disabilities. A health research agenda going forward on health equity and universal health coverage will facilitate evidence-based policy making in inclusive health for people with disabilities in Latin America and the Caribbean.

Contributors

DRG, HK and LMB conceived the study. DRG developed the search strategy and conducted the search. DRG, HK, LMB, SR, KA, and VR conducted the first and second screenings of titles and abstracts. DRG, HK, LMB, and KA performed full text screening. DRG, SR, and KA conducted data extraction and bias evaluation. DRG wrote and revised the manuscript drafts. All authors made intellectual contributions and critically reviewed and accepted the final manuscript before its submission.

Data sharing statement

The protocol of this systematic review can be found in PROSPERO under the following number: CRD42021235797.

Declaration of interests

We declare no competing interests.

Acknowledgements

The authors thank Russell Burke (London School of Hygiene and Tropical Medicine Library) for his support with this systematic review. This study was supported by the Agencia Nacional de Investigación y Desarrollo (ANID); Beca de Doctorado en el Extranjero Becas Chile (Grant 72210471). Hannah Kuper is supported by an NIHR Global Research Professorship (301621); Lena Morgon Banks by the PENDA grant from FCDO and the Arts and Humanities Council (grant 102866EH); and Sara Rotenberg by a Rhodes Scholarship (Rhodes Trust).

Appendix A. Supplementary data

Supplementary data related to this article can be found at https://doi.org/10.1016/j.lana.2024.100701.

References

1 World Health Organization. *Global report on health equity for persons with disabilities*. Geneva. 2022.

2 United Nations. *Convention on the Rights of persons with disabilities—articles*; 2006 [cited 2023 Jul 19]. Available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html.

3 Kuper H, Heydt P. *The Missing Billion: access to health services for 1 billion people with disabilities*. London; 2019 [cited 2023 Jun 29]. Available from: https://www.lshtm.ac.uk/research/centres/international-centre-evidence-disability/missing-billion.

4 Missing Billion Initiative, Clinton Health Access Initiative. *Reimagining health systems that expect, accept and connect 1 billion people with disabilities*; 2022 [cited 2023 Jun 29]. Available from: https://www.themissingbillion.org/the-reports.

5 World Health Organization, World Bank. *World report on disability 2011*; 2011 [cited 2023 Jul 19]. Available from: https://apps.who.int/iris/handle/10665/44575.

6 Rotenberg S, Smythe T, Kuper H. Left behind: modelling the life expectancy disparities amongst people with disabilities in Low and Middle-Income Countries. *medRxiv*; 2023. Available from: http://medrxiv.org/content/early/2023/07/12/2023.07.12.23292565.abstract.

7 World Health Assembly. *Resolution EB148.R6 "The highest attainable standard of health for persons with disabilities"*; 2021 [cited 2023 Jun 29]. Available from: https://apps.who.int/gb/ebwha/pdf_files/WHA74/A74_R8-en.pdf.

8 Bright T, Kuper H. A systematic review of access to general healthcare services for people with disabilities in low and middle income countries. *Int J Environ Res Public Health*. 2018;15(9):1879.

9 Hashemi G, Wickenden M, Bright T, Kuper H. Barriers to accessing primary healthcare services for people with disabilities in low and middle-income countries, a Meta-synthesis of qualitative studies. *Disabil Rehabil*. 2022;44(8):1207–1220.

10 Ganle JK, Baatiema L, Quansah R, Danso-Appiah A. Barriers facing persons with disability in accessing sexual and reproductive health services in sub-Saharan Africa: a systematic review. *PLoS One*. 2020;15(10):e0238585.

11 Oliver S, Douglas J, Winkler D, et al. The healthcare needs and general practice utilization of people with acquired neurological disability and complex needs: a scoping review. *Health Expect*. 2022;25(6):2726–2745. Available from: https://onlinelibrary.wiley.com/doi/10.1111/hex.13640.

12 García Mora ME, Schwartz Orellana S, Freire G. *Disability inclusion in Latin America and the Caribbean: a path to sustainable development*. Washington, DC; 2021 [cited 2023 Jul 19]. Available from: https://documents1.worldbank.org/curated/en/099015112012126833/pdf/P17538305622600c00bf3f09659df1f2f79.pdf.

13 Lorenzoni L, Pinto D, Guanais F, Plaza Reneses T, Daniel F, Auraaen A. *Health systems characteristics: a survey of 21 Latin American and Caribbean countries*. Paris. 2019.

14 Herrera CA, Veillard J, Feune de Colombi N, Neelsen S, Anderson G, Ward K. *Building resilient health systems in Latin American and the Caribbean: lessons learned from the COVID-19 pandemic*. Washington DC. 2022.

15 OECD/The World Bank. *Health at a glance: Latin America and the Caribbean 2023*. Paris: OECD; 2023.

16 Pinilla-Roncancio M, Rodríguez Caicedo N. Recolección de datos durante la pandemia por la COVID-19 y la inclusión de la población con discapacidad en América Latina y el Caribe. *Rev Panam Salud Públic*. 2022;46:1. Available from: https://iris.paho.org/handle/10665.2/56004.

17 World Health Organization. *The world health report 2013: research for universal health coverage*; 2013 [cited 2023 Jul 19]. Available from: https://www.who.int/publications/i/item/world-health-report-2013-research-for-universal-health-coverage.

18 Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*. 2021;372:n71.

19 World Bank. *World Bank country and lending groups*; 2023 [cited 2023 Jul 19]. Available from: https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups.

20 Iemmi V, Gibson L, Blanchet K, et al. Community-based rehabilitation for people with disabilities in low- and middle-income countries: a systematic review. *Syst Rev*. 2015;11(1):1–177.

21 World Health Organization. *International Bank for Reconstruction and Development/the World Bank. Tracking universal health coverage: 2017 global monitoring report*; 2017 [cited 2023 Jul 19]. Available from: https://apps.who.int/iris/bitstream/handle/10665/259817/9789241513555-eng.pdf.

22 Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan—a web and mobile app for systematic reviews. *Syst Rev*. 2016;5(1):210.

23 Scottish Intercollegiate Guidelines Network (SIGN). *SIGN50: a guideline developer's handbook*. Edinburgh; 2019 [cited 2023 Jul 19]. Available from: http://www.sign.ac.uk/.

24 Bisol CA, Sperb TM, Brewer TH, Kato SK, Shor-Posner G. HIV/AIDS knowledge and health-related attitudes and behaviors among deaf and hearing adolescents in southern Brazil. *Am Ann Deaf*. 2008;153(4):349–356.

25 Sato APS, Antunes JLF, Moura RF, de Andrade FB, Duarte YAO, Lebrão ML. Factors associated to vaccination against influenza among elderly in a large Brazilian metropolis. *PLoS One*. 2015;10(4):e0123840.

26 Bernabe-Ortiz A, Diez-Canseco F, Vasquez A, Kuper H, Walsham M, Blanchet K. Inclusion of persons with disabilities in systems of social protection: a population-based survey and case-control study in Peru. *BMJ Open*. 2016;6(8):e011300.

27 Sakellariou D, Rotarou ES. Utilisation of cancer screening services by disabled women in Chile. *PLoS One*. 2017;12(5):e0176270.

28 Araya Vallespir C, Bustos Leal A, Merino Escobar JM, Ulloa Ortega C, Araya J. Quality of public dental service based on intangibles perceptions in patients with and without disabilities. Talcahuano. Chile. *Odontoestomatologia*. 2014;16(23):4–12.

29 Granados-Martínez A, Nava-Bolaños I. Catastrophic health expenditures and households with older adults in Mexico. *Papeles Poblac*. 2019;25:113–141.

30 García-Huidobro D, León T, Vidal G, Poblete F, Rojas P. Increased morbidity and use of primary care medical services in patients with major depressive disorder and their families: a retrospective cohort study. *Aten Primaria*. 2012;44(8):471–477.

31 Miranda MSS, Mourão AM, Lamenha-Lins RM, et al. Pediatric oral health self-reported by caregivers of normal hearing and hearing-impaired children. *Pesqui Bras Odontopediatria Clin Integr*. 2022;22.

32 Oliveira JS, Prado Júnior RR, de Sousa Lima KR, de Oliveira Amaral H, Moita Neto JM, Mendes RF. Intellectual disability and impact on oral health: a paired study. *Spec Care Dent*. 2013;33(6):262–268.

33 Kessler M, Thumé E, Facchini LA, Tomasi E. Prevalence of not receiving a home visit by Community Health Agents in Brazil and associated factors. *Cien Saude Colet*. 2022;27(11):4253–4263.

34 Amorim VMSL, Barros MB, César CLG, Goldbaum M, Carandina L, Alves MCGP. Factors associated with prostate cancer screening: a population-based study. *Cad Saúde Pública*. 2011;27(2):347–356.

35 Castro SS, Carandina L, Barros MB, Goldbaum M, Cesar CLG. Physical disability and hospitalization in São Paulo, Brazil. *Cad Saúde Pública*. 2013;29(5):992–998.

36 Rotarou ES, Sakellariou D. Inequalities in access to health care for people with disabilities in Chile: the limits of universal health coverage. *Crit Public Health*. 2017;27(5):604–616.

37 Macarevich Condessa A, Pilotto LM, Celeste RK, Hilgert JB. Use of dental services by disability status in Brazil in 2013. *Community Dent Oral Epidemiol*. 2021;49(5):471–477.

38 Albanese E, Liu Z, Acosta D, et al. Equity in the delivery of community healthcare to older people: findings from 10/66 Dementia Research Group cross-sectional surveys in Latin America, China, India and Nigeria. *BMC Health Serv Res*. 2011;11(1):153.

39 Nascimento Cde M, Ribeiro AQ, Cotta RMM, et al. Factors associated with functional ability in Brazilian elderly. *Arch Gerontol Geriatr*. 2012;54(2):e89–e94.

40 Dellaroza MSG, Pimenta CA, Lebrão ML, Duarte YA. Association of chronic pain with the use of health care services by older adults in Sao Paulo. *Rev Saude Publica*. 2013;47(5):914–922.

41 Danquah L, Polack S, Brus A, et al. Disability in post-earthquake Haiti: prevalence and inequality in access to services. *Disabil Rehabil*. 2015;37(12):1082–1089.

42 Kuper H, Mactaggart I, Dionicio C, Cañas R, Naber J, Polack S. Can we achieve universal health coverage without a focus on disability? Results from a national case-control study in Guatemala. *PLoS One*. 2018;13(12):e0209774.

43 Montoro Pazzini Watfe G, Fajersztajn L, Ribeiro E, Rossi Menezes P, Scazufca M. Prevalence of older adult disability and primary health care responsiveness in low-income communities. *Life*. 2020;10(8).

44 León-Giraldo S, Cuervo-Sánchez JS, Casas G, et al. Inequalities in catastrophic health expenditures in conflict-affected areas and the Colombian peace agreement: an oaxaca-blinder change decomposition analysis. *Int J Equity Health*. 2021;20(1):217.

45 Gonçalves DM, Kapczinski F. Prevalence of mental disorders at a referral center for the family health program in Santa Cruz do Sul, Rio Grande do Sul State, Brazil. *Cad Saúde Pública*. 2008;24(9):2043–2053.

46 Castelo MS, Hyphantis TN, Macêdo DS, et al. Screening for bipolar disorder in the primary care: a Brazilian survey. *J Affect Disord*. 2012;143(1–3):118–124.

47 Fujii RK, Goren A, Annunziata K, Mould-Quevedo J. Prevalence, awareness, treatment, and burden of major depressive disorder: estimates from the national health and wellness survey in Brazil. *Value Health Reg Issues*. 2012;1(2):235–243.

48 Huang H, Menezes PR, da Silva SA, Tabb K, Barkil-Oteo A, Scazufca M. The association between depressive disorders and health care utilization: results from the São Paulo ageing and health study (SPAH). *Gen Hosp Psychiatry*. 2014;36(2):199–202.

49 Chiavegatto Filho ADP, Wang YP, Malik AM, Takaoka J, Viana MC, Andrade LH. Determinants of the use of health care services: multilevel analysis in the Metropolitan Region of Sao Paulo. *Rev Saude Publica*. 2015;49(0).

50 Freire DB, Gigante LP, Béria JU, Palazzo Ldos S, Figueiredo ACL, Raymann BCW. Access by hearing-disabled individuals to health services in a southern Brazilian city. *Cad Saúde Pública*. 2009;25(4):889–897.

51 Fuentes-López E, Fuente A. Access to healthcare for deaf people: a model from a middle-income country in Latin America. *Rev Saude Publica*. 2020;54:13.

52 da Silva PSL, Fonseca MCM. Which children account for repeated admissions within 1 year in a Brazilian pediatric intensive care unit? *J Pediatr*. 2019;95(5):559–566.

53 Debossan SAT, Deps TD, Prado HV, Abreu MHNG, Borges-Oliveira AC. Access to oral health care services for individuals with rare genetic diseases affecting skeletal development. *Spec Care Dent*. 2022;42(1):32–40.

54 Andiwijaya FR, Davey C, Bessame K, Ndong A, Kuper H. Disability and participation in breast and cervical cancer screening: a systematic review and meta-analysis. *Int J Environ Res Public Health*. 2022;19(15):9465.

55 Hameed S, Maddams A, Lowe H, Davies L, Khosla R, Shakespeare T. From words to actions: systematic review of interventions to promote sexual and reproductive health of persons with disabilities in low- and middle-income countries. *BMJ Glob Health*. 2020;5(10):e002903.

56 Mitra S, Palmer M, Kim H, Mont D, Groce N. Extra costs of living with a disability: a review and agenda for research. *Disabil Health J*. 2017;10(4):475–484.

57 Banks LM, Kuper H, Polack S. *Poverty and disability in low- and middle-income countries: a systematic review*. 2017 [cited 2023 Jun 15]; https://doi.org/10.1371/journal.pone.0189996.

58 Matin BK, Williamson HJ, Karyani AK, Rezaei S, Soofi M, Soltani S. Barriers in access to healthcare for women with

disabilities: a systematic review in qualitative studies. *BMC Womens Health*. 2021;21(1):44.

59 Rotenberg S, Rodríguez Gatta D, Wahedi A, Loo R, McFadden E, Ryan S. Disability training for health workers: a global evidence synthesis. *Disabil Health J*. 2022;15(2).

60 Office of the High Commissioner for Human Rights. *A/HRC/49/60: statistics and data collection under article 31 of the convention on the Rights of persons with disabilities*; 2021 [cited 2023 Dec 5]. Available from: https://www.ohchr.org/en/documents/reports/ahrc4960-statistics-and-data-collection-under-article-31-convention-rights.

Chapter 4

Healthcare access among people with and without disabilities: a cross-sectional analysis of the National Socioeconomic Survey of Chile

4.1 | Chapter preamble

Chapter 3 revealed the limited quantitative evidence available from Chile on health equity among people with disabilities as well as the lack of evidence on coverage, affordability, and quality of healthcare. Building on Chapter 3, the present chapter introduces a secondary data analysis of the 2022 National Socioeconomic Survey of Chile to fill in that knowledge gap. The study aimed to compare healthcare utilization, coverage, and barriers to accessing health services among people with and without disabilities in Chile. This quantitative research defined disability according to a biopsychosocial model of disability presented in Chapter 1 and followed the UHC framework.[30,31]

People with disabilities had increased health needs, worse health coverage, and several barriers to accessing healthcare, compared to those without disabilities. This chapter provides an overview of some of the existing health inequities experienced by people with disabilities in Chile and contributes to bridging the knowledge gap. It also underlies the need to review structural determinants of health inequities, some of which are addressed in Chapter 5 through a health policy analysis of governance and leadership on disability inclusion in Chile. Additionally, the findings of this study have implications for UHC among people with disabilities, health system strengthening in Chile – particularly on the demand side of service delivery – and the measurement of healthcare access in research; all presented in Chapter 7.

This secondary data analysis is under peer-review in the journal *Public Health* since September 2024. Appendices of this study can be found in Appendix B.

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

SECTION A – Student Details

Student ID Number	2004713	**Title**	Mrs
First Name(s)	Danae Harmonia		
Surname/Family Name	Rodríguez Gatta		
Thesis Title	Access to healthcare among people with disabilities in Chile		
Primary Supervisor	Hannah Kuper		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?			
When was the work published?			
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Choose an item.	Was the work subject to academic peer review?	Choose an item.

*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	Public Health
Please list the paper's authors in the intended authorship order:	Danae Rodríguez Gatta, Elena S. Rotarou, Lena Morgon Banks, and Hannah Kuper
Stage of publication	**Undergoing revision**

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I have conceptualized the study, curated, analysed, interpreted and verified data, drafted the paper, and compiled the final manuscript.

SECTION E

Student Signature	Danae Rodríguez Gatta
Date	13 November 2024

Supervisor Signature	Hannah Kuper
Date	13 November 2024

Healthcare access among people with and without disabilities: a cross-sectional analysis of the National Socioeconomic Survey of Chile

Danae Rodríguez Gatta MSc [a,c], Elena S. Rotarou PhD [b,c], Lena Morgon Banks PhD [a], and Prof Hannah Kuper ScD [a]

[a] International Centre for Evidence in Disability, Department of Population Health, Faculty of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, London, United Kingdom.

[b] National Department of Public Health, Faculty of Medicine and Science, Universidad San Sebastián, Santiago, Chile

[c] Millennium Nucleus Studies on Disability and Citizenship (DISCA), Santiago, Chile

Correspondence to: Danae Rodríguez Gatta, International Centre for Evidence in Disability, Department of Population Health, Faculty of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, London WC1E 7HT, United Kingdom, danae.rodriguez@lshtm.ac.uk

Declaration of interests

None

Contributors

DRG, ESR, LMB, and HK collaborated to the design of the study. DRG was responsible for data curation, data analyses, and writing the original draft. DRG, ESR, LMB, and HK contributed to the interpretation and verification of the data. All authors critically reviewed and accepted the final manuscript before its submission.

Funding

This work was supported by the National Agency for Research and Development (ANID) [72210471]; the ANID Millennium Science Initiative Program [NCS2022_039]; the National Institute for Health and Care Research [301621]; the Foreign, Commonwealth and Development Office [PO8073]; and the Arts & Humanities Research Council [AH/X009580/1].

ABSTRACT

Objectives

This study aimed to compare healthcare utilization, coverage, and barriers to accessing health services among people with and without disabilities in Chile.

Study design

Secondary cross-sectional study

Methods

We analysed data of the 2022 National Socioeconomic Survey of Chile. People with disabilities were identified based on the Washington Group Questions. Multivariable logistic regressions were performed to compare the indicators of utilization, coverage, and barriers to accessing healthcare between people with versus without disabilities. Adjusted odds ratios (aOR) were reported with 95% confidence intervals (95% CI).

Results

A total of 192,666 participants were included in the study; persons with disabilities represented 10% of the sample (n = 21,769). People with disabilities were more likely to have had a health problem (aOR, 2·22; 95% CI, 2·12-2·32) and more frequently used any type of health consultation, than those without disabilities. The coverage of adult health check-ups (aOR, 0·88; 95% CI, 0·81-0·96) and Pap tests among women (aOR, 0·76; 95% CI, 0·70-0·82), were lower among those with disabilities. Reports of experiencing any barrier to accessing healthcare were more common among people with disabilities.

Conclusions

People with disabilities in Chile continue to experience health inequities, both in terms of higher healthcare needs and lower coverage, and various barriers to accessing healthcare. Thus, a disability lens needs to be mainstreamed in the health system to leave no one behind.

Keywords

Disability, Healthcare access, Health equity, Chile

Introduction

There are currently 1·3 billion people with disabilities globally, and this number is continuing to increase largely due to population growth and ageing.[1] The experience of disability is inherently human and represents people *"...who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"*.[1,2] Even though people with disabilities can live healthy lives, they commonly experience poorer health than others in the population.[1] The reasons for this inequity include the impacts of pre-existing health conditions, social determinants of health, and increased risk factors. People with disabilities also face many barriers to access health services, including structural issues such as inaccessibility, stigma, and discrimination.[1,3] Hence, the coverage of healthcare is lower among those with disabilities, despite having increased health needs. This context has created critical health inequities, including an average 14-year mortality gap.[4] These deaths could be avoided, in some cases, by quality healthcare.[5]

In Latin America and the Caribbean (LAC), there is a large number of people with disabilities, but little evidence regarding health inequities.[6,7] A recent systematic review highlighted the sparsity of disability-disaggregated data on general healthcare access, especially describing differences in coverage, quality, and affordability of healthcare by disability status in the region.[7] This dearth of data is also apparent in Chile, the focus of the current study, with few notable exceptions. One study analyzed healthcare use, including sexual and reproductive health (SRH) services, among deaf people based on 2011 population-based data.[8] Similarly, other studies used 2013 and 2015 national survey data to investigate barriers to healthcare and use of cancer screening services among people with disabilities in the country.[9,10] These studies showed that women with disabilities were less likely to undergo cancer screening and that reports of barriers experienced in the health system were significantly more common among people with disabilities.[8–10]

To ascertain whether health inequities persist, it is essential to have a comprehensive overview of current healthcare access. Therefore, the aim of this study is to compare healthcare utilization, coverage, and barriers to accessing health services among people with and without disabilities in Chile.

Methods

Study setting

Chile is a South American country with about 20 million inhabitants.[11] In 2022, the multidimensional poverty rate was about 17%.[12] Chile is also characterised by high income inequality (Gini Index: 44).[13] The health system is dual, with a public and private health financing scheme, and mixed health service provision.[14] All workers must pay health contributions to either the private or the public health insurance, to which most of the population is affiliated (79%).[15]

Study design and participants

In this secondary cross-sectional study, we analysed data of the 2022 National Socioeconomic Survey of Chile (NSES).[12] The NSES is a household survey that seeks to ascertain the socioeconomic status of the population and identify priority groups for social policy.[12] The target population are people living in private residences. The 2022 NSES sampling frame of private residences was mainly determined based on the 2017 Census. The sampling design was probabilistic, stratified, and multistage, to obtain a national, regional, and geographically representative sample. In total 72,056 households and 202,231 persons participated in the survey (response rate of 69%). Further details can be found online in the Sampling Design Methodology report.[12] Data were collected between November 2022 and February 2023. The anonymised dataset is freely available in the public domain.[12]

Procedures

The main survey respondent was an adult member of a given household. The survey comprised eight modules, including one on health. In the present analysis health utilization, health coverage, and barriers to accessing healthcare were the main categories of outcomes.

Health utilization was determined based on several questions. First, whether participants had received medical care, if they reported having had a health problem in the last three months (0 = no, 1 = yes). Second, type of health service received was indicated by seven independent variables (yes/no), including general practitioner, mental health, specialist, and dental consultations, emergency care, diagnostics, and hospitalization. Third, the number of visits was calculated among participants who reported having received either general practitioner (GP), emergency, mental health, specialist, or dental consultations, and then categorized as 1, 2, 3, 4, or above 5. Finally, the variable “where received healthcare” was categorized as public, private, mixed health provider, or other, for those who received any type of care.

Health coverage was assessed through reported access to the Preventive Health Check-up program (Supplementary Table S1). This periodic, free, and voluntary program is available to all people with public or private health insurance throughout their life cycle.[16] Three dichotomous variables (yes/no) were included for health check-ups in the last year among children (5-9 years), adults (15-64 years), and older people (65 years or above). Cancer screening among women was determined through two dichotomous variables (yes/no): Pap test (25-64 years) and mammogram (50-59 years).

Barriers were analysed using five dichotomous variables (yes/no) on reported difficulties experienced while accessing healthcare, among those who reported to have received medical care in the last three months, including difficulties in reaching a health center, getting an appointment, receiving care, paying for care due to cost, and obtaining medications. Our analyses compared the differences in health utilization, coverage, and barriers by disability.

The main exposure of interest was disability. This variable was assessed through the Washington Group (WG) Short Set of Questions (Supplementary Table S2). Persons who reported having "a lot of difficulty" or "cannot do at all", in any of six domains (seeing, hearing, mobility, communicating, cognition, and self-care) were considered as having a disability. Moreover, functional difficulty type was categorized as none, seeing, hearing, mobility, communicating, cognition, and multiple.

Further independent variables included were: age (categorized in groups of 10 years), sex (assigned at birth, male/female), indigenous peoples (yes/no), place of birth (born abroad or in Chile), residence (rural, urban), schooling (none, primary, secondary, and higher), income quintile (1st lowest to 5th highest), health insurance (public, private, armed forces and other, and none), level of assistance required (0 = none to 3 = severe dependence; Supplementary Table S2), any health problem (disease/accident, yes/no), under treatment for selected health conditions (0 = Not under treatment, 1 to 8 = different health conditions), any of above health conditions (previous variable dichotomized, yes/no), and child's nutritional state (malnourished [or at risk of], normal, overweight, and obese).

Statistical analysis

Only participants above four years had information on the WG questions. Therefore, observations of participants below five years were dropped (n = 9565), leaving 192,666 participants. Descriptive statistics were used to report the sociodemographic and health characteristics of the participants with and without disabilities. Differences between groups were examined using the p-values drawn from multivariable logistic regression models of a given characteristic and disability, adjusted for age and sex. Multivariable logistic regressions were performed to compare the occurrence of our outcomes of interest between people with versus without disabilities (referent group). Adjusted odds ratios (aOR) were reported with 95% confidence intervals (95% CI). A staged analysis was performed to identify potential confounders. However, age and sex were considered *a priori* confounders and included in all the analyses.[1] Sequential adjustments were undertaken for place of birth, residence, schooling, income, and health insurance, and fully adjusted models were produced. Changes of about 10% from previous odds ratios were an indicator of a potential confounding effect of a variable. Moreover, stratified analyses were conducted by sex.

Only participants with complete information for the outcomes of interest were included in the analyses (i.e. excluding 0·1 to 5·7% of the sample which had missing data, depending on the variables; Supplementary Table S3). We followed official NSES data analysis guidance to account for the complex sampling design of the survey and use survey weights.[12] This study used the STATA 18 statistical software to perform all the analyses.

Results

A total of 192,666 participants were included in the study; 51% were female. Persons with disabilities represented 10% of the total sample (n = 21,769). People with disabilities were more likely to be older in age, female, with no or only primary schooling, in the lowest income quintile, and have public health insurance (all $p<0{\cdot}0001$) (Table 1). The most common functional difficulty types were multiple difficulties (31%). People with disabilities were also more likely to require assistance from someone else to perform an activity.

Health needs were higher among people with disabilities. They were more likely to have had a health problem (aOR, 2·22; 95% CI, 2·12-2·32), than those without disabilities (Table 2). Similarly, people with disabilities had increased odds of being under treatment for hypertension, diabetes, acute myocardial infarction, chronic obstructive pulmonary disease, cancer, asthma, ischemic stroke, or other conditions, as well as any of those reported health conditions (aOR, 2·82; 95%CI, 2·68-2·97). This pattern was especially noted among men with disabilities (aOR, 3·08; 95% CI 2·85-3·32) compared with women with disabilities (aOR, 2·60; 95% CI 2·44-2·77; Supplementary Table S4). Among children aged five to nine years, children with disabilities were more likely to be malnourished (aOR, 3·54; 95%CI, 1·51-8·33), overweight (aOR, 1·35; 95%CI, 1·00-1·82), or obese (aOR, 1·95; 95%CI, 1·20-3·17) as opposed to normal weight, than for children without disabilities.

Across different metrics, healthcare utilization was consistently higher among people with disabilities (Table 3). Amongst participants reporting a health problem, people with disabilities were more likely to have received medical care (aOR, 1·22; 95% CI, 1·07-1·39). General practitioner and diagnostics were the most common outpatient services used by participants. Overall, the use of any type of consultation and number of visits in the last three months were consistently higher among people with disabilities. This pattern was more noted among men with disabilities than women with disabilities in consultations with GPs, mental health services, and specialists, as well as in diagnostics, and hospital admissions (Supplementary Table S5). When controlling for sociodemographic characteristics, income, and health insurance, the differences in healthcare use generally increased, with higher utilization among people with disabilities. Most participants used public health services, while those with disabilities were less likely to have used private providers (aOR, 0·71; 95% CI, 0·65-0·78). Among participants with public health insurance, the odds of using a mix of health providers (aOR, 1·16; 95% CI, 1·08-1·24) and other sources of care (aOR, 1·74; 95% CI, 1·41-2·15) were higher among people with disabilities than those without disabilities (Supplementary Table S6).

The coverage of health screening services by disability is presented in Table 4 and Supplementary Table S7. The general trend appeared to be a lower coverage of health check-ups among people with disabilities, except for the child health check-up. Even though the differences in health coverage between people with and without disabilities were reduced after controlling for sociodemographic characteristics, income, and health insurance, gaps remained among participants. The odds of having an adult health check-up or older people health check-up were lower among people with disabilities. These patterns were broadly similar between women and men with disabilities (Supplementary Table S7). However, the association disappeared for older people health check-up after adjusting for socio-demographic variables. The uptake of the Pap test was lower among women with disabilities (aOR, 0·76; 95% CI, 0·70-0·82) versus those without, as was mammogram (aOR, 0·82; 95% CI, 0·72-0·94). These associations were weakened after adjusting for socio-demographic and health insurance variables, but only disappeared for mammogram coverage.

Table 5 presents the reported barriers experienced by participants who received healthcare in the last three months. Overall, reports of experiencing any difficulty while accessing health services was more common among people with disabilities. For instance, they were more likely to have problems reaching a health center (aOR, 1·87; 95% CI, 1·67-2·10), getting an appointment (aOR, 1.50; 95% CI, 1.30-1.73), receiving care (aOR, 1.54; 95% CI, 1.34-1.78), paying for care (aOR, 1.46; 95% CI, 1.27-1.66), or obtaining medications (aOR, 1.65; 95% CI, 1.46-1.86), than those without disabilities. This pattern was similar between women and men with disabilities (Supplementary Table S8). Furthermore, people with disabilities more frequently reported unmet healthcare need (8%) than those without disabilities (3%) ($p<0.0001$; Supplementary Table S9). The study participants reported that the most common reasons for not seeking healthcare were finding it unnecessary or opting for homemade remedies instead. The main reason for not undergoing a mammogram was forgetting to have one (Supplementary Table S9). Women with disabilities more frequently believed that having a mammogram was unnecessary, whereas women without disabilities more often reported a lack of time as the reason for not having one ($p=0·0356$).

Discussion

This cross-sectional analysis of the 2022 NSES of Chile showed that people with disabilities had greater healthcare needs, as they more frequently reported experiencing health problems or being under treatment for a health condition. In addition, people with disabilities used healthcare services more often than those without disabilities. However, despite the higher use and need for healthcare, people with disabilities had lower health service coverage, especially for the adult health check-up and cervical cancer screening among women with disabilities.

Across all types of barriers, people with disabilities faced more difficulties while accessing healthcare than those without disabilities. Overall, these findings suggests that people with disabilities in Chile experience health inequities, both in terms of healthcare needs and coverage of health services.

Our findings are consistent with previous research reporting a higher use of health services among people with disabilities. Quantitative evidence of a systematic review of LAC similarly reported a higher utilization of general healthcare services among people with disabilities in the region.[7] Within Chile, a study observed that deaf people were more likely to visit a GP (aOR, 1.78; 95% CI, 1.18–2.66), compared with the general population.[8] Furthermore, our results indicated a lower coverage of Pap test screening among women with disabilities. A global meta-analysis also highlighted these health inequities experienced in cancer screening.[17] Similar findings were observed in previous studies using 2011 and 2015 NSES data of Chile.[8,10] These studies found a lower coverage not only for Pap tests (e.g., aOR, 0.70, 95% CI, 0.65–0.75)[10], but also for mammograms (ages 50-75 years).[8,10] In our analyses, the discrepancy in mammogram coverage disappeared after adjustment for the sociodemographic characteristics of the participants. Nevertheless, the quality of care needs to be further assessed in future research, as previous studies in Chile reported that women with disabilities are subject to critical barriers in accessing SRH services.[18,19]

Lower coverage among people with disabilities was also found for the adult preventive health check-up in the last year, which is designed to screen for selected highly prevalent diseases and risk factors.[16] However, evidence appears to be inconsistent across studies. A previous cross-sectional study in Chile found no strong evidence of a relationship between having a disability and using any type of preventive health services.[20] On the contrary, another study in the country found deaf people were more likely to have undergone a health check-up in their lifetime, especially among older adults.[8] The latter could suggest that differences in the health coverage may exist by type of disability, which requires further consideration in future studies.

Our analyses indicate that people with disabilities face several difficulties when accessing healthcare, including problems in reaching a health center, getting an appointment, receiving care, paying for care, and obtaining medications. Similarly, a previous study in Chile also showed that people with disabilities faced higher barriers to access healthcare compared with those without disabilities.[9] These barriers are not unique to Chile but are also experienced in other countries in LAC, including Brazil, Colombia, and Trinidad and Tobago.[21] A meta-synthesis of qualitative studies found that adults with disabilities faced inaccessible health information and infrastructure, inadequate transportation, and attitudinal barriers from healthcare providers.[21]

A global comparison of effective coverage of health services categorized Chile in a relatively high performance (i.e., index value 74 of 100), between the neighboring countries of Peru (76th percentile), Argentina (61th), and Bolivia (52th).[22] However, our findings suggest that people with disabilities continue to experience health inequities in Chile. Thus, a disability lens needs to be mainstreamed in the health system to leave no one behind. The existence of a Preferential Care Law for people with disabilities appears to be insufficient on its own.[23] In line with the call to build inclusive health systems that *expect, accept, and connect* people with disabilities,[24,25] Chile embarked on the first National Policy on Inclusive Health for People with Disabilities.[26,27] Financing, accountability mechanisms, and monitoring of disability inclusion have been considered as key factors for successful implementation.[23] Future research could examine changes in health equity among people with disabilities. In addition, modules on quality healthcare need to be included in national surveys, as this is a crucial element to examine the accessibility of health services and remains a knowledge gap.

This study has some limitations. First, all information on health needs and access was self-reported. Hence, the study could be subject to information bias. Second, we could only estimate the prevalence of having health conditions under treatment, rather than the direct prevalence of health conditions, as this was not included in the survey. Third, the survey's response rate was 69%, and so the findings may not be generalisable to the entire population. Moreover, we could only assess coverage of health services, not whether their quality differed by disability status. Nevertheless, this study makes an important contribution as it presents a complete overview of the most recent trends on health inequities experienced among people with disabilities in Chile. Its strengths lie in the large, nationally representative sample, its comparability with several studies worldwide applying the WG set of questions to measure disability, and the inclusion of participants aged 5 to 17 which had not been included in previous studies.[8–10]

In conclusion, people with disabilities in Chile continue to experience health inequities, both in terms of higher healthcare needs and lower coverage, and various barriers to accessing healthcare. Further monitoring of health inequities is crucial to contribute to evidence-informed policy making, advance in universal health coverage strategies that leave no one behind, and foster the right of people with disabilities in Chile to the highest attainable standard of health as anyone else.

Author statements

Acknowledgements

None

Ethical approval

None required

Data sharing

The 2022 National Socioeconomic Survey database and analytical guidelines are publicly available through the website of the Ministry of Social Development and Family of Chile (https://observatorio.ministeriodesarrollosocial.gob.cl/encuesta-casen-2022)

References

1. World Health Organization. Global report on health equity for persons with disabilities [Internet]. Geneva; 2022 [cited 2023 Jun 13]. Available from: https://www.who.int/publications/i/item/9789240063600

2. United Nations. Convention on the Rights of Persons with Disabilities—Articles. [Internet]. 2006 [cited 2023 Jul 19]. Available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html

3. Kuper H, Heydt P. The Missing Billion: Access to health services for 1 billion people with disabilities [Internet]. London; 2019 [cited 2023 Jun 29]. Available from: https://www.lshtm.ac.uk/research/centres/international-centre-evidence-disability/missing-billion

4. Kuper H, Rotenberg S, Azizatunnisa' L, Banks LM, Smythe T. The association between disability and mortality: a mixed-methods study. Lancet Public Health. 2024 May;9(5):e306–15.

5. Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. Lancet. 2014 Mar 8;383(9920):889–95.

6. García Mora ME, Schwartz Orellana S, Freire G. Disability Inclusion in Latin America and the Caribbean: A Path to Sustainable Development [Internet]. Washington, DC; 2021 [cited 2023 Jul 19]. Available from: https://documents1.worldbank.org/curated/en/099015112012126833/pdf/P17538305622600c00bf3f09659df1f2f79.pdf

7. Rodríguez Gatta D, Rotenberg S, Allel K, Reichenberger V, Banks LM, Kuper H. 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. 2024 Apr;32:100701.

8. Fuentes-López E, Fuente A. Access to healthcare for deaf people: a model from a middle-income country in Latin America. Rev Saude Publica. 2020 Jan 27;54:13.

9. Rotarou ES, Sakellariou D. Inequalities in access to health care for people with disabilities in Chile: the limits of universal health coverage. Crit Public Health. 2017 Oct 20;27(5):604–16.

10. Sakellariou D, Rotarou ES. Utilisation of cancer screening services by disabled women in Chile. PLoS One. 2017 May 1;12(5):e0176270.

11. Instituto Nacional de Estadísticas. Proyecciones de población [Internet]. 2024 [cited 2024 Jan 9]. Available from: https://www.ine.gob.cl/estadisticas/sociales/demografia-y-vitales/proyecciones-de-poblacion

12. Observatorio Social. Encuesta de Caracterización Socioeconómica Nacional [Internet]. 2022 [cited 2024 Jan 19]. Available from: https://observatorio.ministeriodesarrollosocial.gob.cl/encuesta-casen-2022

13. World Bank. World Bank Open Data [Internet]. 2024 [cited 2024 Jul 17]. Available from: https://data.worldbank.org

14. OECD. OECD Reviews of Public Health: Chile. Paris: OECD Publishing; 2019.

15. Sánchez M. Análisis Estadístico del Sistema Isapre con Perspectiva de Género [Internet]. Santiago; 2022 [cited 2024 Jan 18]. Available from: https://www.superdesalud.gob.cl/app/uploads/2023/11/articles-24054_recurso_1.pdf

16. Ministerio de Salud. Decreto 22 aprueba Garantías Explícitas en Salud del Régimen General de Garantías en Salud [Internet]. Santiago; Jul 1, 2019. Available from: https://bcn.cl/2gx51

17. Andiwijaya FR, Davey C, Bessame K, Ndong A, Kuper H. Disability and Participation in Breast and Cervical Cancer Screening: A Systematic Review and Meta-Analysis. Int J Environ Res Public Health. 2022 Aug 1;19(15).

18. Yupanqui-Concha A, Hichins-Arismendi M, Mandiola-Godoy D, Rodríguez-Garrido P, Rotarou ES. Accessing Sexual and Reproductive Health Services in Chile: Women with Disabilities and Their Experience with Gynaecological and Obstetric Violence. Sexuality Research and Social Policy. 2024 Jun 10;21(2):690–703.

19. Hichins-Arismendi M, Yupanqui-Concha A. Barreras en el acceso a salud sexual y reproductiva: experiencias de mujeres con discapacidad en el extremo sur de Chile. ex aequo - Revista da Associação Portuguesa de Estudos sobre as Mulheres. 2022 Dec 15;(46).

20. Rotarou ES, Sakellariou D. Determinants of utilisation rates of preventive health services: evidence from Chile. BMC Public Health. 2018 Dec 6;18(1):839.

21. Reichenberger V, Corona AP, Ramos VD, Shakespeare T, Hameed S, Penn-Kekana L, et al. Access to primary healthcare services for adults with disabilities in Latin America and the Caribbean: a review and meta-synthesis of qualitative studies. Disabil Rehabil. 2024 Mar 3;1–10.

22. Lozano R, Fullman N, Mumford JE, Knight M, Barthelemy CM, Abbafati C, et al. Measuring universal health coverage based on an index of effective coverage of health services in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. The Lancet. 2020 Oct;396(10258):1250–84.

23. Rodríguez Gatta D, Gutiérrez Monclus P, Wilbur J, Hanefeld J, Banks LM, Kuper H. [Pre print] Inclusion of people with disabilities in Chilean health policy: a policy analysis. Research Square [Internet]. 2024 Jul 18 [cited 2024 Jul 19]; Available from: https://doi.org/10.21203/rs.3.rs-4600644/v1]

24. Missing Billion Initiative, Clinton Health Access Initiative. Reimagining health systems that expect, accept and connect 1 billion people with disabilities [Internet]. 2022 [cited 2023 Jun 29]. Available from: https://www.themissingbillion.org/the-reports

25. Kuper H, Azizatunnisa' L, Rodríguez Gatta D, Rotenberg S, Banks LM, Smythe T, et al. Building disability-inclusive health systems. Lancet Public Health. 2024 May;9(5):e316–25.

26. Ministerio de Salud. Hacia una Política de Salud Inclusiva para Personas con Discapacidad [Internet]. 2024 [cited 2024 Jul 16]. Available from: https://rehabilitacion.minsal.cl/hacia-una-politica-de-salud-inclusiva-para-personas-con-discapacidad/

27. Rodríguez Gatta D, Piriz Tapia C, Tagle Schmidt E, Luna Benavides J, Vivar Jara D, Moreno Celis R, et al. [Pre print] Inclusive health for people with disabilities in Chile: a national health system assessment. Research Square [Internet]. 2024 Mar 12 [cited 2024 Jul 16]; Available from: https://doi.org/10.21203/rs.3.rs-4024506/v1

Table 1. Sociodemographic characteristics of people with and without disabilities

	People with disabilities (n=21,769)	**People without disabilities (n=170,837)**	**Age and sex-adjusted p-values**
Age group (years)	**n (%)**	**n (%)**	
5 to 14	1036 (6%)	25,235 (15%)	p <0·0001
15 to 24	1147 (6%)	26,705 (15%)	
25 to 34	1123 (6%)	27,349 (19%)	
35 to 44	1153 (7%)	23,657 (16%)	
45 to 54	2316 (12%)	23,019 (14%)	
55 to 64	4201 (19%)	22,101 (11%)	
≥65	10,793 (45%)	22,771 (11%)	
Sex [a]			
Female	12,835 (57%)	89,008 (50·1%)	p <0·0001
Male	8934 (43%)	81,829 (49·9%)	
Indigenous Peoples [b]			
Yes	2785 (10%)	24,343 (10%)	p <0·0001
No	18,984 (91%)	146,494 (90%)	
Place of birth			
Born in Chile	21,000 (97%)	158,434 (90%)	p <0·0001
Born abroad	489 (3%)	11,138 (10%)	
Residence			
Urban	17,076 (87%)	136,649 (89%)	p <0·0001
Rural	4693 (13%)	34,188 (11%)	
Schooling			
None	2221 (9%)	5645 (3%)	p <0·0001
Primary	9693 (41%)	48,417 (24%)	
Secondary	7238 (36%)	68,944 (39%)	
Higher	2372 (14%)	46,936 (34%)	
Income quintile			
1st quintile	7798 (31%)	42,000 (20%)	p <0·0001
2nd quintile	6018 (27%)	42,383 (22%)	
3rd quintile	4264 (21%)	37,353 (22%)	
4th quintile	2610 (13%)	29,683 (19%)	
5th quintile	1079 (7%)	19,299 (17%)	
Health insurance [c]			
Public	20,091 (90%)	143,111 (79%)	p <0·0001
Private	803 (6%)	18,237 (16%)	
Armed forces and other	475 (2%)	3619 (2%)	
Out-of-pocket	290 (2%)	4394 (3%)	
Functional difficulty type			
Seeing	4773 (22%)	-	
Hearing	1617 (7%)	-	
Mobility	6358 (28%)	-	
Communicating	1516 (8%)	-	

Cognition	538 (3%)	-	
Multiple [d]	6967 (31%)	-	
Level of assistance required [e]			
No dependence	13,888 (68%)	144,199 (99%)	p <0·0001
Mild dependence	1691 (8%)	730 (0·4%)	
Moderate dependence	2284 (10%)	501 (0·3%)	
Severe dependence	2870 (13%)	172 (0·1%)	

Note: Sample weights were considered for all analyses. [a] 99% overlap between participants' reported sex assigned at birth and their gender identity. [b] Belongs to an indigenous group recognized by Chilean law: Aimara, Rapa-Nui/Pascuenses, Quechua, Mapuche, Atacameño (Likan-Antai), Collas, Kawashkar/Alacalufes, Yámana/Yagán, Diaguita, or Chango. [c] Public: National Health Fund (*FONASA*); Private: Private Health Insurances (*ISAPRES*). [d] Including those with difficulties in self-care. [e] Among people above 14 years.

Table 2. Health conditions among people with and without disabilities

	People with disabilities, n (%)	**People without disabilities, n (%)**	**Age, sex-adjusted OR (95% CI) [a]**
Any "health problem" (i.e., disease/accident, in last 3 months) [b]			
No	14,773 (67%)	144,230 (85%)	Baseline
Yes	6767 (33%)	24,550 (15%)	2·22 (2·12-2·32)
Under treatment for selected health conditions (in last 12 months)			
Not treated for any health condition	6642 (33%)	119,024 (72%)	Baseline
Hypertension	4668 (20%)	15,922 (8·2%)	1·93 (1·82-2·05)
Diabetes	3085 (13%)	8853 (4·5%)	2·66 (2·49-2·84)
Acute myocardial infarction	275 (1·2%)	526 (0·3%)	3·21 (2·53-4·07)
COPD	321 (1·5%)	581 (0·3%)	4·75 (3·95-5·71)
Cancer [c]	416 (1·9%)	1119 (0·6%)	2·75 (2·35-3·21)
Asthma	417 (2·1%)	2895 (1·7%)	2·45 (2·13-2·82)
Ischemic stroke	186 (0·9%)	96 (0·1%)	16·25 (11·87-22·24)
Other [d]	5537 (27%)	19,793 (12%)	3·56 (3·35-3·79)
Any of above health conditions [e]	14,905 (67%)	49,785 (27%)	2·82 (2·68-2·97)
Child's nutritional state (aged 5-9 years)			
Normal	326 (73%)	9391 (81%)	Baseline
Malnourished (or at risk of)	12 (3%)	118 (1%)	3·54 (1·51-8·33)
Overweight	92 (20%)	2011 (16%)	1·35 (1·00-1·82)
Obese	27 (4%)	280 (2%)	1·95 (1·20-3·17)

Note: Sample weights were considered for all analyses. Abbreviation: COPD, Chronic Obstructive Pulmonary Disease. [a] Results of multivariable logistic regression models for the associations between each dependent variables on health conditions and disability, adjusted for age and sex. [b] Including common disease, work-related disease, work/school related accident, or any type of accident. [c] Including: Stomach, Cervical, Breast, Testicular, Prostate, Colorectal cancer, and Leukaemia. [d] Other includes Kidney Failure, Lupus, dental emergency, Depression, Cataracts, Cholecystectomy, Bipolar Disorder, and others specified by the informant. [e] Any of the health conditions listed above or reported by the participant versus no reported health condition under treatment.

Table 3. Healthcare utilization among people with and without disabilities

	People with disabilities, n (%)	People without disabilities, n (%)	Age and sex-adjusted OR (95% CI)	Age, sex, and sociodemographic-adjusted OR (95% CI) [a]	Age, sex, and health insurance-adjusted OR (95% CI)
Received medical care, if had "health problem" (in last 3 months) [b]					
No	622 (10%)	2404 (11%)	Baseline	Baseline	Baseline
Yes	6136 (91%)	22,126 (89%)	1·15 (1·01-1·31)	1·22 (1·07-1·39)	1·17 (1·03-1·33)
Type of health service received (in last 3 months)					
General practitioner consultation	7993 (37%)	34,256 (20%)	1·65 (1·58-1·73)	1·67 (1·59-1·75)	1·68 (1·60-1·76)
Emergency care	4800 (21%)	20,369 (11%)	2·05 (1·95-2·15)	1·89 (1·80-1·99)	1·99 (1·89-2·09)
Mental health consultation	2252 (12%)	9244 (6%)	2·57 (2·36-2·80)	2·92 (2·66-3·20)	2·74 (2·50-3·00)
Specialist consultation (any type)	6018 (30%)	24,274 (16%)	1·83 (1·75-1·93)	2·25 (2·13-2·37)	2·04 (1·93-2·14)
Dental care consultation	2488 (12%)	22,499 (14%)	0·98 (0·92-1·05)	1·16 (1·09-1·23)	1·04 (0·97-1·11)
Diagnostics [c]	9230 (42%)	39,302 (24%)	1·59 (1·52-1·66)	1·73 (1·65-1·81)	1·66 (1·59-1·74)
Hospitalization (in last 12 months)	2937 (14%)	9950 (6%)	2·03 (1·88-2·20)	2·11 (1·94-2·29)	2·11 (1·94-2·28)
Number of health consultations (in last 3 months) [d]					
1	3640 (26%)	25,276 (34%)	Baseline	Baseline	Baseline
2	2620 (19%)	15,157 (21%)	1·20 (1·11-1·30)	1·21 (1·12-1·31)	1·22 (1·13-1·32)
3	2125 (15%)	10,962 (16%)	1·33 (1·23-1·45)	1·39 (1·28-1·51)	1·36 (1·25-1·48)
4	1329 (10%)	5991 (9%)	1·44 (1·31-1·57)	1·46 (1·33-1·61)	1·48 (1·35-1·62)
>5	3696 (30%)	14,145 (21%)	2·01 (1·86-2·17)	2·16 (1·99-2·34)	2·09 (1·93-2·26)
Where received healthcare [e]					
Public health provider	12,634 (65%)	57,578 (46%)	Baseline	Baseline	Baseline
Private health provider	2569 (18%)	32,957 (41%)	0·44 (0·41-0·47)	0·71 (0·65-0·78)	0·54 (0·49-0·59)
Mixed (public or private)	2329 (14%)	11,389 (11%)	0·95 (0·88-1·02)	1·15 (1·07-1·24)	0·97 (0·90-1·04)
Other	321 (2·1%)	1528 (1·6%)	1·07 (0·90-1·27)	1·44 (1·21-1·71)	1·18 (0·99-1·42)

Note: Sample weights were considered for all analyses. Adjusted odds ratios were derived from multivariable logistic regression models for the associations between each dependent variables on healthcare utilization and disability. [a] Adjusted for age, sex, place

---

of birth, residence, schooling, and income. [b] Including common disease, work-related disease, work/school related accident, or any type of accident. [c] Including laboratory, radiology, and imaging. [d] Among those who received either general practitioner, emergency, mental health, specialist, or dental consultations. [e] Among those who were hospitalised, underwent a medical check-up or diagnostics, or received general medical, emergency, mental health, specialist, or dental consultations.

Table 4. Coverage of preventive health screening services among people with and without disabilities

	People with disabilities, n (%)	**People without disabilities, n (%)**	**Age and sex-adjusted OR (95% CI)**	**Age, sex, and sociodemographic adjusted OR (95% CI) [a]**	**Age, sex, and health insurance-adjusted OR (95% CI)**
Child health check-up (5-9 years)	210 (50%)	5148 (48%)	1·06 (0·82-1·38)	1·07 (0·82-1·38)	1·11 (0·85-1·45)
Adult health check-up (15-64 years)	1400 (15%)	18,581 (17%)	0·75 (0·70-0·82)	0·88 (0·81-0·96)	0·81 (0·75-0·88)
Older people health check-up (≥65 years)	3260 (34%)	6614 (32%)	0·91 (0·84-0·97)	0·94 (0·87-1·01)	0·92 (0·86-0·99)
Pap test (25-64 years) [b]	3211 (65%)	32,962 (71%)	0·76 (0·70-0·82)	0·84 (0·77-0·91)	0·79 (0·73-0·85)
Mammogram (50-59 years) [b]	1325 (67%)	8125 (72%)	0·82 (0·72-0·94)	0·93 (0·81-1·06)	0·86 (0·76-0·98)

Notes: Sample weights were considered for all analyses. These free and voluntary health check-ups are part of a funded national health program and are guaranteed by law to people with public or private health insurance. All health check-ups in the last 12 months. Adjusted odds ratios were derived from multivariable logistic regression models for the associations between each dependent variables on health check-ups and disability. [a] Adjusted for age, sex, place of birth, residence, schooling, and income. [b] Pap test or mammogram among women in the last 3 years.

Table 5. Difficulties presented while accessing healthcare among people with and without disabilities

	People with disabilities, n (%)	People without disabilities, n (%)	Age and sex-adjusted OR (95% CI)	Age, sex, and sociodemographic-adjusted OR (95% CI) [a]	Age, sex, and health insurance-adjusted OR (95% CI)
Reaching health center [b]	1341 (21%)	2367 (10%)	2·11 (1·89-2·35)	1·87 (1·67-2·10)	1·97 (1·77-2·20)
Getting an appointment [c]	1721 (28%)	4366 (19%)	1·62 (1·41-1·85)	1·50 (1·30-1·73)	1·55 (1·35-1·78)
Receiving care [d]	1750 (29%)	4626 (19%)	1·73 (1·52-1·97)	1·54 (1·34-1·78)	1·62 (1·41-1·85)
Paying for care due to cost	735 (12%)	1910 (9%)	1·46 (1·28-1·66)	1·46 (1·27-1·66)	1·44 (1·26-1·64)
Obtaining medications [e]	930 (16%)	2286 (10%)	1·70 (1·51-1·92)	1·65 (1·46-1·86)	1·61 (1·43-1·81)

Note: Sample weights were considered for all analyses. Difficulties reported in the last three months. Adjusted odds ratios were derived from multivariable logistic regression models for the associations between each dependent variables on barriers and disability. [a] Adjusted for age, sex, place of birth, residence, schooling, and income; for the last two difficulties, income was excluded from the model. [b] Distance, transport connectivity, etc. [c] Long waiting times, postponement of appointments, etc. [d] At the health center, e.g., delays, time changes, lack of staff, etc. [e] Including difficulties in obtaining free prescribed medication supplied by health facilities and difficulties for those who must pay for medication out of pocket.

Chapter 5

Inclusion of people with disabilities in Chilean health policy: a policy analysis

5.1 | Chapter preamble

Chapter 3 and 4 revealed the higher demand for health services among people with disabilities and the existing health inequities, compared to those without disabilities. These issues experienced at the individual level can arise from important system level failures.[25] Therefore, building on the evidence presented in previous chapters, the present chapter introduces a health policy analysis of governance and leadership related to disability and health, to explore structural roots of health inequities. Namely, it aimed to assess the inclusion of people with disabilities in Chilean general healthcare policy documents and to explore the perceptions of key national stakeholders regarding the policy context, policy processes, and actors involved. This mixed methods study – including an analysis of 12 policy documents and primary data collection through 15 key informant interviews – considered the explicit reference to disability following a human rights approach [8] and is in line with the Missing Billion Inclusive Health Systems framework.[2,3]

Further progress is required in both the design and implementation of health policies to progress disability-inclusive healthcare in Chile. This chapter provides an overview of the level of inclusion of people with disabilities in paper as well as the level of implementation of health policies with disability inclusion in practice. It also helps identify key progress and gaps in governance and leadership on disability and health. Consequently, it serves as key evidence for the overall health system assessment following in Chapter 6. Additionally, the findings of the health policy analysis have implications for health system strengthening in Chile as well as for research, particularly on the framing of disability, as presented in Chapter 7.

This health policy analysis was published in the *International Journal for Equity in Health* in August 2024. Appendices of this study can be found in Appendix C.

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

SECTION A – Student Details

Student ID Number	2004713	**Title**	Mrs
First Name(s)	Danae Harmonia		
Surname/Family Name	Rodríguez Gatta		
Thesis Title	Access to healthcare among people with disabilities in Chile		
Primary Supervisor	Hannah Kuper		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	International Journal for Equity in Health		
When was the work published?	29 August 2024		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	**Yes**	Was the work subject to academic peer review?	**Yes**

*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	
Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I have conceptualized the study, collected primary data, reviewed, analyzed, and interpreted data, drafted the paper, and compiled the final manuscript.

SECTION E

Student Signature	Danae Rodríguez Gatta
Date	4 September 2024

Supervisor Signature	Hannah Kuper
Date	4 September 2024

Rodríguez Gatta *et al. International Journal for Equity in Health* (2024) 23:174
https://doi.org/10.1186/s12939-024-02259-4

International Journal for Equity
in Health

RESEARCH **Open Access**

Inclusion of people with disabilities in Chilean health policy: a policy analysis

Danae Rodríguez Gatta[1,2*], Pamela Gutiérrez Monclus[2,3], Jane Wilbur[1], Johanna Hanefeld[4,5], Lena Morgon Banks[1] and Hannah Kuper[1]

Abstract

Background Around 18% of the population in Chile has disabilities. Evidence shows that this population has greater healthcare needs, yet they face barriers to accessing healthcare due to health system failures. This paper aims to assess the inclusion of people with disabilities in health policy documents and to explore the perceptions of key national stakeholders regarding the policy context, policy processes, and actors involved.

Methods A policy content analysis was conducted of 12 health policy documents using the EquiFrame framework, adapted to assess disability inclusion. Documents were reviewed and rated on their quality of commitment against 21 core concepts of human rights in the framework. Key national stakeholders ($n = 15$) were interviewed, and data were thematically analysed under the Walt and Gilson Policy Analysis Triangle, using NVivo R1.

Results Core human rights concepts of disability were mentioned at least once in nearly all health policy documents (92%). However, 50% had poor policy commitments for disability. Across policies, *Prevention* of health conditions was the main human rights concept reflected, while *Privacy* of information was the least referenced concept. Participants described a fragmented disability movement and health policy, related to a dominant biomedical model of disability. It appeared that disability was not prioritized in the health policy agenda, due to ineffective mainstreaming of disability by the Government and the limited influence and engagement of civil society in policy processes. Moreover, the limited existing policy framework on disability inclusion is not being implemented effectively. This implementation gap was attributed to lack of financing, leadership, and human resources, coupled with low monitoring of disability inclusion.

Conclusions Improvements are needed in both the development and implementation of disability-inclusive health policies in Chile, to support the achievement of the right to healthcare for people with disabilities and ensuring that the health system truly "leaves no one behind".

Keywords Health policy analysis, Health equity, People with disabilities, Chile, Disability-inclusive health, EquiFrame, Health policy triangle

Abstract in Spanish

Introducción Alrededor del 18% de la población de Chile tiene discapacidad. Los datos demuestran que esta población tiene mayores necesidades de salud, pero se enfrenta a barreras para acceder a la salud debido a las

---

*Correspondence:
Danae Rodríguez Gatta
danae.rodriguez@lshtm.ac.uk

Full list of author information is available at the end of the article

deficiencias del sistema sanitario. El objetivo de este estudio es evaluar la inclusión de las personas con discapacidad en las políticas sanitarias y explorar las percepciones de actores nacionales en relación al contexto político, los procesos políticos y los actores implicados.

Métodos Se realizó un análisis de contenido de 12 políticas sanitarias utilizando el marco EquiFrame, adaptado para discapacidad. Se calificó la calidad de compromiso de las políticas con respecto a 21 conceptos de derechos humanos del EquiFrame. Se entrevistó a 15 actores nacionales, y los datos se analizaron temáticamente según el Triángulo de Políticas de Walt y Gilson, utilizando NVivo R1.

Resultados Los conceptos de derechos humanos en materia de discapacidad se mencionaron al menos una vez en casi todas las políticas sanitarias (92%). Sin embargo, en el 50% de los casos los compromisos políticos en materia de discapacidad eran escasos. En todas las políticas, la *Prevención* de los problemas de salud fue el principal concepto de derechos humanos reflejado, mientras que la *Privacidad* de la información fue el concepto menos mencionado. Los participantes describieron un movimiento de la discapacidad y una política sanitaria fragmentados, relacionados con un modelo biomédico dominante de la discapacidad. Pareciera que la discapacidad no es prioritaria en la agenda política sanitaria, debido a su ineficaz integración por parte del Gobierno y a la limitada participación de la sociedad civil en los procesos políticos. Además, el limitado marco político existente sobre salud inclusiva no se está implementando eficazmente. Esta deficiencia en la implementación se atribuyó a la falta de financiamiento, liderazgo y recursos humanos, junto con el escaso monitoreo de la discapacidad.

Conclusiones Se requieren mejoras tanto en el desarrollo como en la implementación de políticas de salud inclusivas de la discapacidad en Chile, para apoyar el alcance del derecho a la salud de las personas con discapacidad y asegurar que el sistema de salud realmente "no deje a nadie atrás".

Background

People with disabilities represent about 1.3 billion of the world's population [1] and include *"those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"* [2]. On average, people with disabilities die 14 years earlier, including due to preventable health inequities [1, 3]. In Latin America and the Caribbean (LAC) there are about 85 million people with disabilities (15% of the total population) [4]. Systematic review evidence indicates that they use health services more frequently than the general population and face inequities in terms of coverage, quality, and affordability of healthcare, related to access barriers [5]. A meta-synthesis of qualitative studies conducted in LAC confirms that adults with disabilities face broad-ranging access barriers both in the supply and demand sides of primary healthcare (e.g., poor health worker training and inaccessible information) [6]. This overall situation in LAC is also apparent in Chile, the focus of the current study, where there are about 3 million people with disabilities (18% of the population) [7]. For instance, evidence from Chile shows that people with disabilities are more likely to experience difficulties accessing health centers [8] and are less likely to undergo cancer screening [9, 10]. Moreover, about 77% of primary healthcare workers report a lack of protocols for patients with disabilities, and 59% describe inaccessible health infrastructure [11].

In this context, it is crucial that people with disabilities are meaningfully involved and that their rights are promoted and mainstreamed in the health sector [1, 12]. Hence, to realize disability-inclusive care, health systems should "expect, accept, and connect" people with disabilities to access quality health services that are intentionally designed to include them, on an equal basis as those without disabilities and without incurring additional costs [13, 14]. The Missing Billion Framework identifies core components relevant for achieving disability-inclusive health, operating at the systems level (governance, leadership, financing, data and evidence), demand-side service level (autonomy and awareness, affordability) and supply-side service level (human resources, health facilities, rehabilitation and assistive technology) [14]. Achievement of disability inclusion across these components should improve health outputs for people with disabilities (e.g. service coverage) and therefore reduce inequities in health outcomes (e.g. mortality gaps) [14].

Barriers to accessing healthcare often arise from health system level failures, in particular lack of governance, as health policies are structural determinants of the organization of healthcare and health equity [15]. The policy framework in Chile appears to support the inclusion of people with disabilities in healthcare. In 2008, Chile ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) [16] and in 2010 the National Disability Law was enacted [17]. Furthermore, the last National Health Strategy (2010–2020) included provisions for better access to rehabilitation, education of caregivers, and access to treatment for people with psychosocial disabilities [18]. However, amidst the upcoming review of Chile before the Committee on the Rights of Persons with Disabilities, civil society expressed concerns about implementation gaps in health [19]. For instance, they raised issues about the continuation of forced sterilization of women with disabilities and lack of health worker protocols for attending to patients with disabilities, inaccessible health information, and lack of mental health funding [19]. Moreover, there is evidence that the needs of people with disabilities were not fully addressed in government responses to COVID-19 in South America, including in Chile, where this group remained invisible in data collection for decision-making in public policy [20, 21].

Health policy analyses on disability are critical for understanding the gaps between policy formulation and implementation, the strengths and weaknesses of policy documents, and the level of commitment to disability [22–24]. However, health policies have been largely understudied using a disability lens. Previous policy analyses in Chile have focused on disability-specific policies [25, 26] or programs [27, 28]. Therefore, it is necessary to understand the broad health policy framework impacting access of people with disabilities to general healthcare across the Chilean health system. The aim of this study is to assess the inclusion of people with disabilities in Chilean general healthcare policy documents and to explore the perceptions of key national stakeholders regarding the policy context, policy processes, and actors involved.

Methods

Study design and setting

This study consisted of a policy content analysis of 12 policy documents and 15 key informant interviews. The study was conducted in Chile, a geographically diverse high-income country of 20 million inhabitants [29–31]. Chile has a two-tiered health system including both public and private insurance schemes and a mixed health service provision [32, 33]. It is led by the Ministry of Health, structured through the under secretariats of Public Health and Healthcare Networks. The National Health System of Healthcare Services includes 29 autonomous health services across 16 regions, overseeing mainly hospitals. Local municipalities manage the provision of decentralized primary healthcare services.

Policy analysis

Selection of policies

Health policy documents were selected that fulfilled the following eligibility criteria: (1) overarching documents (policies, strategies, or plans), (2) issued by official government bodies (e.g. Ministry of Health (MoH)), (3) currently in force (i.e., published within the last 5 to 10 years, or targets not outdated), (4) of national scope, and (5) considered to relate to access to general healthcare for the overall population. Laws, technical guidance and recommendations were excluded. Key stakeholders related to disability policy and health systems in Chile were consulted to refine the selection criteria, including the MoH, the Ministry of Social Development and Family, the Pan American Health Organization and four academic experts. Eligible policies were searched through official websites of the national libraries of the MoH, the Ministry of Social Development and Family, and the National Congress of Chile.

Data extraction and analysis

The EquiFrame framework was used to guide the content analysis of health policy documents [34]. The EquiFrame is a systematic policy analysis framework developed to assess the inclusion of 21 core concepts of human rights and 12 vulnerable groups in health policies, to improve equity in healthcare. Each core concept has a description of its key language and questions, which were adapted to be relevant to people with disabilities and general healthcare (Table 1). For example, the key language for the concept of *Non-discrimination* was: *"Persons with disabilities are not discriminated against based on their distinguishing characteristics"*, and the key question: *"Does the policy support the rights of persons with disabilities with equal opportunity to receive healthcare?"*. Moreover, we searched for the explicit mention of "people with disabilities" within documents and what was defined as disability under each policy.

Core concepts were then translated into Spanish and the translation was checked by an external assessor (Additional File 1). Support was sought from the authors of the EquiFrame to review and approve the adaptations. Two reviewers (DRG and PGM) independently assessed each policy document for the inclusion of core concepts. Referenced concepts were rated based on their quality of commitment on a continuum from 1 (i.e., only mentioned) to 4 (i.e., intention to monitor) and then extracted and recorded in a Microsoft Excel spreadsheet (Table 2).

The scores were compared and aligned by the reviewers, after resolving any discrepancies. Four summary indices were developed: core concept coverage, core concept quality, core concept reference, and average score (Table 2).

Key informant interviews

Sampling and recruitment

Fifteen key national stakeholders were interviewed to explore the policy context, process and actors involved (Table 3). A stratified purposive sampling was applied to ensure the representation of different views and expertise

Table 1 List of EquiFrame adapted core concepts of human rights for people with disabilities

Nº	Concept	Key question	Key language
1	Non-Discrimination	Does the policy support the rights of persons with disabilities with equal opportunity to receive healthcare?	Persons with disabilities are not discriminated against on the basis of their distinguishing characteristics.
2	Individualized Services	Does the policy support the rights of people with disabilities with individually tailored services to meet their needs and choices?	People with disabilities receive appropriate, effective, and understandable services.
3	Entitlement	Does the policy indicate how people with disabilities may qualify for specific benefits relevant to them?	People with disabilities who have limited resources are entitled to some services free of charge or may be entitled to respite grant.
4	Capability-based services	Does the policy recognize the capabilities existing within people with disabilities?	For instance, peer to peer support among people with disabilities, advocacy groups and organizations of people with disabilities.
5	Participation	Does the policy support the right of people with disabilities to participate in the decisions that affect their lives and enhance their empowerment?	People with disabilities can exercise choices and influence decisions affecting their life. Such consultation may include planning, development, implementation, and evaluation.
6	Coordination of Services	Does the policy support assistance of people with disabilities in accessing services from within a single provider system (intragency) or more than one provider system (inter-agency) or more than one sector (inter- sectoral)?	People with disabilities know how services should interact where inter-agency, intra- agency, and inter-sectoral collaboration is required.
7	Protection from harm	Are people with disabilities protected from harm during their interaction with health and related systems?	People with disabilities are protected from harm during their interaction with health and related systems.
8	Liberty	Does the policy support the right of people with disabilities to be free from unwarranted physical or other confinement?	People with disabilities are protected from unwarranted physical or other confinement while in the custody of the service system/provider.
9	Autonomy	Does the policy support the right of people with disabilities to consent, refuse to consent, withdraw consent, or otherwise control or exercise choice or control over what happens to him or her?	People with disabilities can express "independence" or "self-determination". For instance, person with an intellectual disability will have recourse to an independent third-party regarding issues of consent and choice.
10	Privacy	Does the policy address the need for information regarding people with disabilities to be kept private and confidential?	Information regarding people with disabilities need not be shared among others.
11	Integration	Does the policy promote the use of mainstream services by people with disabilities?	People with disabilities are not barred from participation in services that are provided for general population.
12	Contribution	Does the policy recognize that people with disabilities can be productive contributors to society?	People with disabilities make a meaningful contribution to society.
13	Family Resource	Does the policy recognize the value of the family members of people with disabilities in addressing health needs?	The policy recognizes the value of family members of people with disabilities as a resource for addressing health needs.
14	Family Support	Does the policy recognize individual members of people with disabilities may have an impact on the family members requiring additional support from healthcare services?	Caring for persons with disabilities may have mental health effects on other family members, such that these family members themselves require support.
15	Cultural responsiveness	Does the policy ensure that services respond to the beliefs, values, gender, interpersonal styles, attitudes, cultural, ethnic, or linguistic, aspects of the person?	i) People with disabilities are consulted on the acceptability of the service provided. ii) Health facilities, goods and services must be respectful of ethical principles and culturally appropriate, i.e. respectful of the culture of people with disabilities
16	Accountability	Does the policy specify to whom, and for what, services providers are accountable?	People with disabilities have access to internal and independent professional evaluation or procedural safe guard.
17	Prevention	Does the policy support people with disabilities in seeking primary, secondary, and tertiary prevention of health conditions?	
18	Capacity building	Does the policy support the capacity building of health workers and of the system that they work in addressing health needs of people with disabilities?	
19	Access	Does the policy support people with disabilities – physical, economic, and information access to healthcare services?	People with disabilities have accessible health facilities (i.e., transportation; physical structure of the facilities; affordability and understandable information in appropriate format).

Table 1 (continued)

Nº	Concept	Key question	Key language
20	Quality	Does the policy support quality services to people with disabilities through highlighting the need for evidence-based and professionally skilled practice?	People with disabilities are assured of the quality of the clinically appropriate services.
21	Efficiency	Does the policy support efficiency by providing a structured way of matching health system resources with service demands in addressing health needs of people with disabilities?	

Note **Concepts adapted from Amin M, MacLachlan M, Mannan H, El Tayeb S, El Khatim A, Swartz L, et al. EquiFrame: a framework for analysis of the inclusion of human rights and vulnerable groups in health policies. Health Hum Rights. 2011;13:1–20, and Wilbur J, Scherer N, Mactaggart I, Shrestha G, Mahon T, Torondel B, et al. Are Nepal's water, sanitation and hygiene and menstrual hygiene policies and supporting documents inclusive of disability? A policy analysis. Int J Equity Health. 2021;20:157**

Table 2 Scoring of quality of commitment and summary indices

Scoring	Quality of commitment
0	Concept not mentioned
1	Concept only mentioned
2	Concept mentioned and explained
3	Specific policy actions identified to address the concept
4	Intention to monitor concept was expressed
Summary indices	
Each policy	**Core concept coverage [(n/21) x 100]**: the proportion (%) of core concepts included in a policy, where n is the number of core concepts rated above 0 and 21 is the total number of core concepts.
	Core concept quality [(n/N) x 100]: the proportion (%) of core concepts included in a policy with top quality, where n is the total number of core concepts rated "3" or "4" and N is the total number of core concepts referenced. *
Across policies	**Total references [(n/377) x 100]**: the proportion (%) of references to core concepts across policies, where n is the total number of references made to a core concept and 377 is the total number of references to all core concepts across policies.
	Average score [(n/N)]: the average score of core concepts across policies, where n is the total number of references to a core concept and N is the total score of the concept across all policies

*** Several references to a single core concept can be found in each policy**

Table 3 Participants of key informant interviews (n = 15)

Sector	Department, Institution
Government (n = 6)	1) Rehabilitation and Disability, Ministry of Health
	2) Mental Health, Ministry of Health
	3) Non-Communicable Diseases, Ministry of Health
	4) Care Network Management, Ministry of Health
	5) Autonomy and Dependency, National Disability Agency
	6) Evaluation and Studies, National Disability Agency
Parliament (n = 2)	7) Senate, National Congress of Chile
	8) Chamber of Deputies, National Congress of Chile
Health provider (n = 3)	9) National Specialized Referral Hospital
	10) Life Cycle, Regional Health Service
	11) Life Cycle, Regional Health Service
Civil Society (n = 2)	12) Human Rights Organization
	13) Patients' Association
International (n = 2)	14) Mental Health, Pan American Health Organization
	15) Special Envoy, United Nations Secretary-General

Note **The National Disability Agency (in Spanish,** *Servicio Nacional de la Discapacidad***) is under the Ministry of Social Development and Family**

of sectors related to health policy and disability. We recruited participants through recommendations of governmental officials and academic experts. Potential participants were also identified from policy documents. For example, authors, contributors, technical advisors, and those designated to implement and monitor policies.

Data collection and analysis

Interviews were held in Spanish between October and December 2022. Most interviews were conducted face-to-face at the participant's workplace or public locations, although some were online through Zoom, due to COVID-19 pandemic public health regulations. Semi-structured interview guides with open-ended questions were used to frame discussions with participants. Interviews lasted between 45 and 60 min and were audio-recorded and transcribed. The Walt and Gilson Policy Analysis Triangle was used to guide the analysis of the key informant interviews [35, 36]. This framework presents a simplified model of the complex interplay between health policy content, systemic factors of the policy context, policy making processes, and the actors involved in a particular issue [35, 36]. Interview transcripts were analysed thematically supported by the NVivo R1 software. Audio recordings were transcribed in Spanish and only selected quotes were translated into English; the quality of the translation was assessed by an external assessor. Transcriptions were coded deductively, with preliminary codes developed based on the interview guide and the emergent topics of the interview. Codes were selected based on frequency, relevance to the research question and level of divergence, and final themes were developed. Codes were revised by co-authors and triangulated with the health policy documents to corroborate information. This study received ethical approval from the Ethics Committees of University of Chile and London School of Hygiene and Tropical Medicine.

Results

Summary indices of the policy content analysis using the EquiFrame

Twelve policy documents were analysed (n=1 (8%) strategy, n=4 (33%) policies, and n=7 (58%) plans) (Table 4, Additional File 2, and Fig. 1) [35–46]. Core human rights concepts of people with disabilities were referenced, at least once, in nearly all policies (n=11, 92%), except for the National Food and Nutrition Policy. The National Mental Health Plan had the highest reference to core concepts (90%), followed by the National Health Strategy (76%) (Table 4). In contrast, the National Plan on Cancer (5%) and Non-Communicable Diseases (10%) had few references to core concepts. However, the high number of references did not reflect the highest strength of policy commitment. For instance, only 1% of concepts referenced in the National Health Strategy described specific policy actions or monitoring of interventions for people with disabilities. The highest quality of commitment was found in the National Mental Health Action Plan (91%), followed by the National Oral Health Plan (83%). Overall, 50% of policies had low (0–3%) quality of commitment.

Table 4 Core concept coverage and quality of health policy documents included (n = 12)

Year	Title	Core concept coverage (%)	Core concept quality (%)*
2016	National Policy on Childhood and Adolescence	48%	12%
2017	National Plan on Dementia	62%	0%
2017	National Plan on Mental Health	90%	28%
2017	National Policy on Food and Nutrition	0%	0%
2018	National Policy on Sexual and Reproductive Health	38%	0%
2018	National Plan on Cancer	5%	33%
2021	National Health Policy to address Gender-Based Violence	52%	3%
2021	National Health Plan for the Elderly and its Action Plan	38%	38%
2021	National Action Plan on Mental Health	38%	91%
2022	National Health Strategy for the 2030 Health Goals	76%	1%
2022	National Plan on Non-Communicable Diseases	10%	0%
2022	National Plan on Oral Health	14%	83%

*Core concepts scored 3 (specific policy actions identified to address the concept) or 4 (intention to monitor concept was expressed)

Table 5 shows the aggregated results across policy documents. The concepts of *Prevention* (17%), *Entitlement* (12%) and *Individualized services* (11%) were the top three most frequently mentioned concepts across all policies analysed. The least referenced concept was *Privacy* (0.3%), although several others were also infrequently mentioned (1%) including *Capability-based services*, *Contribution*, *Cultural responsiveness*, and *Efficiency*. The highest average quality scores were found in *Capacity Building* (2.7), and *Coordination of Services* (2.2). Again, frequency and quality could differ, as with *Accountability*, which only represented 1% of total references but obtained the highest average score of 3.5. Examples of references scored 3 or 4 are in Additional File 3.

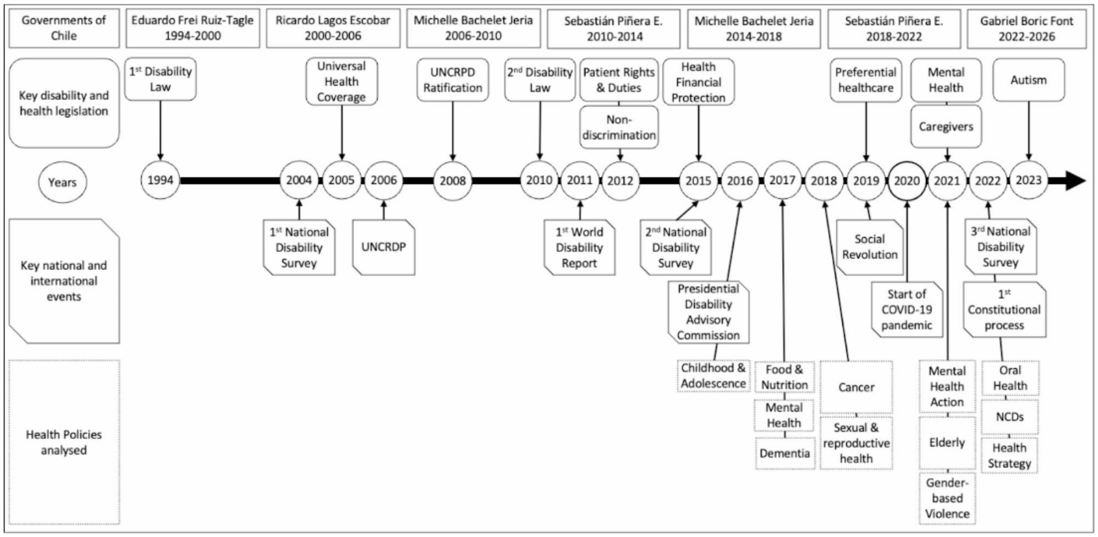


Fig. 1 Timeline of key legislation, events, and health policies analysed. *Legend* UNCRPD, United Nations Convention on the Rights of People with Disabilities; NCDs, Non-Communicable Diseases

Table 5 References to core concepts and average score across health policy documents (*n* = 12)

Nr.	Concept	Health policies (n = 377 references across policies)	
		Total references (%)	Average quality score (max. 4)
1	Non-Discrimination	8%	1.4
2	Individualized Services	11%	1.9
3	Entitlement	12%	2.0
4	Capability-based services	1%	1.5
5	Participation	3%	1.6
6	Coordination of Services	8%	2.2
7	Protection from Harm	7%	1.8
8	Liberty	2%	1.6
9	Autonomy	5%	1.7
10	Privacy	0.3%	1.0
11	Integration	4%	1.9
12	Contribution	1%	1.5
13	Family Resource	2%	1.0
14	Family Support	2%	1.3
15	Cultural responsiveness	1%	1.5
16	Accountability	1%	3.5
17	Prevention	17%	1.6
18	Capacity building	2%	2.7
19	Access	7%	1.8
20	Quality	6%	1.7
21	Efficiency	1%	2.0
	Total	100%	

Key informant interviews

A fragmented disability movement and health policy

A key issue raised by participants was that fragmentation in the disability movement weakens their influence on the health policy agenda. Interviewees reported that civil society organizations were grouped by impairments or medical diagnoses and advocated for their own health needs, rather than for disability inclusion more holistically.

Fragmentation was also reflected in health policies, which were described as hyper-focalized by health conditions, instead of being formulated more comprehensively for all disabilities. In addition, it was argued that the focus has been on physical and sensory impairments rather than intellectual and psychosocial impairments. This was viewed as inefficient for policy processes. Some participants considered that inclusive health has received some government attention, but mostly focusing on people with autism, thus reinforcing fragmentation.

Participants expressed concerns about parliamentarians supporting causes advocated for by civil society, regardless of rational health prioritizations. They suggested that policy makers should lead policy formulation focusing holistically on the needs of people with disabilities. Ideally, solutions would include a comprehensive and intersectoral disability-inclusive health policy, and mainstreaming of disability in existing health policies.

Role of international agencies in disability perspectives

Two international initiatives were perceived as key to shaping the disability landscape in Chile, by introducing elements of a more social perspective of disability. The World Health Organization (WHO), well recognized as an influential governing body, installed the International Classification of Functioning, Disability and Health (ICF) and biopsychosocial model of disability in Chile. Furthermore, the UNCRPD installed a human rights perspective and was recognized as a relevant legal framework for policy. Nevertheless, some participants reported that the dominant model of disability in Chile remains biomedical.

> *"Unfortunately, people with disabilities in the health movement are not considered, unless they belong to an organization that obeys a pathologizing or biomedical model [...] But these organizations obey the past model, the past! They relate to health in a charitable, rehabilitative way, not in a model of inclusion." Interview 2, civil society organization.*

Disability as low politics in the health policy agenda

Inclusion of all people with disabilities in general healthcare was viewed as a low priority issue for regional or central government. For instance, government officials noted that the accessibility of health services for people with disabilities has remained as a government measure, but without an implementation strategy. Moreover, participants especially argued that there is a lack of policy actions for people with disabilities in the Sexual and Reproductive Health (SRH) Policy, as reaffirmed in this content analysis. Improvement of disability awareness and accessibility mindset among policy makers from the start of policy formulation was seen as fundamental for improving the prioritization of disability, especially in the Ministry of Health.

Ineffective mainstreaming of disability and coordinated action among governing bodies

Government officials consistently noted that disability-related policy is mainly led by the Rehabilitation and Disability Department of the MoH. The Department has an acknowledged role in ensuring disability is mainstreamed across teams, but was criticized for a low interdepartmental work by government officials. However, it was also agreed that it is a general Ministerial challenge to integrate actions across sub-secretaries of health.

Moreover, disability was described as a cross-cutting issue, which should be addressed by several ministries and a complex network of actors, besides the health sector alone. However, government officials and civil society actors noted a lack of coordinated action between ministries. There is a relevant agency - National Disability Agency (NDA; *Servicio Nacional de la Discapacidad*, *SENADIS*, for its Spanish abbreviation) of the Ministry of Social Development and Family – whose formal role is to lead disability inclusion in the policy agenda of all governing bodies. However, their effectiveness in fulfilling this role was questioned by participants.

> *"The NDA is not an institution that is truly a governing body, in terms of putting the issue of disability and inclusion as strongly as it needs to be." Interview 7, ex-member of parliament.*

Civil society's limited influence in the health policy agenda and engagement in policy formulation

Participants identified four main pathways for influencing the health agenda by civil society, including Organizations of People with Disabilities (OPDs). The first is through advocacy to parliament. The second route includes the participation of people with disabilities in temporary task forces led by the Executive, where issues are recognized. However, civil society and international actors reported that even though task forces were created, policy implementation was uncertain. Third, it is possible for people with disabilities to raise issues at primary care level, when health teams lead participatory assessments of the population's health needs. Finally, the judicialization of cases and the media has been used by civil society to increase pressure and promote disability inclusion.

However, government officials perceived that OPDs have not managed to influence the health agenda and noted that they still lack capacity for health policy making. A government official also reported that many organizations of civil society lack a structure, are difficult to reach or are not interested in participating in policy processes. One exception highlighted was the autism movement.

> *"We are recognizing that organizations of civil society are valid actors for needs assessments. This is how is it being done, so when they work on autism, all [autism] organizations participate in the parliament." Interview 5, government official.*

Furthermore, participants reported a limited engagement of civil society in health policy formulation. Their participation is not institutionalized in the MoH, and it depends on the political will of policy makers. Government officials considered that OPDs should be involved in policy design, although their inclusion has been slow. The institutional culture of Government was reported to have acted as a barrier, as technical expert knowledge is prioritized over lived experience of disability.

Gap in implementation of the existing limited policy framework for disability inclusion

Some disability inclusion was reported in the National Health Strategy and the national policies on Mental Health, Elderly, and Childhood and Adolescence, which supports the findings of the document review. The Preferential Care Law for Elderly and People with Disabilities was also regarded as a relevant policy framework for disability inclusion, as it guarantees priority access to appointments, emergencies, medicines, and examinations [37]. However, participants identified a gap between policy formulation and implementation. For example, government officials and health providers reported that the monitoring of the Preferential Care Law revealed a lack of execution, poor preparation of health teams and limited public information on this law.

> *"The health centers were not implementing this [Preferential Care Law] [...] The teams were not prepared. So, while it is true that the spirit of the law is fine, it is often the case that to apply these laws, some kind of resources are needed." Interview 12, health provider.*

Lack of financing, leadership, and human resources affecting policy implementation

Participants identified three main reasons for the policy implementation gap. These included: lack of disability financing, an inconsistent political approach to disability and lack of leadership, and gaps in human resources.

Lack of resources for disability and lack of disability-related pay for performance indicators – the main incentive mechanism for primary care teams [33] – were identified by participants as barriers for policy implementation. For example, the SRH policy did not include resources to improve the accessibility of infrastructure.

> *"But certainly, one of the problems that we have had in Chile and in many other countries is that action plans are not associated to budget, or budgets are so low that they do not relate to the objectives set for the action plan [...] This causes many problems, because it is a dead public policy at the end, without any type of effect". Interview 15, international actor.*

The policy implementation gap was also attributed to changes in government or political authorities and lack of leadership. The political will and perspectives of the government in power and the legislature were recognized as key factors in prioritizing health issues and successful policy implementation (specially from the President and mid-level policy officers). However, regardless of who is in power, the approach to disability appeared inconsistent as policies are either discontinued or restarted from scratch. Moreover, some participants perceived that there was no strong leadership on disability in central government, with diffused responsibilities between the MoH and the NDA. Similarly, at the regional level, health providers considered that disability leadership is fragmented.

> *"In a way, I am in charge of disability, I see the whole musculoskeletal, neurological rehabilitation program […] It is kind of fragmented, there is no unit that concentrates a strategic and cross-cutting view of disability" Interview 12, health provider.*

Different policy solutions were identified to improve leadership on disability inclusion. Government officials and health providers suggested the implementation of dedicated disability units at central and regional levels, while members of parliament proposed a new interministerial governance. Other participants proposed strengthening existing leadership or reinforcing interdepartmental and multisectoral work.

Finally, implementation is perceived to be affected by gaps in human resources. Participants identified a lack of personnel to implement additional services, lack of training among health teams about disability, and high health professional turnover.

Low monitoring of disability inclusion

Government officials, health providers, and civil society actors observed limited monitoring of disability inclusion in general healthcare policies. For example, they reported that the current National Health Strategy includes indicators on health conditions but not on disability. Government officials, health providers, and members of parliament suggested that monitoring could be strengthened through official complaints or consultations with civil society. Finally, international and civil society actors highlighted the need for an independent disability monitoring mechanism in Chile.

Discussion

This health policy analysis on disability in Chile included a content analysis of 12 policy documents on general healthcare and 15 key informant interviews. Disability was mentioned in nearly all health policy documents reviewed (92%). However, 50% of policies had low or no policy commitments to disability. *Prevention* was the main human rights concept reflected across policies, while *Privacy* was the least referenced concept. Furthermore, interviews revealed a fragmented disability movement and health policy, related to a dominant biomedical model of disability. It appeared that disability was not prioritized in the health policy agenda due to ineffective mainstreaming of disability from Government and the limited influence and engagement of civil society in policy processes. Moreover, the limited existing policy framework on disability inclusion is not being implemented. Lack of financing, leadership, and human resources were attributed to this implementation gap, coupled with low monitoring of disability inclusion.

Most mainstream Chilean health policies analysed in this study included at least one core human rights concept of people with disabilities. In contrast, previous studies using the EquiFrame found more limited reference to people with disabilities in water, sanitation and hygiene (WASH) policies of Nepal, Bangladesh and Cambodia [22, 23]. Similarly, an international study on WASH policy during the COVID-19 pandemic found gaps in attention to disability [38]. Whilst reference to disability was higher in Chile, the low policy commitment to disability in Chile's health policies was consistent with previous research on WASH reporting almost non-existent actions for disability [22]. Our findings indicated that policies mainly focused on the prevention of health conditions, although with a stronger emphasis on preventing disability rather than improving access to preventive healthcare among people with disabilities. In contrast, previous analyses highlighted a focus on infrastructure and information accessibility [22, 23, 38].

Our findings showed only an incipient inclusion of disability and human rights perspectives in health policy. This appears not to be exclusive to disability, however, but also more generally. A policy analysis of 171 documents found a lack of human-rights perspective in public policy in Chile [36]. In addition, previous studies in Chile analysing disability-specific policies and programs found varying levels of inclusion of health as a right of people with disabilities [25–28]. Nevertheless, our findings suggest a continuation of a biomedical framing of disability, which remains engrained in health systems [39]. Health policies were described as hyper-focalized by health conditions or impairment type. Similarly, the disability movement was depicted as fragmented by medical diagnoses. Their influence seemed to be limited to health needs assessments without further involvement in policy processes, even though their participation in policies that concern them is imperative [2, 4]. This has been pointed out as one of the weaknesses of the Chilean Health System, where there is a lack of engagement with other stakeholders of civil society in public health [31].

Our analyses suggested that there was some inclusion of disability in government discourse, but with poor policy implementation strategies and resources. This has been similarly observed in African Union Policies [40] and in the Philippines [41]. Thus, this raises questions about both the quality of health policies but also the actual prioritization of disability in Chile. An analysis of Chilean public policy with a human rights approach found that policy instruments were of low quality, as they lacked structure, budget, and mechanisms for monitoring, accountability and participation [42]. Additionally, disability was regarded as an issue of "low politics". During the COVID-19 pandemic, Chile prioritized populations within national plans based on their clinical risk, whereas the health systems of the Bahamas, Mexico, and Peru prioritized populations given their vulnerability (e.g. people with disabilities and migrants) [43]. Despite Chile's prioritisation of people with certified and severe disabilities for COVID-19 vaccination [44], evidence suggests that the government lacked a comprehensive strategy to fully address the needs of all people with disabilities [20]. Furthermore, questions on disability were excluded from the pandemic version of a national survey, a key instrument used to identify and prioritise groups for public policy [21].

Poor policy commitment to disability in paper is compounded by the lack of policy execution in practice. This issue was well illustrated in the Sexual and Reproductive Health Policy [45], which indicated no strong commitment about disability and poor implementation, also due to a lack of resources. These policy and implementation gaps may help to explain why women with disabilities in Chile have lower coverage of cancer screening services [9, 10] and face critical gaps in SRH services [19, 46]. Challenges with implementation of disability-inclusive policies have been observed in other settings, such as in Uganda for SRH [47], and in relation to COVID-19 responses in South America [20].

Some limitations of this study should be noted. The lack of mainstreaming of disability and coordinated action was reflected in the poor harmonization of disability models and terminology across health policy documents. This issue was evident in the previous 2011–2020 National Health Strategy of Chile, whose disability indicators could not be monitored due to changes in the conceptualization of disability [48], and it has been an issue similarly observed for older people in Chile [49]. Therefore, as we only considered the explicit mention of people with disabilities, some references of groups that could have experienced disability could have been missed (e.g. children with special healthcare needs, elderly with dependency). Furthermore, health policies using universal terms (e.g., "all", "entire population", "everybody") could have implicitly included people with disabilities. However, it has been recognized that not explicitly targeting minorities or vulnerable groups could further perpetuate health inequities [1, 34, 50].

Moreover, participants had different conceptions of health policy, and the type of documents they translated into, which has been previously found [42]. Thus, there was not a complete overlap between our document selection and what participants referred to as health policy. In addition, our identification of documents could have been subject to selection bias and some health policies may have been missed. We also acknowledge the relevance of other social determinants of health; however, these were beyond the scope of this study [15]. Future assessment could be enriched with the analysis of additional multisectoral policies (e.g. housing, transportation, etc.). Despite these limitations, the strengths of this study lie in using a structured tool that allowed a systematic and independent assessment of documents by two reviewers who were native Spanish speakers and familiar with the context. In addition, data could be triangulated with information from key informant interviews.

Conclusion

Improvements are needed in both the development and implementation of disability-inclusive health policies in Chile, to support the achievement of the right to healthcare for people with disabilities, and ensuring that the health system truly "leaves no one behind".

Abbreviations

ICF	International Classification of Functioning, Disability and Health
LAC	Latin America and the Caribbean
MoH	Ministry of Health
NDA	National Disability Agency
OPDs	Organizations of Persons with Disabilities
SRH	Sexual and Reproductive Health
UNCPRD	United Nations Convention on the Rights of Persons with Disabilities
WASH	Water, Sanitation and Hygiene

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12939-024-02259-4.

Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Acknowledgements

We thank student assistants Andrea Coloma, Bárbara Pabst, Maitte Carimán, María Elisa Berríos, Rosario Coloma and Trinidad Gilabert from University of Chile, as well as all the research participants for their involvement in the study.

Author contributions

DRG, HK, JW, JH, and LMB collaborated to the design of the work. DRG collected primary data. DRG and PGM reviewed, analysed, and interpreted data. DRG drafted the article. PGM, HK, LMB, JW and JH critically revised the manuscript. All authors read and approved the final manuscript.

Funding
This work was supported by the Agencia Nacional de Investigación y Desarrollo de Chile [72210471 to DRG]; the ANID Millennium Science Initiative Program [NCS2022_039 to DRG]; the National Institute for Health and Care Research [301621 to HK]; the Foreign, Commonwealth and Development Office [PO8073 to LMB]; the Arts & Humanities Research Council [AH/X009580/1 to LMB]; and the Australian Government, Department of Foreign Affairs and Trade's Water for Women Fund [CR01 to JW].

Data availability
The dataset generated during the current study is not publicly available due to the privacy of individuals that participated in the study but is available from the corresponding author on reasonable request.

Declarations

Ethical approval and consent to participate
This study obtained ethical approval from the Ethics Committee of London School of Hygiene and Tropical Medicine (No28068) and the Ethics Committee of Research with Human Beings of the Faculty of Medicine, of University of Chile (No152-2022). This research project adheres to the Declaration of Helsinki and relevant regulatory and ethical requirements. Informed consent to participate was obtained from all participants of key informant interviews.

Reflexivity statement
Our team reflects a diverse group of women from high-income countries (Canada, Chile, Germany, and the United Kingdom) and different ethnic backgrounds (e.g. White, Latino). We represent a mixed positioning on disability, including disability allies and lived family experiences of disability. The team is multidisciplinary, and different sectors are represented (government, academia, disability, health), with experience in conducting analysis of policies using similar methods in other countries. Co-authors reflect diverse seniority levels in research, ranging from early career to senior researchers. These varied backgrounds ensured that we considered the complexity of disability, considering the different needs across types of disabilities, ages, and genders. This approach allowed us to evaluate health policies through a comprehensive and inclusive lens.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Author details
[1]International Centre for Evidence in Disability, Department of Population Health, Faculty of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, London, WC1E 7HT, UK
[2]Millennium Nucleus Studies on Disability and Citizenship (DISCA), Santiago, Chile
[3]Department of Occupational Therapy and Occupational Science, Faculty of Medicine, University of Chile, Santiago, Chile
[4]Centre for International Health Protection, Robert Koch Institute, Berlin, Germany
[5]Department of Global Health and Development, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine, London, UK

Received: 18 June 2024 / Accepted: 22 August 2024

References
1. World Health Organization. Global report on health equity for persons with disabilities [Internet]. Geneva. 2022. https://www.who.int/publications/i/item/9789240063600
2. United Nations. Convention on the Rights of Persons with Disabilities—Articles. [Internet]. 2006. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html
3. Kuper H, Rotenberg S, Azizatunnisa' L, Banks LM, Smythe T. The association between disability and mortality: a mixed-methods study. Lancet Public Health. 2024;9:e306–15.
4. García Mora ME, Schwartz Orellana S, Freire G. Disability Inclusion in Latin America and the Caribbean: A Path to Sustainable Development [Internet]. Washington, DC; 2021. https://documents1.worldbank.org/curated/en/099015112012126833/pdf/P17538305622600c00bf3f09659df1f2f79.pdf
5. Rodríguez Gatta D, Rotenberg S, Allel K, Reichenberger V, Banks LM, Kuper H. Access to general health care among people with disabilities in Latin America and the Caribbean: a systematic review of quantitative research. Lancet Reg Health - Americas. 2024;32:100701.
6. Reichenberger V, Corona AP, Ramos VD, Shakespeare T, Hameed S, Penn-Kekana L et al. Access to primary healthcare services for adults with disabilities in Latin America and the Caribbean: a review and meta-synthesis of qualitative studies. Disabil Rehabil. 2024;1–10.
7. Rozas Assael F, González Olave F, Cerón Cañoles G, Guerrero Hurtado M, Vergara Henríquez R, Pinto Mora S. III Estudio Nacional de la Discapacidad [Internet]. Santiago; 2023. https://www.senadis.gob.cl/pag/693/2004/iii_estudio_nacional_de_la_discapacidad
8. Rotarou ES, Sakellariou D. Inequalities in access to health care for people with disabilities in Chile: the limits of universal health coverage. Crit Public Health. 2017;27:604–16.
9. Sakellariou D, Rotarou ES. Utilisation of cancer screening services by disabled women in Chile. PLoS ONE. 2017;12:e0176270.
10. Fuentes-López E, Fuente A. Access to healthcare for deaf people: a model from a middle-income country in Latin America. Rev Saude Publica. 2020;54:13.
11. Symbolon Consultores, Subsecretaría de Redes Asistenciales. Brechas en atención de salud de personas en situación de discapacidad en atención primaria [Internet]. Santiago. 2018 Feb. http://www.symbolon.cl/uploads/7/5/2/8/75280781/sintesis_resultados_psd_en_aps_2018.pdf
12. World Health Organization. Health equity for persons with disabilities: a guide for action [Internet]. 2024 Jan. https://cdn.who.int/media/docs/default-source/ncds/sdr/disability/info-sheet-disability-guide-for-action.pdf?sfvrsn=23bc00fa_4&download=true
13. Missing Billion Initiative, Clinton Health Access Initiative. Reimagining health systems that expect, accept and connect 1 billion people with disabilities [Internet]. 2022. https://www.themissingbillion.org/the-reports
14. Kuper H, Azizatunnisa' L, Rodríguez Gatta D, Rotenberg S, Banks LM, Smythe T, et al. Building disability-inclusive health systems. Lancet Public Health. 2024;9:e316–25.
15. Solar O, Irwin A. A conceptual framework for action on the social determinants of health. Social Determinants of Health Discussion Paper 2 (Policy and Practice) [Internet]. Geneva; 2019. https://www.who.int/publications/i/item/9789241500852
16. Ministerio de Relaciones Exteriores. Decreto 201 promulga la Convención de las Naciones Unidas sobre los Derechos de las personas con Discapacidad y su protocolo facultativo [Internet]. Santiago: Poder Ejecutivo; Sep 17, 2008. https://bcn.cl/2ho2o
17. Ministerio de Planificación. Ley N°20.422 Establece normas sobre Igualdad de Oportunidades e Inclusión Social de Personas con Discapacidad [Internet]. Santiago: Cámara de Diputados; Feb 10, 2010. https://bcn.cl/2irkh
18. Ministerio de Salud. Estrategia Nacional de Salud. Para el cumplimiento de los Objetivos Sanitarios de la Década 2011–2020 [Internet]. Santiago. 2011. https://www.minsal.cl/portal/url/item/c4034eddbc96ca6de0400101640159b8.pdf
19. United Nations. CRPD/C/CHL/QPR/2–4. List of issues prior to submission of the combined second to fourth reports of Chile. [Internet]. Geneva. 2020 Oct. https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Countries.aspx
20. Sakellariou D, Malfitano APS, Rotarou ES. Disability inclusiveness of government responses to COVID-19 in South America: a framework analysis study. Int J Equity Health. 2020;19:131.
21. Pinilla-Roncancio M, Rodríguez Caicedo N. Recolección de datos durante la pandemia por la COVID-19 y la inclusión de la población con discapacidad en América Latina y el Caribe. Revista Panamericana de Salud Pública [Internet]. 2022;46:1. https://iris.paho.org/handle/10665.2/56004
22. Wilbur J, Scherer N, Mactaggart I, Shrestha G, Mahon T, Torondel B, et al. Are Nepal's water, sanitation and hygiene and menstrual hygiene policies and supporting documents inclusive of disability? A policy analysis. Int J Equity Health. 2021;20:157.
23. Scherer N, Mactaggart I, Huggett C, Pheng P, Rahman M, Biran A, et al. The inclusion of rights of people with disabilities and women and girls in Water,

Sanitation, and Hygiene Policy documents and programs of Bangladesh and Cambodia: Content Analysis using EquiFrame. Int J Environ Res Public Health. 2021;18:5087.
24. Lyra TM, Veloso de Albuquerque MS, Santos de Oliveira R, Morais Duarte Miranda G, Andréa de Oliveira M, Eduarda Carvalho M, et al. The National Health Policy for people with disabilities in Brazil: an analysis of the content, context and the performance of social actors. Health Policy Plan. 2022;37:1086–97.
25. Minoletti A, Sepúlveda R, Gómez M, Toro O, Irarrázabal M, Díaz R et al. Análisis De La gobernanza en la implementación del modelo comunitario de salud mental en Chile. Revista Panam De Salud Pública. 2018;42.
26. Seijas V, Hrzic KM, Neculhueque XZ, Sabariego C. Improving Access to and Coverage of Rehabilitation Services through the Implementation of Rehabilitation in Primary Health Care: a Case Study from Chile. Health Syst Reform. 2023;9.
27. Díaz Ruiz A, Sánchez Durán N, Palá A. An analysis of the intentions of a Chilean disability policy through the Lens of the Capability Approach. J Hum Dev Capabil. 2015;16:483–500.
28. Bustos-Rubilar M, Kyle F, Luna E, Allel K, Hormazabal X, Tapia-Mora D, et al. A country-wide health policy in Chile for deaf adults using cochlear implants: analysis of health determinants and social impacts. PLoS ONE. 2023;18:e0286592.
29. Biblioteca del Congreso Nacional de Chile. Chile Nuestro País [Internet]. 2024 [cited 2024 May 31]. https://www.bcn.cl/siit/nuestropais/index_html
30. World Bank. World Bank Country and Lending Groups [Internet]. 2023 [cited 2023 Jul 19]. https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups
31. Instituto Nacional de Estadísticas. Proyecciones de población [Internet]. 2024 [cited 2024 Jan 9]. https://www.ine.gob.cl/estadisticas/sociales/demografia-y-vitales/proyecciones-de-poblacion
32. Missoni E, Solimano G. Towards Universal Health Coverage: The Chilean experience [Internet]. 2010. https://cdn.who.int/media/docs/default-source/health-financing/technical-briefs-background-papers/4chile.pdf?sfvrsn=2a6c48a1_3&download=true
33. OECD. OECD Reviews of Public Health: Chile. Paris: OECD Publishing; 2019.
34. Amin M, MacLachlan M, Mannan H, El Tayeb S, El Khatim A, Swartz L, et al. EquiFrame: a framework for analysis of the inclusion of human rights and vulnerable groups in health policies. Health Hum Rights. 2011;13:1–20.
35. WALT G. Reforming the health sector in developing countries: the central role of policy analysis. Health Policy Plan. 1994;9:353–70.
36. Walt G, Shiffman J, Schneider H, Murray SF, Brugha R, Gilson L. Doing' health policy analysis: methodological and conceptual reflections and challenges. Health Policy Plan. 2008;23:308–17.
37. Ministerio de Salud. Decreto 2 aprueba reglamento que regula el derecho a la atención preferente dispuesto en la ley No20.584 [Internet]. Santiago: Cámara de Diputados; Jan 21. 2020. https://bcn.cl/2mggp
38. Scherer N, Mactaggart I, Huggett C, Pheng P, Rahman M, Wilbur J. Are the rights of people with disabilities included in international guidance on WASH during the COVID-19 pandemic? Content analysis using EquiFrame. BMJ Open. 2021;11:e046112.
39. Lundberg DJ, Chen JA. Structural ableism in public health and healthcare: a definition and conceptual framework. Lancet Reg Health - Americas. 2024;30:100650.
40. Lang R, Schneider M, Kett M, Cole E, Groce N. Policy development: an analysis of disability inclusion in a selection of African Union policies. Dev Policy Rev. 2019;37:155–75.
41. Velasco JV, Obnial JC, Pastrana A, Ang HK, Viacrusis PM, Lucero-Prisno DE III. COVID-19 and persons with disabilities in the Philippines: a policy analysis. Health Promot Perspect. 2021;11:299–306.
42. Centro de Sistemas Públicos, Subsecretaría de Derechos Humanos. Análisis de políticas públicas con enfoque de Derechos Humanos [Internet]. Santiago. 2019 Jun. https://biblioteca.digital.gob.cl/items/aaf8bcce-50cc-422e-9b42-c15e65d9f3a6
43. Vélez C-M, Aguilera B, Kapiriri L, Essue BM, Nouvet E, Sandman L, et al. An analysis of how health systems integrated priority-setting in the pandemic planning in a sample of Latin America and the Caribbean countries. Health Res Policy Syst. 2022;20:58.
44. Government of Chile. Authorities announce expansion of bivalent vaccination to new groups: find out who is being incorporated [Internet]. 2023 [cited 2024 Jul 30]. https://www.gob.cl/en/news/authorities-announce-expansion-bivalent-vaccination-new-groups-find-out-who-being-incorporated/
45. Ministerio de Salud. Política Nacional de Salud Sexual y Salud Reproductiva [Internet]. Santiago. 2018 Mar. https://diprece.minsal.cl/wrdprss_minsal/wp-content/uploads/2018/03/POLITICA-NACIONAL-DE-SALUD-SEXUAL-Y-REPRODUCTIVA-.pdf
46. Yupanqui-Concha A, Hichins-Arismendi M, Mandiola-Godoy D, Rodríguez-Garrido P, Rotarou ES. Accessing Sexual and Reproductive Health Services in Chile: women with disabilities and their experience with gynaecological and obstetric violence. Sexuality Res Social Policy. 2024;21:690–703.
47. Mac-Seing M, Ochola E, Ogwang M, Zinszer K, Zarowsky C. Policy implementation challenges and barriers to Access sexual and Reproductive Health services Faced by People with disabilities: an intersectional analysis of policy actors' perspectives in Post-conflict Northern Uganda. Int J Health Policy Manag. 2021.
48. Ministerio de Salud. Evaluación de final de la década Estrategia Nacional de Salud para los objetivos sanitarios 2011–2020 [Internet]. Santiago. 2022 Feb. https://estrategia.minsal.cl/wp-content/uploads/2022/03/Evaluacio%CC%81n-de-Final-de-la-Decada-2011-2020.pdf
49. Villalobos Dintrans P, Izquierdo C, Guzmán R, Gálvez MJ, Santander S. Defining 'older people' in Chile: challenges in planning policies for ageing populations. Health Policy Plan. 2021;35:1347–53.
50. O'Donovan M, Mannan H, McVeigh J, Mc Carron M, McCallion P, Byrne E. Core Human Rights Concepts in Irish Health and Housing Policy documents: in search of equity for people with ID. J Policy Pract Intellect Disabil. 2018;15:307–13.

Publisher's note

Chapter 6

Inclusive health for people with disabilities in Chile: a national health system assessment

6.1 | Chapter preamble

Chapter 5 revealed system level gaps in governance and leadership, showing that improvements are required both in the formulation and implementation of health policies with disability inclusion in Chile. Building on Chapter 5, the present chapter introduces a health system assessment, broadening the analysis to all the key components of the health system. The study aimed to undertake a national assessment of the inclusion of people with disabilities in the health system of Chile and define recommendations for improvement based on the evidence. A task team was formed to conduct the assessment, including the Ministry of Health and civil society organizations. Primary data collection with 20 key informant interviews, three workshops, and a scoping review of grey literature were undertaken. Additionally, the findings of the systematic review (Chapter 3) and the health policy analysis (Chapter 5) were also used as data sources. This study defined disability according to a human rights approach [8] and followed the Missing Billion Inclusive Health Systems Framework.[2,3]

The health system of Chile appeared to have an overall low progress towards disability-inclusive healthcare. Governance, leadership, and human resources were the three recommended priority areas to further progress disability inclusion in the health sector. This chapter provides a comprehensive and robust overview of the existing development and gaps related to disability in the health system. It also serves as key evidence to inform policy and guide action for disability-inclusive healthcare. The findings of this study have implications for UHC among people with disabilities, health system strengthening in Chile, and research frameworks assessing access to healthcare among people with disabilities, as presented in Chapter 7.

This health system assessment has been accepted for publication in *Health Research Policy and Systems* in October 2024 following peer-review. Appendices of this study can be found in Appendix D.

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

SECTION A – Student Details

Student ID Number	2004713	**Title**	Mrs
First Name(s)	Danae Harmonia		
Surname/Family Name	Rodríguez Gatta		
Thesis Title	Access to healthcare among people with disabilities in Chile		
Primary Supervisor	Hannah Kuper		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?			
When was the work published?			
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Choose an item.	Was the work subject to academic peer review?	Choose an item.

*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	Health Research Policy and Systems
Please list the paper's authors in the intended authorship order:	Danae Rodríguez Gatta, Constanza Piriz Tapia, Elvira Tagle Schmidt, Jimena Luna Benavides, Daniel Vivar Jara, Rodrigo Moreno Celis, Gonzalo Tobar Carrizo, Judit Vilaró Cáceres, Phyllis Heydt, Lena Morgon Banks, and Hannah Kuper

Stage of publication	**In press**

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I have conceptualized the study,collected primary data, reviewed, analysed, and interpreted data, drafted the paper, and compiled the final manuscript.

SECTION E

Student Signature	Danae Rodríguez Gatta
Date	29 October 2024

Supervisor Signature	Hannah Kuper
Date	29 October 2024

Inclusive health for people with disabilities in Chile: a national health system assessment

Danae Rodríguez Gatta MSc [a], Constanza Piriz Tapia BSc [b], Elvira Tagle Schmidt MSc [b], Jimena Luna Benavides BSc [c], Daniel Vivar Jara BSc [d], Rodrigo Moreno Celis BSc [e], Gonzalo Tobar Carrizo BA [f], Judit Vilaró Cáceres BSc [g], Phyllis Heydt MA [h], Lena Morgon Banks PhD [a], and Prof Hannah Kuper ScD [a]

[a] International Centre for Evidence in Disability, Department of Population Health, Faculty of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, London, United Kingdom.

[b] Department of Rehabilitation and Disability, Ministry of Health, Chile

[c] Center for Development of Inclusive Technologies (CEDETi) at Pontificia Universidad Católica de Chile; Independent Living Foundation Chile; Muscular Dystrophy Association Chile

[d] Corporación para la Inclusión de personas con Discapacidad visual y Sordociegas (CIDEVI)

[e] Red Nacional de Fibromialgia; Fundación Fibromialgia en Acción

[f] Agrupación Lupus Chile

[g] Disautonomía Chile; Federación Chilena de Enfermedades Raras (FECHER)

[h] Missing Billion Initiative

Correspondence to: Danae Rodríguez Gatta, International Centre of Evidence and in Disability, Department of Population Health, Faculty of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, London WC1E 7HT, United Kingdom, danae.rodriguez@lshtm.ac.uk , ORCID ID: 0000-0001-5423-0336

ABSTRACT

Background: Globally, one in six people have disabilities. They often experience health inequities and many of them arise from system-level failures. This study aimed to assess the inclusion of people with disabilities in the health system of Chile and define recommendations for improvement based on the evidence. Methods: A health system assessment was conducted between June and November 2023 following the Missing Billion Disability-Inclusive Health Systems Framework and System Level Assessment Toolkit. The assessment was led by the Ministry of Health and conducted by a task team, including organizations of people with disabilities. Mixed methods were used to collect data on nine system-level and service delivery components for a set of 33 indicators, including through a health policy review, systematic review, key informant interviews and a scoping review. Scores were assigned to indicators, components, and the overall health system. With this assessment, key recommendations were developed and agreed upon based on a prioritization analysis of impact and feasibility during workshops. Results: The Chilean health system was assessed to have a low progress towards disability-inclusive health. Among system-level components, intermediate progress has been made in governance, health financing, and data and evidence. However, progress in leadership on disability seems low. Among service delivery components, the accessibility of health facilities and rehabilitation and assistive technology showed the best results. However, there were notable gaps in the autonomy and awareness and ability to afford care by people with disabilities, and the capacity of human resources to support this group. The task team defined priority actions in governance, leadership, and human resources. Conclusions: Short-term actions for the country should involve foundational governance on inclusive health, strengthened leadership of people with disabilities, and mandatory training of healthcare workers to improve healthcare access among this population. Future reassessments

should be conducted to monitor and evaluate progress on effective healthcare coverage and health status among people with disabilities.

Keywords: Health policy and systems research, People with Disabilities, Disability-Inclusive Health, Chile

BACKGROUND

Globally, one in six people have disabilities [1]. According to the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD), they include “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” [2]. Global evidence demonstrates that people with disabilities frequently experience health inequities [1, 3], including a 10 to 20 years mortality gap [1, 4]. They often experience increased morbidity, with more than double the prevalence of diabetes, cerebrovascular disease, or depression [1]. They also frequently require disability-related services, such as rehabilitation and specialist services [3]. Consequently, people with disabilities can be described as having greater healthcare needs, although they often face systemic barriers to receiving required care.

Health inequities are an important concern in the Americas Region, which also has one of the highest prevalences of disability worldwide (19%) [1]. Chile is a high-income country of nearly 20 million people with an increasingly ageing population [5, 6], including approximately three million people with disabilities (18%) [7]. A recent literature review of Latin America and the Caribbean (LAC) showed that people with disabilities use health services more frequently than those without disabilities, yet gaps remain in the coverage, affordability, and quality of healthcare due to access barriers [8]. Addressing these gaps is essential for the advancement of the right to health and universal health coverage, as well as making better healthcare for all [1, 3].

Disability inclusive health means that people with disabilities have the same access to the full range of health services (e.g. prevention, promotion, treatment) as people without disabilities, in line with the human rights model of disability. Thus, to realize disability inclusion in the health sector, the rights and meaningful participation of people with disabilities should be ensured as well as health services intentionally designed to “expect, accept, and connect” them to quality care [3, 9]. Health systems therefore need to be strengthened to include people with disabilities, such as through improving health policies, leadership on disability in the Ministry of Health (MoH), financing of inclusive health, or appropriate training of the health workforce [1, 3]. However, current approaches to assess health systems to identify where action is needed have not been designed to focus on disability [10, 11]. Therefore, the Missing Billion Disability-Inclusive Health System Framework and System Level Assessment Toolkit was developed to support MoHs to evaluate the extent of disability inclusion in their health system and identify potential areas for improvement (Figure 1) [3, 12]. The framework is based on the World Health Organization (WHO) Building Blocks [10] and Primary Health Care Performance Initiative framework [11], with additional emphasis on components needed to enable disability inclusion [3, 12]. It includes system-level components on governance, leadership on disability within the MoH and representation of people with disabilities, financing of inclusive health, rehabilitation, and assistive technology (AT), and data and evidence about disability and health. It also has service delivery components across the demand and supply side of healthcare: autonomy and awareness of people with disabilities, affordability of healthcare, health worker training on disability, accessibility of health centres, and availability of rehabilitation services and AT. The framework has an accompanying indicator set, to allow assessment of inclusion for each of the framework components. The framework and indicators were reviewed by a range of experts (governmental and UN stakeholders, health systems specialists, academics, and disability rights organizations) and pilot-tested in the Maldives and Zimbabwe [12].

The aim of this study is to undertake an assessment of the inclusion of people with disabilities in the health system of Chile and define recommendations for improvement based on the evidence.

METHODS

Study design

A health system assessment was carried out between June and November 2023 following the Missing Billion Disability-Inclusive Health Systems framework (Figure 1) and System Level Assessment Toolkit [3, 12]. Mixed methods were used to collect data for a set of indicators related to components of the framework, including a health policy review, systematic review, key informant interviews, and scoping review of grey and scientific literature, and population-based data. Workshops were held to agree on recommendations and priority actions.

Study team

The assessment was conducted in Chile and led by the Department of Rehabilitation and Disability of the Ministry of Health of Chile and London School of Hygiene and Tropical Medicine. The MoH convened a task team to conduct the assessment of 11 members, including government representatives (n=2), academia (n=1), and civil society (n=8) (Additional Table 1). All Organizations of Persons with Disabilities (OPDs) engaged in a voluntary role and had previously participated in advisory roles at Ministerial or Parliamentary level.

Study setting

Chile has a dual health system mainly based on a public health insurance scheme provided by the National Health Fund (FONASA), covering healthcare for about 79% of the population, and the

Private Health Insurances (ISAPRES) covering around 16% [13, 14]. All workers pay compulsory health contributions (7% of their income) into FONASA or ISAPRES [15]. FONASA covers all workers (formal or informal), pensioners, and those without income, as well as their legal dependents, regardless of age, gender, income level, health state or nationality [16]. Health services are delivered by both public and private providers, and the public health network is mostly state funded [13, 16]. About 88% of people with disabilities in Chile are covered by FONASA [7].

Table 1. Framework components and number of indicators

Component	**Description**	**Number of indicators**
1.- Governance	Appropriate in-country laws and policies assert the right to reasonable accommodation and outlaw discrimination based on disability.	6
2.- Leadership	Disability is clearly articulated and represented in the Ministry of Health, health sector structures, and coordination mechanisms.	3
3.- Health financing	There is sufficient earmarked disability inclusion, assistive technology, and rehabilitation budget.	3
4.- Data & evidence	Data showing the health situation of people with disabilities, evidence to understand and improve health services.	4
5.- Autonomy & Awareness	People with disabilities make their own decisions about health care and are aware of their rights and options.	3
6.- Affordability	People with disabilities can afford to access health.	4
7.- Human Resources	Health workforce is knowledgeable about disabilities and has the skills and flexibility to provide quality care.	5
8.- Health Facilities	Health-care services, including health-care facility infrastructure and information, are accessible for people with disabilities.	2

9.- Rehabilitation services & Assistive Technology	Rehabilitation and specialist services are available, affordable and of good quality for people with disabilities.	3

Source: *Missing Billion Initiative and Clinton Health Access Initiative (2022) Reimagining health systems that expect, accept, and connect 1 billion people with disabilities. Available at:* *https://www.themissingbillion.org/the-reports* *(Accessed: 29 June 2023).*

Data collection

We collected data for a set of 33 indicators across 9 framework components: 16 in the system-level and 17 in the service delivery domains (Table 1). Each indicator included a definition, metric, and scoring logic (Table 2 and Additional Table 2).

[Table 2]

For instance, the first governance indicator consists of the ratification and adoption of the UNCRPD, and its metric requires evidence of it being actioned (e.g. dedicated budget, action plans, and initiatives). The indicators were translated into Spanish and the translation was revised by an external assessor. The following sources of data were collated, across the indicators:

a. **Health policy review:** 13 national health policy documents were reviewed. Policies must have been in place at the national level and impact the provision of health services for people with disabilities [17]. Eligible documents were searched through official websites of the MoH [18], Ministry of Social Development and Family [19], and the library of the National Congress of Chile [20].

b. **Systematic review:** Peer-reviewed scientific articles of quantitative research about healthcare access among people with disabilities (utilization, coverage, quality, and affordability of healthcare), published since 2000 in Latin America and the Caribbean, were searched in EMBASE, MEDLINE, LILACS, MedCarib, PsycINFO, SciELO, CINAHL, and Web of Science [8].

c. **Scoping review:**

  - Grey literature, including public or internal government and civil society reports sought through official government websites and the database of the Committee on the Rights of Persons with disabilities [21].
  - Peer-reviewed scientific articles published in the last ten years. Search strategies included keywords of the indicator set and were developed in Spanish and English using relevant databases (SciELO, EMBASE, MEDLINE).
  - Publicly available reports of national population-based surveys, conducted in the last ten years, on disability, healthcare, and socio-economic characterization, disaggregated by disability, sought on the website of the Department of Epidemiology of the MoH [22] and in the Social Observatory of the Ministry of Social Development and Family [23].

d. **Key informant interviews:** The lead researcher interviewed 20 key national stakeholders, either in person or via Zoom. A purposive sampling was applied to ensure representation of areas of expertise across the framework components. Participants were recruited through recommendations of the task team and snowball sampling was applied throughout the interviews. Informants included government officials (directors, head of departments, policy officers), academic experts with and without disabilities, and OPDs (Table 3). Semi-structured interview guides focusing on each framework component were used. Interviews lasted between 45 to 60 minutes and were audio-recorded.

Table 3. Participants of key informant interviews (n=20)

Sector	Department, Institution
Government (n=11)	1) Life Cycle Department, MoH 2) Rehabilitation and Disability Department, MoH 3) Cabinet, Subsecretariat of Public Health, MoH 4) Division for Disease Prevention and Control, MoH 5) National Commission on Preventive Medicine and Incapacity, MoH 6) Emergency and Disaster Risk Management Department, MoH 7) Care Management Department, MoH 8) Social Welfare Institute, Ministry of Labour and Social Security 9) National Office, National Disability Agency, Ministry of Social Development and Family 10) Evaluation and Studies Department, National Disability Agency, Ministry of Social Development and Family 11) Health Department, National Board for Student Aid and Scholarships, Ministry of Education
Civil society (n=5)	12) National Organization of People with Disabilities 13) National Organization for Independent Living 14) International Organization for the Deaf 15) National Organization of People with Autism Spectrum 16) National Organization for Women with Disabilities
Academia (n=4)	17) Sociology School, Diego Portales University 18) Public Health School, University of Chile 19) Chilean Association of Medical Education

20) Chilean Association of Nursing Education

Abbreviations: Ministry of Health (MoH)

Data analysis

Scoring of indicators

Interviews were transcribed and qualitative descriptions were made of the transcripts against the corresponding framework components. Information from the different data sources – peer-reviewed, grey literature and public records – were then triangulated, validating, enlarging, and articulating information from interviews with documentary sources [24]. The task team held monthly sessions to collectively assess preliminary responses to indicators, identify additional sources of information, and agree on final scoring of indicators. Scores were assigned to each indicator based on the evidence available, ranging from 0 (lowest; no criteria met or evidence of inclusion) to 1 (maximum; all criteria met) [12] (Additional Table 2). Thereafter, each framework component was assigned a score based on the average score of its indicators. The average score was categorized as low (below 0.5), intermediate (between 0.5 and 0.74), or advanced (between 0.75 and 1). Finally, an overall score was calculated for the health system based on the average of its components (each weighted equally). A global average score of other countries (Brazil, Maldives, Zimbabwe, New York State, Singapore, Uganda, Australia, United Kingdom, France, South Africa, among others) was available for reference (Figure 2) [12].

Recommendations and priority actions

The lead author developed provisional recommendations for all indicators that obtained scores below one. Additional emergent recommendations were added from the task team and key informant interviews. Then, all provisional recommendations were assessed based on their potential for impact and feasibility. Criteria of impact included: (1) foundational importance, (2) opportunity for improvement, (3) number of people with disabilities benefited from the intervention, and (4) time to impact. Criteria of feasibility included: (1) time to implementation, (2) cost, (3) stakeholder and (4) technical complexity [12]. The MoH assigned a score to each criterion based on their technical expertise, ranging from one (low) to three (high). Thereafter, an average score of impact and feasibility criteria was calculated for each recommendation. A high average score was two or above, whereas a low score was below two. Finally, all provisional recommendations were distributed in a prioritization matrix by level of impact and feasibility (Figure 3) [12].

Three half-day workshops (one in person and two virtual) were held with the task team to review the assessment's findings and agree on key priority actions for improvement. The task team discussed the relevance and appropriateness of the provisional recommendations and their distribution in the prioritization matrix in the context of Chile. Subsequently, amendments were made according to the discussions and a final list of recommendations was consolidated. Ultimately, three main priority actions were agreed.

Ethical Approval: This study obtained ethical approval by the Ethics Committee of the authors' institute.

RESULTS

The health system in Chile, with respect to disability-inclusive health, obtained an overall low average score of 49% (Figure 2).

System-level components

1. Governance

1.1 UNCRPD (Score=1)

Chile ratified the UNCRPD in 2008 and subsequently adopted specific measures for action (e.g. it created the national disability law Nº20.422, restructured the National Disability Agency (SENADIS) of the Ministry of Social Development and Family, and expanded the Rehabilitation Program) [25, 26].

1.2 National Law (Score=1)

Law No. 20.422 "Establishing Rules on Equal Opportunities and Social Inclusion of Persons with Disabilities" prohibits discrimination in health and demands the implementation of reasonable accommodations for people with disabilities [27]. Additional disability-related laws exist, which protect access to healthcare for people with disabilities. For instance:

- Law Nº 20.584, Regulates the rights and duties of individuals in relation to actions related to their healthcare [28].
- Law Nº21.331, On the recognition and protection of the rights of persons in mental healthcare [29].
- Law Nº21.545, Establishes the promotion of inclusion, comprehensive care, and the protection of the rights of persons with autism spectrum disorder in the social, health and educational spheres [30].

1.3 National Health Policy or Decree (Score=1)

Currently, there is no national policy on inclusive health for people with disabilities. However, National Supreme Decree Nº2 approves the regulations governing the right to preferential care [31]. It guarantees priority access for people with disabilities to appointments for primary care, specialists, emergencies, medicines, and examinations, and establishes measures for its implementation.

1.4 National Health Sector Plan(s) (Score=0.2)

The National Health Strategy 2030 includes objectives for functioning and disability [32]. It prioritizes specific health conditions, including childhood developmental disorders, rare diseases, musculoskeletal disorders, autism spectrum disorders, rheumatoid arthritis, and severe dependency. However, it does not include actions and targets for general healthcare and specialist services for all people with disabilities. It also does not include basic statistics about people with disabilities and health.

1.5 National Disease Plans (Score=0)

National plans exist for certain diseases (e.g. HIV/AIDS, cancer, silicosis, etc.), and although these plans are described as universal, in some cases, certain groups are prioritized. For instance, the National Plan for the Prevention and Control of HIV/AIDS, targets only migrants and indigenous peoples [33]. However, the plan does not explicitly mention people with disabilities to ensure their access to testing, treatment, and information programs.

1.6 Cross ministry governance (Score=1)

Law Nº20.530 established the Interministerial Committee on Social Development and Family. It is chaired by the Ministry of Social Development and Family and includes the participation of the MoH [34]. The committee advises on the government's social policy and facilitates coordination, guidance, information, and agreement among its members, including on disability issues. There is collaboration between the MoH and SENADIS in the certification and qualification of disability, provision of AT, and implementation of Law Nº21.545 on people with Autism Spectrum Disorder

[26]. However, this collaboration does not occur for inclusive health for all people with disabilities. Furthermore, there is no technical counterpart in SENADIS with an exclusive role in healthcare access.

2. Leadership

2.1 MoH Leadership (Score=1)

Leadership on disability inclusion is diffused and different teams address disability-related issues within the MoH. The Department of Rehabilitation and Disability of the Subsecretariat of Public Health was considered as the lead on disability inclusion by interviewees. The department endorses disability inclusion, although its stated role focusses on disability prevention and habilitation and rehabilitation strategies, not on general healthcare for people with disabilities [35]. This department has historically addressed only the needs of people with physical and sensory disabilities, while the Department of Mental Health has addressed the needs of persons with psychosocial disabilities [36]. Additional teams that address disability-related issues include the National Commission of Preventive Medicine and Disability (COMPIN) and the rehabilitation officers of the Division of Healthcare Network Management and the Division of Primary Care.

2.2 National health sector coordination (Score=0)

There is no national health sector coordination with formal representation of people with disabilities at the highest level. Current temporary participation occurs for certain health conditions and mental health services, but not on overarching disability-related issues. For example, the ENLACE task team includes representatives of the MoH and organizations of people with autism to implement the new law on autism. As another example, some people with psychosocial disabilities participate in the Mental Health Advisory Council 2022-2024 [37] and in the National Commission for the Protection of the Rights of Persons with Mental Illness [38].

2.3 Pandemic preparedness structures (Score=0)

The National Pandemic Response Commission COVID-19 is made up of external scientific advisors, technical teams from the MoH and an inter-ministerial committee [39, 40]. Although civil society could participate, no formal representation of people with disabilities exists. However, SENADIS led a temporary Intersectoral Taskforce on Disability and COVID-19 with representation of people with disabilities [41]. The taskforce developed recommendations for the care of people with disabilities in health services during the COVID-19 pandemic [42].

3. Health Financing

3.1 Disability inclusion budget (Score=1)

The Department of Rehabilitation and Disability of the MoH receives USD 18 668 per year for governance in rehabilitation, disability prevention, and disability inclusion. However, the budget is considered by interviewees to be insufficient to implement public policies on inclusive health. Furthermore, the Subsecretariat of Healthcare Networks has no budget for the implementation of the law on preferential care for people with disabilities [43].

3.2 Reimbursement adjustments (Score=0)

There are no health insurance reimbursements or adjusted capitation rates for people with disabilities in FONASA or ISAPRES. However, all beneficiaries of FONASA, including people with disabilities, can apply for reimbursement of expenses associated with the purchase of prostheses and orthoses, or travel associated with the purchase through the public system [44]. It reimburses hip prostheses, cane or tripod, orthopaedic insoles, optical lenses, hearing aids, crutch, rubber heel pad, and spinal orthosis.

3.3 Rehabilitation/AT budget (Score=1)

In 2023, the Subsecretariat of Healthcare Networks of the MoH had an annual budget of about USD 15 941 million for the Comprehensive Rehabilitation Program in Primary Healthcare. It also had a 2022 annual budget of USD 38 976 million for the financing of AT, through the Explicit Health Guarantees (GES) scheme and the Ricarte Soto scheme, which establishes a system of financial protection for high-cost diagnosis and treatment regardless of health insurance type [45, 46]. In addition, SENADIS had an annual 2023 budget for its AT Program of USD 6540 million.

4. Data and Evidence

4.1 Maturity of disability and health data collection method (Score=0.33)

The main data collection on disability and health is through population-based surveys [7], including the national disability survey from 2022. Census 2024 will incorporate questions on disability [47]. There is a National Register of Disability, where in June 2023 only 23% of the population with disabilities (n=625 848) were included [48]. Currently, the register facilitates access to social benefits, but it does not keep integrated statistics with health information of people with disabilities. Furthermore, health information records collect data on disability status in public and private health facilities [49]. This data is mandatory and requires the Community Assessment of Performance Evaluation (IVADEC-CIF) by health professionals to determine the origin and extent of disability of the person. However, data collected from health facilities do not include health indicators of people with disabilities [50].

4.2 Quality of disability and health data collection method (Score=1)

The disability national survey from 2022, is based on the Model Disability Survey, a tool recommended and validated by the World Health Organization, is nationally representative and disaggregates results by six types of disabilities [7].

4.3 Maturity of disability and health data usage (Score=0.5)

Data on disability and health collected through national surveys are analysed and published [7]. The data are used to define targets in the national health strategy and for budget allocation. However, only findings related to rehabilitation and AT have been used to guide policy changes, in contrast to general healthcare of people with disabilities [46, 51]. Available statistics on disability and health are currently not harmonized. Consequently, there is a lack of robust figures on the total population with disabilities and their needs at regional/community level.

4.4 Quality of disability and health data usage method (Score=1)

Data collected on disability and health are analysed and published in public repositories within one to two years of collection [7, 52]. The reports describe the methods of data analysis, maintain analyses at national and regional level, and full databases are shared for different statistical software.

Service delivery components

5. Autonomy and Awareness

5.1 Organizations of People with Disabilities advocacy (Score=1)

Some people with disabilities and OPDs have advised the MoH. For instance, through the current ENLACE task team for the implementation of Law No. 21.545 for people with autism or the Mental Health Advisory Council [30, 37].

5.2 Autonomy and awareness (Score=0)

There is a lack of data on autonomy and awareness of healthcare access for people with disabilities from within the last ten years from population-based surveys and qualitative data.

5.3 Accessibility of health information (Score=0)

The Ministry of Health's website and its partner websites, which are the main sources of online health information, have few accessible formats available [18, 53]. For example, they feature accessibility tools (e.g. text-to-speech function), and some videos include sign language interpretation. However, no accessible formats such as easy-to-read, sign language interpretation on all videos, Braille, or information for caregivers are observed. Nor do links exist to request the delivery of health information in alternative formats.

6. Affordability

6.1 Health coverage (Score=0.5)

Coverage associated with disability: There are stipulations that guarantee financial coverage for people with certified disabilities. For instance, free healthcare is provided in the public network to people with severe or profound disabilities, under 18 years of age, affiliated to FONASA, and belonging to the 60% lowest socio-economic levels, through the disability subsidy [54, 55]. There is also an adjustment of coverage for people with disabilities affiliated to FONASA for rehabilitation services (physio, occupational, and speech therapy) received outside the public network [56]. This benefit does not modify service fees but eliminates the annual care cap and also applies to ISAPRES beneficiaries.

Coverage associated with medical diagnoses: The GES scheme guarantees financial protection for 87 health conditions, some that could lead to disability, including depression, schizophrenia, bipolar disorder, arthritis, Parkinson's disease, epilepsy, multiple sclerosis, bilateral hypoacusis, refractive errors, Systemic Lupus Erythematosus, and retinopathies [57]. GES also covers orthoses and AT, cataract surgery, and COVID-19 rehabilitation. Similarly, the Ricarte Soto scheme covers the diagnosis (in some cases) and treatment of 27 health conditions, some of them possibly associated with disability, such as multiple sclerosis, rheumatoid arthritis, bilateral sensorineural hearing loss, Systemic Lupus Erythematosus, among others [45]. Finally, FONASA launched a Diagnosis Associated Payment voucher for the diagnosis and treatment of people with autism up to 18 years of age outside the public network with fixed service fees [16].

Universal coverage: The entire population affiliated to FONASA receives free medical care in the public network [58]. As a result, people with disabilities would have access to free healthcare because they are covered by FONASA and not because they have a disability. However, 12% of people with disabilities are not affiliated to FONASA and so will not have free access to medical care through this route [7]. Moreover, health coverage is not free if people with certified disabilities choose to receive healthcare outside the public network, either because of access, timeliness or quality of care. Furthermore, only certain pharmacological treatments are covered by FONASA.

6.2 Transport subsidy (Score=0)

There is currently no national transport subsidy for people with disabilities in Chile [59]. Some local subsidies exist at regional or municipal level, where vehicles are available for the transport of patients with disabilities, although they typically focus on people with physical impairments.

6.3 Disability allowance (Score=0.5)

There is a disability subsidy for people under 18 with severe or profound disabilities, of any impairment type, who are among the 60% lowest socio-economic levels of the population [54].

This group receives a monthly monetary benefit of USD 112 (as of November 2023). This subsidy includes free medical coverage in the public network for FONASA affiliates. Adults with certified disabilities could receive a disability pension (USD 225), if they belong to the 80% lowest socio-economic groups [60]. However, there is no disability allowance for all people with disabilities in Chile.

6.4 Co-payments (Score=0)

FONASA beneficiaries, including people with disabilities, have zero co-payments when receiving medical care in the public network [58]. However, this benefit does not apply to care received by private healthcare providers. In addition, 12% of people with disabilities who do not belong to FONASA are exempted from receiving this benefit.

7. Human Resources

7.1 Training of medical doctors (Score=0)

There is no mandatory national training standard on disability for medical schools, including medical and non-medical aspects. Each medical school determines the curriculum for its students, although the Single National Medical Knowledge Test (EUNACOM) would influence the standard of undergraduate training [61]. At present, EUNACOM does not include an exclusive component on disability as such, only health conditions that could result in disability (e.g. mental health disorders, hearing loss, low vision, etc.).

7.2 Training of nurses (Score=0)

There is no national curriculum for nursing schools; each school determines their own curriculum. However, there is a voluntary National Nursing Examination (ENENF) that could influence the standard of training [62]. The ENENF includes questions on health conditions (e.g. children and adolescents with special healthcare needs) but there is no exclusive content on disability.

7.3 Training of Community Health Workers (CHWs) (Score=0.33)

The training manual for CHWs of the Primary Healthcare Division of the MoH includes some elements regarding legal regulations and rights of people with disabilities, use of language around disability, and OPDs [63]. However, this training is not mandatory.

7.4 Representation of people with disabilities in health workforce (Score=0)

There are no official records of the number of health workers with disabilities. However, it is estimated that between 0.05 to 3.5% of health workers in hospitals (Coyhaique Regional Hospital, La Florida Dra. Eloísa Díaz Hospital, and Peñaflor Hospital) have disabilities, which is lower than expected for the working age population with disabilities (at least 4% for high-income countries, such as Chile) [64].

7.5 Satisfaction (Score=0)

There are no surveys on user satisfaction or quality of treatment in health facilities that disaggregate data by disability and allow comparison with the population without disabilities, or qualitative studies in this area.

8. Health Facilities

8.1 National accessibility standards (Score=1)

There are national accessibility standards for the infrastructure of all public spaces, including both public and private health facilities [65–67]. For example, health facilities must have toilets for people with disabilities, ramps, handrails, etc. There are also universal accessibility standards for web systems and websites of state administration bodies [68]. However, there are no mandatory technical national standards for health communication and information, except for the mandatory provision of sign language interpretation and closed captioning [27].

8.2 Accessibility audit (Score=0.33)

In the last ten years, the MoH has neither conducted nor commissioned nationally representative accessibility audits of healthcare facilities. However, an independent evaluation in the northern Atacama region of 18 primary healthcare facilities found low levels of accessibility to information and participation [69].

9. Rehabilitation Services and Assistive Technology

9.1 National assessments of rehabilitation or AT (Score=0)

There is no national assessment of rehabilitation or AT. However, an inter-ministerial taskforce was recently established to design the National System of Assistive Technology with a unified catalogue and register of AT [70].

9.2 Cross-ministry coordination for rehabilitation services and AT (Score=1)

Currently, there is an inter-ministerial taskforce for the development of a national system of AT in which several ministries participate, including the MoH [70].

9.3 Trained workforce available to provide rehabilitation services and AT (Score=1)

There are about 19.8 physiotherapists per 10,000 inhabitants in Chile, meeting the standard expected for high-income countries [71]. In addition, there are 6.7 occupational therapists, 9.9 speech therapists, and 40.3 psychologists per 10,000 inhabitants.

Recommendation and priority actions

A total of 14 recommendations were considered (Table 4) and three priorities were defined and agreed on to progress disability-inclusive health in Chile in terms of governance, leadership, and human resources:

1. Formulate a National Policy on Inclusive Health for People with Disabilities. It was considered important that this policy is both comprehensive and specific to the diverse health needs, has a budget for implementation, adopts an inclusive approach in all health programs, and is led by staff with disabilities and/or with the permanent and binding participation of OPDs in the design, monitoring, and evaluation of its implementation.
2. Ensure formal representation of people with disabilities, including through their OPDs, in the highest-level health sector coordination structure and in pandemic preparedness structures, avoiding silos, and duplication of existing participatory bodies. For example, through a permanent advisory committee on disability and all health matters.
3. Establish a mandatory training program on disability, with a human rights perspective and including both medical and non-medical aspects, for health workers (professional, technical, and administrative staff) in both public and private health facilities.

Additional, but not prioritized recommendations, would be incorporated into the prioritized actions (Table 4). For example, the national policy on inclusive health should include the development of a healthcare protocol for people with disabilities, inclusion of disability targets in the National Health Strategy 2040, and of people with disabilities in national disease plans. Likewise, the training program should include the development and communication of health information in accessible formats (e.g. in web pages, prescriptions, leaflets, educational materials, etc.).

[Table 4]

DISCUSSION

The Chilean healthcare system appears to have made gradual progress towards inclusive health for people with disabilities, but significant gaps remain. Among system-level components, intermediate progress has been made in governance, health financing, and data and evidence. However, progress in leadership on disability in the MoH seems low. Among service delivery components, the physical accessibility of health facilities and rehabilitation services and assistive technology showed the best results. However, autonomy and awareness, affordability, and human resources achieved the lowest scores.

Chile's intermediate progress on governance, health financing, data and evidence, health facilities, and rehabilitation services and AT is consistent with the results of international outside-in assessments using the Missing Billion framework [12]. Similarly, Chile's low progress on leadership and human resources is consistent with the global average on these areas. However, in contrast to the general intermediate progress on affordability and autonomy and awareness, Chile has a limited development. Although, to date, no previous disability-inclusion health systems assessments have been reported in Chile and globally, other assessments have focused on mental healthcare. In 2014, the mental health system in Chile was assessed using the World Health Organization Assessment Instrument for Mental Health Systems [72]. The assessment revealed progress in governance, mental health budget, data collection systems, and increased availability of specialized mental health services. However, weaknesses remained in the availability of specialized staff and services for children and adolescents, quality of care, equity (by location, minority groups, and health insurance type), and leadership of users and their families. These findings are consistent with the gaps and strengths found in disability inclusion.

The Missing Billion Framework is an innovative tool that captures essential issues of disability-inclusive health systems and facilitates its replication in other settings. However, given that the framework offers a standard overview of health systems, some nuance is missed. For instance, the focus in Chile remains mainly on rehabilitation and AT for people with disabilities and initiatives on disability-inclusive health are taking place in silos (i.e., across ministries, and between ministries and OPDs) [26, 73, 74]. Also, the actual prioritization of disability inclusion within the MoH appears to be low [17]. Furthermore, the simple fulfilment of the criteria that was applied might not capture the complexity of health systems. For example, despite Chile scored the highest for the ratification and adoption of the UNCRPD, gaps might remain in its implementation. Shadow reports of civil society have highlighted the lack of implementation on health and rehabilitation rights (e.g. health worker protocols, accessible health information, Chilean Sign Language interpretation services, mental health budget, low coverage of rehabilitation services and AT) [75]. Similarly, some existing legal frameworks expected to protect the right to healthcare are not exempted from criticism. For instance, civil society has also raised competing issues with Law Nº 20.584 and Decree Nº 570 regarding psychiatric hospitalization and involuntary sterilization, pertaining particularly people with psychosocial and intellectual disabilities [75, 76].

Some limitations exist regarding this assessment. The framework could be further improved, with the revision of a few scoring criteria. Some indicators achieved the highest score, although further improvement could be made in the areas assessed. For example, while the MoH allocates a disability-inclusive health budget, it is largely underfunded, and the scoring criteria of this indicator does not assess budget sufficiency. Furthermore, scoring of the accessibility audit does not mention the scope of the evaluation and the maximum score can still be obtained even if poor accessibility were to be found in health facilities. Similarly, the rehabilitation and assistive technology assessment indicator does not include scoring criteria regarding the availability of AT and the mechanisms for their acquisition. In addition, indicators could specify whether it relates to all people with disabilities or a subset, as eligibility for benefits varies depending on disability type, severity, and certification status. Moreover, health financing and affordability indicators should account more for countries with dual health systems and mixed service provision such as Chile. People with disabilities who are not covered by public health insurance can be excluded from financial adjustments despite the additional living costs associated with disability. [1, 77].

Assessments could take greater account on differences amongst people with disabilities (e.g. rural/urban, type of impairment) and direct representation of all disability groups should be strengthened [78]. Confusion on organization types, lack of funding for advisory roles, and poor cohesion of the disability movement have been pointed out as barriers in the participation of OPDs in policy processes and should be addressed in the future [78]. Ultimately, guidance could be provided on how to identify and select OPDs to facilitate wider engagement, as well as accessible materials and work dynamics (e.g. right disability language, reasonable accommodations, etc.).

This assessment has important strengths. It is the first comprehensive assessment on disability-inclusive health in Chile with participation of civil society. Findings will serve as a disability-inclusive health benchmark both for Chile, but also globally. It is the first assessment using the Missing Billion Framework in its complete format with MoH and OPD engagement. The collaboration provided exchange and learning experiences on health and disability for all actors, especially OPDs, who gained skills to monitor and evaluate progress in the future. In addition, the task team compounded technical expertise and lived experience of disability. Information was independently assessed by representatives and their organizations, and multiple key national stakeholders were consulted. Finally, the three priorities for action recommended for Chile at this stage are aligned with the WHO measures for the inclusion of disability in health systems [1] and the ownership of the MoH in this assessment could positively impact policy implementation [79].

CONCLUSIONS

In conclusion, our findings suggest that only some progress has been made towards disability-inclusive healthcare in Chile. Short-term actions for the country should involve foundational governance on this topic, strengthened leadership of people with disabilities, and mandatory training of healthcare workers to improve healthcare access among this group. Future reassessments should be conducted to monitor and evaluate progress on effective healthcare coverage and health status among people with disabilities.

List of abbreviations

UNCPRD	United Nations Convention on the Rights of Persons with Disabilities
LAC	Latin America and the Caribbean
MoH	Ministry of Health
WHO	World Health Organization
AT	Assistive Technology
OPDs	Organizations of Persons with Disabilities
FONASA	National Health Fund
ISAPRES	Private Health Insurances

SENADIS	National Disability Agency
COMPIN	National Commission of Preventive Medicine and Disability
GES	Explicit Health Guarantees
IVADEC-CIF	Community Assessment of Performance Evaluation
EUNACOM	Single National Medical Knowledge Test
ENENF	National Nursing Examination

Supplementary Information

Additional file 1 (File format: .Docx):

Additional Table 1. Civil society representation by type of organization and impairment group (n=8)

Additional Table 2. List of indicators, metric and scoring logic

DECLARATIONS

Ethics approval and consent to participate

This study obtained ethical approval by the Ethics Committee of London School of Hygiene and Tropical Medicine (Nº28068) and the Ethics Committee of Research with Human Beings of the Faculty of Medicine, of University of Chile (Nº152-2022). Informed consent was obtained from participants of key informant interviews.

Consent for publication

Not applicable

Availability of data and materials

The dataset generated during the current study is not publicly available due to the privacy of individuals that participated in the study but is available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

This work was supported by the Agencia Nacional de Investigación y Desarrollo de Chile [72210471 to DRG]; the National Institute for Health and Care Research [301621 to HK]; and the Foreign, Commonwealth and Development Office [PO8073 to LMB]

Authors' contributions

DRG, HK, LMB, and PH collaborated to the design of the work**.** DRG, CPT, ETS, JLB, DVJ, RMC, GTC, JVC collected data. DRG, CPT, ETS, JLB, DVJ, RMC, GTC, JVC analysed and interpreted data. DRG drafted the article. JLB, GTC, JVC, PH, LMB, and HK critically revised the manuscript. All authors read and approved the final manuscript.

Acknowledgements

We thank the contributions of Miguel Rojas Varela, María Isabel Robles Meza and Lía Muñoz Ramírez. We also thank the local research support of Professor Pamela Gutiérrez Monclus and student assistants Maitte Carimán and Rosario Coloma from University of Chile as well as all the interviewees for their time, generosity, and contributions.

REFERENCES

1. World Health Organization (2022) Global report on health equity for persons with disabilities. Geneva
2. United Nations (2006) Convention on the Rights of Persons with Disabilities—Articles.
3. Missing Billion Initiative, Clinton Health Access Initiative (2022) Reimagining health systems that expect, accept and connect 1 billion people with disabilities .
4. Rotenberg S, Smythe T, Kuper H (2023) [preprint] Left Behind: Modelling the life expectancy disparities amongst people with disabilities in Low and Middle-Income Countries. medRxiv 2023.07.12.23292565
5. World Bank (2023) World Bank Country and Lending Groups. https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups. Accessed 19 Jul 2023
6. Instituto Nacional de Estadísticas (2024) Proyecciones de población. https://www.ine.gob.cl/estadisticas/sociales/demografia-y-vitales/proyecciones-de-poblacion. Accessed 9 Jan 2024
7. Rozas Assael F, González Olave F, Cerón Cañoles G, Guerrero Hurtado M, Vergara Henríquez R, Pinto Mora S (2023) III Estudio Nacional de la Discapacidad. Santiago
8. Rodríguez Gatta D, Rotenberg S, Allel K, Reichenberger V, Banks M, Kuper H (2023) [Pre Print] Access to General Health Care Among People with Disabilities in Latin America and the Caribbean: A Systematic Review of Quantitative Research. SSRN. https://doi.org/http://dx.doi.org/10.2139/ssrn.4579884
9. World Health Organization (2024) Health equity for persons with disabilities: a guide for action.
10. World Health Organization (2007) Everybody’s Business: strengthening health systems to improve health outcomes: WHO’s framework for action. Geneva

11. Veillard J, Cowling K, Bitton A, et al (2017) Better Measurement for Performance Improvement in Low- and Middle-Income Countries: The Primary Health Care Performance Initiative (PHCPI) Experience of Conceptual Framework Development and Indicator Selection. Milbank Q 95:836–883

12. Missing Billion Initiative (2023) Missing Billion Toolkit - System Level Assessment. https://www.themissingbillion.org/system-assessment. Accessed 10 Jan 2024

13. OECD (2019) OECD Reviews of Public Health: Chile. https://doi.org/10.1787/9789264309593-en

14. Sánchez M (2022) Análisis Estadístico del Sistema Isapre con Perspectiva de Género. Santiago

15. Missoni E, Solimano G (2010) Towards Universal Health Coverage: The Chilean experience.

16. FONASA (2022) Cuenta Pública Participativa 2022. Santiago

17. Rodríguez Gatta D, Gutiérrez Monclus P, Wilbur J, Hanefeld J, Banks LM, Kuper H (2024) Inclusion of people with disabilities in Chilean health policy: a policy analysis. Int J Equity Health 23:174

18. Ministerio de Salud (2024) Ministerio de Salud. https://www.minsal.cl. Accessed 18 Jan 2024

19. Ministerio de Desarrollo Social y Familia (2024) Ministerio de Desarrollo Social y Familia. https://www.desarrollosocialyfamilia.gob.cl. Accessed 19 Jan 2024

20. Biblioteca del Congreso Nacional de Chile (2024) Biblioteca del Congreso Nacional de Chile. https://www.bcn.cl/portal/. Accessed 18 Jan 2024

21. United Nations Human Rights (2023) UN Treaty Body Database. https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Countries.aspx. Accessed 17 Jan 2024

22. Ministerio de Salud (2023) Departamento de Epidemiología. http://epi.minsal.cl/. Accessed 18 Jan 2024

23. Observatorio Social M de DS y F (2022) Encuesta de Discapacidad y Dependencia 2022. https://observatorio.ministeriodesarrollosocial.gob.cl/endide-2022. Accessed 19 Jan 2024

24. Green J (2018) Qualitative methods for health research, 4th edition. SAGE, Los Angeles

25. Ministerio de Relaciones Exteriores (2008) Decreto 201 promulga la Convención de las Naciones Unidas sobre los Derechos de las personas con Discapacidad y su protocolo facultativo. Poder Ejecutivo, Santiago
26. Estado de Chile (2022) CRPD/C/CHL/2-4. Santiago
27. Ministerio de Planificación (2010) Ley Nº20.422 Establece normas sobre Igualdad de Oportunidades e Inclusión Social de Personas con Discapacidad. Cámara de Diputados, Santiago
28. Ministerio de Salud (2012) Ley 20.584 regula los derechos y deberes que tienen las personas en relación con acciones vinculadas a su atención en salud. Cámara de Diputados, Santiago
29. Ministerio de Salud (2021) Ley Nº21.331 del reconocimiento y protección de los derechos de las personas en la atención de salud mental. Cámara de Diputados, Santiago
30. Ministerio de Salud (2023) Ley Nº21.545 establece la promoción de la inclusión, la atención integral, y la protección de los derechos de las personas con trastorno del espectro autista en el ámbito social, de salud y educación. Cámara de Diputados, Santiago
31. Ministerio de Salud (2020) Decreto 2 aprueba reglamento que regula el derecho a la atención preferente dispuesto en la ley Nº20.584 . Cámara de Diputados, Santiago
32. Departamento Estrategia Nacional de Salud (2022) Estrategia Nacional de Salud para los Objetivos Sanitarios al 2030 . Santiago
33. Departamento del Programa Nacional de Prevención y Control del VIH/SIDA y las ITS (2021) Plan Nacional para la prevención y control del VIH/SIDA y las ITS, 2021-2022. Santiago
34. Ministerio de Planificación (2011) Ley Nº20530 crea el Ministerio de Desarrollo Social y Familia y modifica cuerpos legales que indica. Senado, Santiago
35. Ministerio de Salud (2024) Departamento de Rehabilitación y Discapacidad . https://rehabilitacion.minsal.cl/. Accessed 18 Jan 2024
36. Ministerio de Salud (2024) Misión y visión del Departamento de Salud Mental . https://diprece.minsal.cl/conozcanos/departamentos/departamento-de-salud-mental/. Accessed 18 Jan 2024
37. Ministerio de Salud (2021) Resolución Exenta 443 crea comisión especial electora de integrantes del consejo asesor en salud mental . Santiago

38. Ministerio de Salud (2012) Decreto 23 crea Comisión Nacional de Protección de los Derechos de las Personas con Enfermedad Mental . Santiago

39. Ministerio de Salud (2022) Resolución 473 exenta crea comisión nacional de respuesta pandémica covid-19 y deja sin efecto consejo asesor covid-19 . Santiago

40. Departamento de Comunicaciones y Relaciones Públicas (2022) Covid-19 en Chile. Pandemia 2020-2022. Ministerio de Salud, Santiagoo

41. SENADIS (2020) Directora Nacional de SENADIS encabezó sesión de la Mesa Intersectorial Discapacidad y COVID-19 . https://www.senadis.gob.cl/sala_prensa/d/noticias/8326. Accessed 18 Jan 2024

42. SENADIS, Pontificia Universidad Católica de Chile, Enviada Especial del Secretario General de Naciones Unidas sobre Discapacidad y Accesibilidad, Universidad de Los Andes, Mesa Intersectorial por la Discapacidad Intelectual, Oficina Regional para América del Sur del Alto Comisionado de las Naciones Unidas para los Derechos Humanos (2020) Recomendaciones para la atención a personas con discapacidad en el contexto de la pandemia de COVID-19 . https://www.senadis.gob.cl/sala_prensa/d/noticias/8226/recomendaciones-para-la-atencion-de-personas-con-discapacidad-en-el-contexto-de-la-pandemia-por-covid-19. Accessed 18 Jan 2024

43. Ministerio de Salud (2021) Programa de Atención Preferencial . https://www.dipres.gob.cl/597/w3-article-212525.html. Accessed 18 Jan 2024

44. FONASA (2023) Reembolso de prótesis y órtesis . https://www.fonasa.cl/sites/fonasa/adjuntos/PROTESIS. Accessed 18 Jan 2024

45. Ministerio de Salud (2015) Ley 20.850 crea un sistema de protección financiera para diagnósticos y tratamientos de alto costo y rinde homenaje póstumo a Don Luis Ricarte Soto Gallegos. Cámara de Diputados, Santiago

46. SENADIS (2023) Informe Final Programa Ayudas Técnicas 2022-2023. Santiago

47. Instituto Nacional de Estadísticas (2024) CENSO 2024. https://www.ine.gob.cl/censo. Accessed 18 Jan 2024

48. SENADIS (2021) Calificación y certificación de la discapacidad . Santiago

49. Departamento de Estadísticas e Información de Salud (2023) Norma Técnica 820 sobre los Estándares de Información de Salud . Santiago

50. Departamento de Estadísticas e Información de Salud (2023) Manual Series de Resúmenes Estadísticos Mensuales . Santiago

51. Departamento Estrategia Nacional de Salud (2020) Resumen Análisis Crítico Temas Estrategia Nacional de Salud 2011-2020. Santiago

52. SENADIS (2016) II Estudio Nacional de la Discapacidad. Santiago

53. Ministerio de Salud (2023) Salud Responde . https://saludresponde.minsal.cl/. Accessed 18 Jan 2024

54. Chile Atiende (2023) Subsidio de Discapacidad para menores de 18 años. https://www.chileatiende.gob.cl/fichas/43187-subsidio-de-discapacidad-para-menores-de-18-anos. Accessed 18 Jan 2024

55. Ministerio del Trabajo y Previsión Social (2008) Ley 20.255 establece reforma previsional. Cámara de Diputados, Santiago

56. SENADIS (2023) Beneficios en Prestaciones de Kinesiología, Fonoaudiología y Terapia Ocupacional. https://www.senadis.gob.cl/pag/568/1857/beneficios_en_prestaciones_de_kinesiologia_fonoaudiologia_y_terapia_ocupacional. Accessed 18 Jan 2024

57. Salud Responde (2022) AUGE/GES, patologías y garantías . https://saludresponde.minsal.cl/auge-ges/. Accessed 19 Jan 2024

58. Gobierno de Chile (2022) Copago 0 – Red Pública de Salud Gratuita . https://www.gob.cl/copagocero/. Accessed 18 Jan 2024

59. Ministerio de Transportes y Telecomunicaciones (2009) Ley 20.378 crea un subsidio nacional para el transporte público remunerado de pasajeros. Cámara de Diputados, Santiago

60. Chile Atiende (2023) Pensión Básica Solidaria de Invalidez. https://www.chileatiende.gob.cl/fichas/5178-pension-basica-solidaria-de-invalidez-pbsi. Accessed 6 Feb 2024

61. EUNACOM (2024) Examen Único Nacional de Conocimientos de Medicina. https://www.eunacom.cl/. Accessed 18 Jan 2024

62. ACHIEEN (2024) Examen Nacional de Enfermería .

63. Fundación EPES, División de Atención Primaria (2016) Manual de Apoyo a la Incorporación de Agentes Comunitarios en Salud. Santiago

64. Departamento de Gestión del Riesgo en Emergencias y Desastres (2019) Implementación de la Metodología Inclusión para la Gestión del Riesgo de Desastres en Hospitales. Santiago

65. Ministerio de Vivienda y Urbanismo (2015) Decreto 50 modifica decreto supremo Nº47, de vivienda y urbanismo, de 1992, ordenanza general de urbanismo y construcciones en el sentido de actualizar sus normas a las disposiciones de la ley nº20.422, sobre igualdad de oportunidades e inclusión social de personas con discapacidad. Santiago

66. Ministerio de Vivienda y Urbanismo (2021) Decreto 30 modifica decreto supremo Nº47, de vivienda y urbanismo, de 1992, ordenanza general de urbanismo y construcciones, en el sentido de actualizar diversas disposiciones relacionadas con la normativa de accesibilidad universal en espacios públicos . Santiago

67. SENADIS (2017) Informe técnico de accesibilidad . Santiago

68. Ministerio Secretaría General de la Presidencia (2015) Decreto 1 aprueba norma técnica sobre sistemas y sitios web de los órganos de la administración del estado. Santiago

69. Campillay-Campillay M, Calle-Carrasco A, Dubo P, Moraga-Rodríguez J, Coss-Mandiola J, Vanegas-López J, Rojas A, Carrasco R (2022) Accessibility in People with Disabilities in Primary Healthcare Centers: A Dimension of the Quality of Care. Int J Environ Res Public Health 19:12439

70. SENADIS (2023) Mesa Interministerial continúa trabajando para avanzar a un Sistema Nacional de Ayudas técnicas . https://www.senadis.gob.cl/sala_prensa/d/noticias/9014/mesa-interministerial-continua-trabajando-para-avanzar-a-una-sistema-nacional-de-ayudas-tecnicas. Accessed 18 Jan 2024

71. Subsecretaria de Redes Asistenciales (2023) Dotación de personal del sistema nacional de servicios de salud 2023 . Santiago

72. Minoletti A, Alvarado R, Rayo X, Minoletti M (2014) Sistema de Salud Mental de Chile. Santiago

73. SENADIS (2022) Balances Históricos de Gestión Integral. Santiago

74. SENADIS (2023) Campaña Conversemos Discapacidad y Sexualidad . https://www.senadis.gob.cl/participacion/d/noticias/9022/campana-conversemos-discapacidad-y-sexualidad. Accessed 18 Jan 2024

75. United Nations (2020) CRPD/C/CHL/QPR/2-4. List of issues prior to submission of the combined second to fourth reports of Chile. Geneva

76. Ministerio de Salud (2024) Construyendo Salud Mental. Santiago

77. North J (2020) Private Health Insurance. https://doi.org/10.1017/9781139026468

78. United Nations Partnership on the Rights of Persons with Disabilities (2022) Global Situational Analysis of the Rights of Persons with Disabilities.

79. Espinoza MA, Cabieses B, Goic C, Andrade A (2024) The legal path for priority setting in Chile: a critical analysis to improve health planning and stewardship. Front Public Health. https://doi.org/10.3389/fpubh.2023.1302640

Table 2. Health system assessment results per indicator

Component	Indicator	Definition	Indicator score	Component score
Governance	1.1 UNCRPD	Ratification and adoption of UNCRPD	1 – Ratified and evidence of action	0.7
	1.2 National Law	Existence of a national law protecting the right to health for people with disabilities	1 – National law exists that prohibits discrimination and requires reasonable accommodations	
	1.3 National Health Policy or Decree	Existence of a national policy or decree on health for people with disabilities	1 – National decree exists, ensuring access to general healthcare, specialists, and measures for implementation	
	1.4 National Health Sector Plan(s)	Inclusion of people with disabilities in National Health Sector Plan(s)	0.2 – National Health Sector Plan includes people with disabilities	
	1.5 National Disease Plan(s)	Inclusion of people with disabilities in National Disease Plan (e.g. HIV, hepatitis)	0 – No	
	1.6 Cross ministry governance	Cross-ministry structure to coordinate work on disability inclusion	1 – Structure exists, including the MoH	
Leadership	2.1 MoH leadership	Existence of a focal point/team in MoH that is responsible for ensuring health access for people with disabilities	1 – Yes	0.3

	2.2 National health sector coordination	National health sector with formal representation of people with disabilities in highest-level	0 – No	
	2.3 Pandemic preparedness structures	Formal representation of people with disabilities in national taskforce	0 – No	
Health financing	3.1 Disability inclusion budget	Budget for department in MoH working on disability inclusion	1 – Yes, at the central level	0.7
	3.2 Reimbursement adjustments	Reimbursement adjustments available for services provided to patients with disabilities	0 – No	
	3.3 Rehabilitation/AT budget	Funding for rehabilitation/AT in MoH budget	1 – Yes	
Data & Evidence	4.1 Maturity of disability and health data collection	Health information records tag people with disabilities (electronic integrated system)	0.33 – Data is collected through national surveys	0.7
	4.2 Quality of disability and health data collection method	a) Data collection method is valid b) Data collection is recent (in <10 years) c) Data is nationally representative d) 5+ impairment types are covered	1 – Yes	
	4.3 Maturity of disability and health data usage	Data collected is analysed, published, and used to direct policy change	0.5 – Data is analysed and published	

	4.4 Quality of disability and health data usage method	a) Method is transparent and valid b) Data is analysed and published within three years of collection and c) the analysis is nationally representative d) Publications and raw data are easily accessible	1 – Yes	
Autonomy and awareness	5.1 OPDs advocacy	OPDs advocate on the right to health for people with disabilities with government	1 – Yes, with the MoH	0.3
	5.2 Autonomy and awareness	People with disabilities report autonomy and awareness about health access	0 – Not reported	
	5.3 Accessibility of health information	Health information is available in accessible formats	0 – No, there are less than two accessibility formats available	
Affordability	6.1 Health coverage	People with disabilities are fully covered for free healthcare	0.5 – Partial coverage	0.3
	6.2 Disability transport subsidy	Transport subsidy is available, including travel to medical care	0 – No	
	6.3 Disability allowance	Available to cover healthcare fees not covered by existing insurance to people with moderate to severe disabilities	0.5 – For some people with disabilities	

	6.4 Co-payments	Any co-pays for services in either health insurance or taxation-based systems are waved for people with disabilities	0 – For some people with disabilities and health providers	
Human Resources	7.1 Training of medical doctors	Information about disability delivered as part of the national curricula for medical schools/colleges	0 – No	0.1
	7.2 Training of nurses	Information about disability delivered as part of the national curricula for nurses/nursing colleges	0 – No	
	7.3 Training of CHWs	Information about disability delivered as part of the national CHW training curricula	0.33 – Voluntary training with some content covered	
	7.4 Representation in health workforce	People with disabilities are represented in the health workforce	0 – Representation is below 4%	
	7.5 Satisfaction	People with disabilities report that they feel well treated by health workers	0 – Not reported	
Health facilities	8.1 National accessibility standards	Existence of national accessibility standards for healthcare facilities	1 – Yes	0.7
	8.2 Accessibility of facilities	Accessibility audit of health facilities has been undertaken in the last 10 years	0.33 – Local accessibility audit	

Rehabilitation and AT	9.1 National assessments	National assessment of AT/rehabilitation conducted in the last 10 years	0 – No	0.7
	9.2 Cross-ministry coordination for rehabilitation and AT	Coordination mechanism cross-Ministry for rehabilitation services and AT where more than one ministry is involved	1 – Yes	
	9.3 Trained workforce	Physiotherapists available and trained to provide rehabilitation services and AT	1 – Yes	

Abbreviations: Assistive Technology (AT), Community Health Workers (CHWs), High-Income Countries (HIC), Low- and Middle-Income Countries (LMICs) Ministry of Health (MoH), Organizations of People with Disabilities (OPDs), United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Table 4. Additional list of recommendations to improve disability-inclusive healthcare in Chile

Component	Description
QUICK WINS	
1) Health facilities	Establish a mandatory healthcare protocol for people with disabilities, for the public and private sector, with minimum standards of care that: a. alerts the visit of a patient with disabilities and the rights and benefits associated with disability certification b. schedules healthcare with flexible agendas according to the needs of each person and the prevalence of disability in the territory c. requests informed consent and support for decision-making, especially for persons with psychosocial and intellectual disabilities d. ensures accessibility of processes, information, and communication (e.g. sign language, plain language, alternative communication, or visual aids)
LOW EFFORT GAINS	
2) Human resources	Promote cross-sectoral coordination with academia for disability training of undergraduate medical and nursing students, and advocate for the inclusion of disability questions in national exams (EUNACOM and ENENF).
3) Human resources	Increase the recruitment of people with disabilities in health facilities in collaboration with OPDs, to promote inclusion in the workplace, raise awareness among health facility staff and patients, and reduce discrimination and stigma towards people with disabilities.
4) Health facilities	Encourage the improvement of accessibility and universal design of health facilities (not only infrastructure standards) and the implementation of reasonable accommodations.
MAJOR CHANGES	
5) Data and Evidence	Collect data on disability and health from health records, including issues of autonomy and awareness and satisfaction, and link the National Disability Register with health data. Use findings from the data collected to drive program and policy changes.
6) Autonomy and Awareness	Ensure that health information issued from all digital information systems and websites of the MoH (subsecretariats, departments, etc.) and its agencies (SEREMIAS, health services, etc.) is available in accessible formats (e.g. easy-to-read, sign language, Braille, etc.) and/or indicate a link to request alternative formats. In addition, create a section on inclusive on the website of the Department of Rehabilitation and Disability of the MoH.
7) Rehabilitation and AT	Review and expand coverage of both physical and mental rehabilitation services for all persons with disabilities in primary health care.
GRADUAL IMPROVEMENT	
8) Governance	Include disability-inclusive health goals and actions in the forthcoming National Health Strategy 2030-2040, incorporating disability and health data as well as monitoring and evaluation indicators.
9) Governance	Prioritize people with disabilities in National Disease Plans (e.g. HIV, TB, etc.).

10) Rehabilitation and AT	Conduct a national evaluation, including cost-effectiveness and impact indicators, of AT and rehabilitation every 10 years, ensuring that it is nationally representative and that findings are published.
11) Health Facilities	Conduct a health facility information and communication accessibility audit.

Note: This list excludes the three prioritized recommendations which belonged to "quick wins". **Abbreviations:** Assistive Technology (AT), Ministry of Health (MoH), National Nursing Examination (ENEF), Organizations of People with Disabilities (OPDs), Regional Health Ministry Secretariats (SEREMIAS), Single National Medical Knowledge Test (EUNACOM)

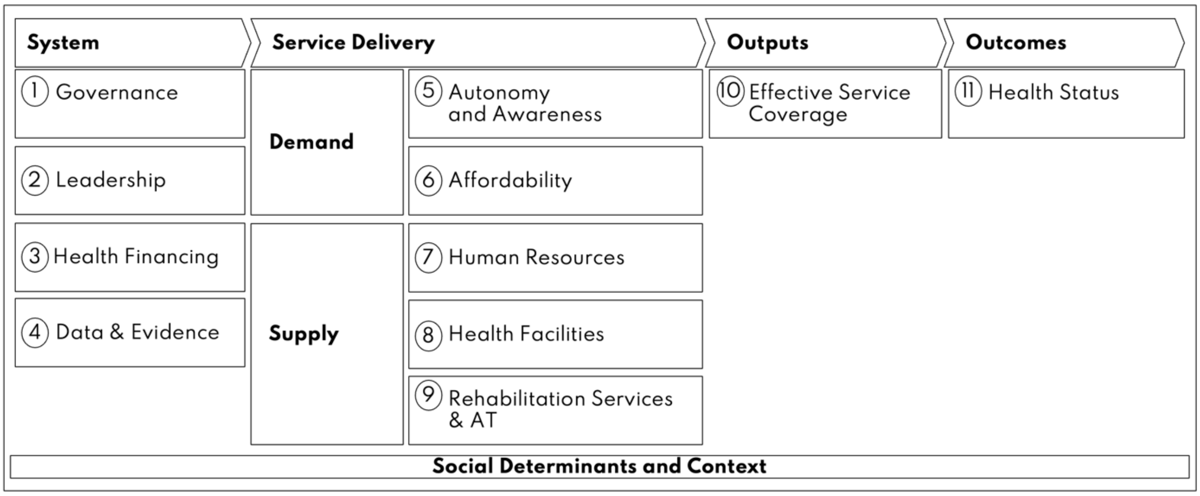


Figure 1. Missing Billion Inclusive Health Systems framework (Source: Missing Billion Initiative and Clinton Health Access Initiative (2022) Reimagining health systems that expect, accept, and connect 1 billion people with disabilities. Available at: https://www.themissingbillion.org/the-reports)

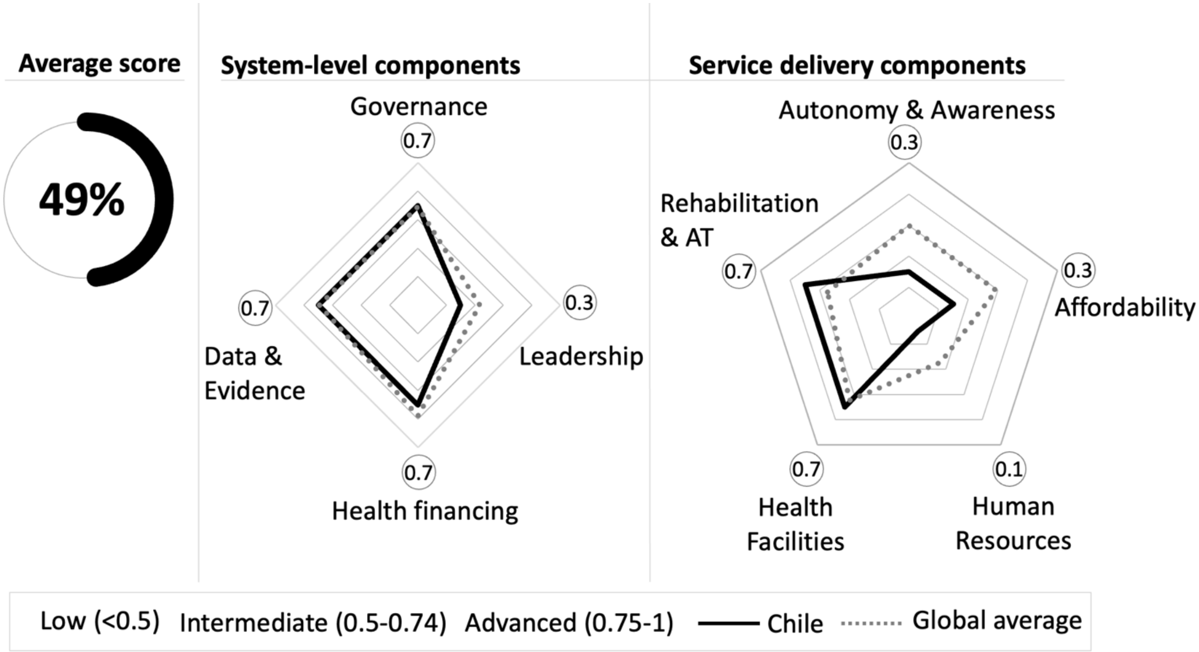


Figure 2. Average scores of the Chilean health system by system-level and service delivery components

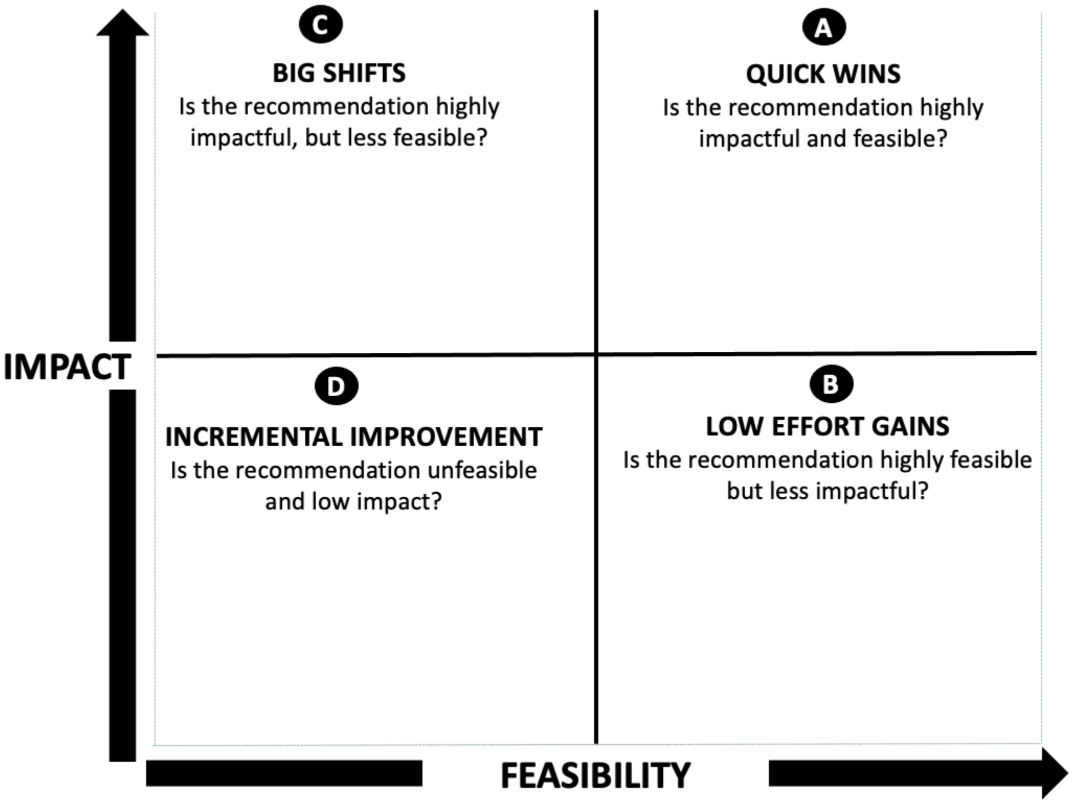


Figure 3. Prioritization matrix based on impact and feasibility criteria (Source: Missing Billion Initiative (2023) Missing Billion Toolkit - System Level Assessment. Available at: https://www.themissingbillion.org/system-assessment)

Chapter 7

Discussion and conclusion

7.1 | Summary of findings

This thesis aimed to assess the inclusion of people with disabilities in the health system of Chile and to provide evidence-based recommendations for improvement. Namely, this thesis sought to answer the following four research objectives presented below using mixed methods.

7.1.1 Research objective 1

> To systematically review the quantitative literature on access to general healthcare among people with disabilities, compared to those without disabilities, in Latin America and the Caribbean.

The systematic review (Chapter 3) revealed the dearth of studies in Latin America and the Caribbean region on access to general healthcare by people with disabilities. Only 30 studies of quantitative research – published between 2000 and 2023 – compared access to healthcare between people with and without disabilities, with most evidence originating from Brazil. In line with previous research,[35] the review showed that people with disabilities use health services more often than the general population. Only limited evidence was available for other key UHC dimensions, namely health service coverage, quality of care, and affordability of health services. These results are consistent with UHC global monitoring reports underscoring the lack of information disaggregated by vulnerable groups, including people with disabilities.[34,92] Nevertheless, the review suggested that people with disabilities might experience health inequities, particularly lower coverage of cancer screening and lower quality and affordability of health services. The large heterogeneity in the measurement of disability and healthcare access meant that it was not possible to conduct a meta-analysis. Thus, the review showed the need to further harmonize data collection in the region, and collect, analyse, and report more evidence on health inequities experienced by people with disabilities.

7.1.2 Research objective 2

> To compare healthcare utilization, coverage, and barriers to accessing health services among people with and without disabilities in Chile.

The secondary cross-sectional study aimed to investigate healthcare access among people with and without disabilities in Chile (Chapter 4) and to help fill the knowledge gap identified in Chapter 3 by the systematic review. The analysis of 2022 National Socioeconomic Survey data of Chile from 192,666 participants showed that people with disabilities experience health inequities in the country. First, it confirmed that people with disabilities use health services more often, consistently across any type of service, whether this is inpatient or outpatient general, emergency, or specialist care. It additionally demonstrated that they have increased health needs compared to people without disabilities. For instance, people with disabilities had increased odds of being under treatment for a health condition (diabetes, cancer, etc.) and children with disabilities presented with worse nutritional state. Second, the study showed that adults with disabilities had worse health coverage of preventive screening and that women with disabilities had lower coverage of cervical cancer screening, the latter being previously observed in Chile[78,79] and worldwide[93]. Finally, people with disabilities more often had unmet health needs and among those who were able to access healthcare, numerous barriers were frequently presented. People with disabilities reported increased difficulties with reaching a health facility, getting an appointment, receiving and paying for care, and obtaining medications.

7.1.3 Research objective 3

> To assess the inclusion of people with disabilities in Chilean general healthcare policy documents and to explore the perceptions of key national stakeholders regarding the policy context, policy processes, and actors involved.

The health policy analysis (Chapter 5) examined the inclusion of people with disabilities in 12 national governmental policies, strategy, and plans on general healthcare for the population in Chile (i.e., oral health, sexual and reproductive health, etc.), in order to help understand how some of the inequities and barriers reported in Chapter 4 could arise from system level determinants, such as gaps in governance and leadership. While the content analysis showed that disability was frequently mentioned across documents, at least half of them had low or no policy commitments related to disability. Reference to disability in Chilean policy documents was higher than in other settings,[94,95] although the low policy commitment is consistent with previous research.[96] The analysis also illustrated a strong focus on prevention of health conditions that could lead to disabilities, whereas privacy of health information was rarely emphasized. Next, the analysis of 15 key informant interviews with participants of various sectors – government, parliament, healthcare provision, international sector, and civil society – elucidated how the policy context, process, and actors were involved. Participants described a fragmented health policy and disability movement and a dominant medical model of disability. Interviews revealed that disability was not a priority in the Chilean health policy agenda, underlying an unsuccessful mainstreaming of disability by government bodies, and limited participation of civil society in policy processes. Informants also reported a lack of effective implementation of the few existing policies with disability inclusion. A gap in policy implementation was related to a lack of financing, leadership, and skilled health workforce, compounded by low monitoring of disability inclusion. The latter confirms previous chapters 3 and 4, were data paucity on disability and healthcare access drawn from Chile was found.

7.1.4 Research objective 4

> To undertake a national assessment of the inclusion of people with disabilities in the health system of Chile and define recommendations for improvement based on the evidence.

The health system assessment (Chapter 6), conducted together with the Ministry of Health of Chile and civil society organizations, including OPDs, investigated the inclusion of people with disabilities across system-level and service delivery components of the health system in Chile. The study found an overall low progress towards disability inclusion in the health system, despite its advances in some areas, which could explain the worse health outputs and outcomes evidenced in Chapter 4. At the system level, governance, health financing, and data and evidence showed an intermediate progress. The country has some policies and laws in place (Chapter 5), some budget for disability inclusion, rehabilitation and assistive technology, and data provided mainly through National Disability Surveys. In contrast, leadership on disability scored as low progress due to lack of formal representation of people with disabilities at high level structures in the health sector, which was similarly found in Chapter 5. At the service delivery level, health facilities and rehabilitation services and assistive technology represented the highest progress with enhanced accessibility standards of infrastructure, interministerial coordination for assistive technology, and sufficient availability of rehabilitation professionals. Significant gaps, however, were found in aspects related to the demand for care, such as lack of data on autonomy and awareness, accessibility of health information, and affordability of health services and transportation. Similarly, the assessment showed lack of disability training among health workers, poor representation of disability in the health workforce, and no data on user satisfaction or quality of health interventions disaggregated by disability. Ultimately, the study identified three priority actions for the health system in Chile: a new policy on disability-inclusive health, strengthened leadership of people with disabilities, and mandatory disability training of healthcare workers.

7.2 | Implications of research findings

This doctoral thesis evidenced that people with disabilities face health inequities in Chile, which are linked to system level gaps. The findings contribute to the body of knowledge of disability-inclusive healthcare in health policy and systems research and universal health coverage. Its novelty lies in its pioneering analysis of disability inclusion in mainstream health policies of Chile and in the Chilean health system, with the participation of the Ministry of Health and organizations of people with disabilities. Its main impact is on disability and health governance, as policy makers decided to uptake the first recommended priority action of the health system assessment and are formulating the first National Policy on Inclusive Health for People with Disabilities in Chile. Additionally, this thesis contributes to filling the evidence gap on disability and UHC in Chile and the Latin America and the Caribbean region. Finally, it also contributes to methodological advances in research, for instance, by implementing the first comprehensive Missing Billion Inclusive Health Systems framework in partnership with key stakeholders.

The detailed implications of the research findings of this doctoral thesis are presented below and are structured by implications for (1) Universal Health Coverage, (2) health system strengthening, and (3) research.

7.2.1 Universal Health Coverage for people with disabilities in Chile

The research findings of this thesis have implications for the achievement of Universal Health Coverage in Chile, including people with disabilities. Below are presented the implications for the three dimensions of UHC, namely population coverage, service coverage, and financial protection.

Population coverage

In Chile, a high proportion of people with disabilities are enrolled in health insurance schemes (Chapter 4), particularly in the public health insurance (between 88 to 90%).[77] Due to the country's commitment to UHC, everyone can be covered, regardless of people's age, gender, nationality, socioeconomic, or health status (Chapter 6). Those publicly insured receive free healthcare in the public network. A small number of people with disabilities (2%) are not insured and pay out-of-pocket for health services (Chapter 4). Thus, there is an overall minor population coverage gap by disability to be addressed in Chile. Therefore, the population without coverage should be characterized and reasons for lack of health insurance explored, to extend population coverage to those non-covered.

Service coverage

In Latin America and the Caribbean, including Chile, people with disabilities use health services more often than people without disabilities, a finding consistently evidenced in Chapters 3 and 4. Thus, people with disabilities in need of care might often seek and demand healthcare. Utilization of health services, however, is only a proxy of service coverage and does not represent the proportion of the population in need of care that truly receive it.[97] Fortunately, Chile's household surveys intend to capture service coverage and some of the unmet health needs as well as the reasons for forgoing care for selected services.[58]

Research findings (Chapter 3 and 4) indicated that important service coverage gaps exist, which were evidenced in preventive care and sexual and reproductive health services. The secondary data analysis in Chapter 4 found that in targeted health services where people might have a realized or unrealized need for care – such as preventive health check-ups and cancer screening – most programs were below national coverage targets and people with disabilities had particularly lower coverage of services. Pap tests and health check-ups (for adults and older adults) were below national coverage targets for the eligible populations. However, mammograms surpassed coverage targets. In this context, compared to those without disabilities, adults with disabilities had lower odds of having a health check-up to screen for key risk factors including alcoholism, smoking, obesity, hypertension, diabetes, as well as syphilis and tuberculosis. Similarly, women with disabilities were less likely to undergo cervical cancer screening with Pap tests. Moreover, people with disabilities were generally more likely to experience unmet need for care (i.e. they sought care but could not get an appointment), than those without disabilities.

These gaps pose negative implications for people with disabilities who are already more likely to have risk factors for disease and may have untimely detection of a highly burdensome disease such as cancer.[1] This information is particularly relevant as current UHC global estimates do not report cancer screening coverage. Most countries do not have the information available, and indicators disaggregated by people with disabilities.[34,92] Chile, in turn, has preventive programs in place with financial coverage [70] and the data available to contribute to the monitoring of UHC [58], but coverage is not equitably reaching those with disabilities. Furthermore, effective service coverage – sufficient quality and quantity of health interventions – is not being captured in the Chilean socioeconomic household survey.[58] Ultimately, Chile’s UHC implementation strategy requires a revision of health equity to first reach sub-populations, such as people with disabilities, that are currently some of the furthest behind. In addition, data collection urgently needs to incorporate measures of effectiveness of interventions as well as the reasons for forgoing health check-ups. Finally, further service coverage of some interventions should be evaluated, including family planning and immunization, and rehabilitation and assistive technology, which could be especially relevant to some people with disabilities.

Financial protection

Generally, global evidence indicates that people with disabilities face problems with affordability of care, which is related to poverty (i.e., lower capacity to pay), higher healthcare costs due to the frequent use of general and disability-related health services and assistive technology, uncovered services by benefit packages, and indirect costs (e.g., lack of employment).[1,26,98,99] In this context, the systematic review (Chapter 3) suggested some evidence that affordability of health services may be lower among people with disabilities, as they more often reported difficulties to pay for health treatments due to cost and catastrophic health expenditures. These findings were similarly observed in Chapter 4, where some people with disabilities in Chile could not access the services they needed because of financial barriers, while others reported problems to pay for care and obtain medication, due to cost, when using services. Additionally, compared to those without disabilities, people with disabilities enrolled in the public health insurance had higher odds of using a mix of both public and private health providers and other sources of care (e.g., at home by a doctor in their family or acquaintance, school health services, or medical/dental school teaching clinics offering services supervised by faculty members at no or reduced cost), than only providers of the public network. The higher use of mixed and alternative sources of care by people with disabilities requires further exploration, as it could signify out-of-pocket payments for private health providers, reflect the higher need of care, and/or underlie a response to the overall barriers accessing healthcare. Furthermore, it is necessary to examine whether the use of private health providers and potential out-of-pocket payments bear catastrophic or impoverishing health spending among people with disabilities. As Chile moves to enhanced financial protection with zero co-payments and universal primary healthcare,[75,100] it is crucial to foster a special focus on people with disabilities who still face financial barriers in accessing health services.

7.2.2 Implications for health system strengthening in Chile

The research findings of this thesis have implications for strengthening the health system of Chile. These implications are presented below and are structured in line with the Missing Billion Framework, including system level components and the demand and supply side of health service delivery.

System level components

Observable health inequities and barriers in accessing healthcare presented underlie considerable gaps at system level. Disability inclusion has shown not to be a priority in Chile’s health policy agenda, particularly within general healthcare, and initiatives in this matter are developing in silos (Chapter 5 and 6). Instead, efforts and advances have been focussed on rehabilitation, assistive technology, and caregiving support (Chapter 6). Policies with disability inclusion or aiming at disability-inclusive care are of poor quality, as they lack concrete goals, strategies, and resources towards disability (Chapter 5). Additional gaps were found in health financing. For instance, disability inclusion is largely underfunded in the Ministry of Health (Chapter 6). Moreover, primary healthcare teams are subject to pay for performance indicators as the main incentive mechanism to reach specific goals set by the central government (Chapter 5). However, there are no incentives targeting patients with disabilities (Chapter 6), such as disability-related pay for performance indicators, which was perceived as a barrier for the implementation of policies in Chile (Chapter 5). All these issues have resulted in a policy implementation gap that compromises access to healthcare and explains health inequities, particularly regarding sexual and reproductive health (Chapter 4).

Poor leadership has also hampered disability inclusion. Ineffective mainstreaming of disability and lack of leadership and coordinated action was not only observed in the Ministry of Health and Ministry of Social Affairs and Family, but similarly at regional level (Chapter 5 and 6). The latter is coupled with poor participation of people with disabilities in policy processes (Chapter 5). Hence, clear guidance is required to improve participation mechanisms and inclusive working dynamics (Chapter 6). Finally, although Chile has national household surveys that allow disaggregation by disability, [58,76] other advanced forms of measuring disability and health data – such as through integrated health information systems – are still missing (Chapter 6). Likewise, there is still little monitoring of disability inclusion of policies with set targets for disability (Chapter 5 and 6). Collectively, an array of systemic challenges needs to be addressed. However, to gradually advance at system level and considering that some areas require major changes, the health system assessment recommended the prioritization of governance and leadership to foster disability-inclusive health in Chile. These two priority areas were considered feasible for implementation in the short term and to potentially have a high impact.

Demand side

Health inequity in coverage of services is compounded by barriers in accessing healthcare. People with disabilities generally face more difficulties while accessing health services, which may impact their health seeking behaviour in the future. In comparison to those without disabilities, they more frequently face long waiting times to get an appointment or problems at the health facility such as delays or lack of staff (Chapter 4). Furthermore, women with disabilities eligible by age and health insurance for cervical and breast cancer screening, often consider it unnecessary, compared to women without disabilities (Chapter 4). The latter relates to the findings of Chapter 6, where Chile scored worse than other countries in autonomy and awareness of people with disabilities, in part due to lack of accessible health information. In addition, accessibility standards only exist for infrastructure of health facilities, while none are available for accessibility of information (Chapter 6). Hence, lack of accessible information of preventive care could impact the ability of people with disabilities to perceive health needs and seek healthcare. Deeper understanding of autonomy and awareness among this population is therefore key and requires its monitoring in national household surveys.

Furthermore, disability has not been effectively mainstreamed across sectors despite being a cross-cutting issue that goes beyond the health sector (Chapter 5). In terms of transportation, people with disabilities reported more difficulties to reach health facilities because of the distance or transportation issues (Chapter 4) and there is no national disability transport subsidy available in Chile (Chapter 6). Regarding social protection, the disability subsidy and the disability pension are subject to policy targeting and are therefore not universally available to all people with disabilities (Chapter 6). Beneficiaries are targeted based on age, severity of the impairment, income level, and disability certification status. Hence, non-eligible people with disabilities may still face financial barriers and likely precarious, fragile circumstances. In addition, the process of disability assessment has been characterized as inaccessible and disability determination as a potentially discriminatory tool for people with psychosocial disabilities, resulting in low certification of disability (8-10%).[77,85] Thus, some people with disabilities eligible for social benefits may not be accessing them. Therefore, renewed and strengthen collaboration is crucial across sectors (e.g., health, social affairs, and transportation) to develop tailored strategies that account for the extra disability-related costs and reach most people with disabilities.[1,101]

Supply side

In line with results of Chapter 4 and as described above under service coverage, important data gaps exist regarding the quality of health services delivered. The health system assessment (Chapter 6) confirmed the lack of data on satisfaction levels with healthcare. Hence, the perception of people with disabilities about how they are treated by health workers is not being fully captured. Quality of care requires a refined assessment, as it could be one of the key drivers why people seek healthcare in the private healthcare sector and is also determinant in the achievement of desired health outcomes.

Furthermore, the health policy analysis underlined an existing policy implementation gap, partly due to lack of resources for accessibility of infrastructure. Chile has accessibility mandates for health facilities, but these have not been evaluated through nationally representative accessibility audits (Chapter 6). Assessing health facilities’ infrastructure, medical equipment, and information and communication could help identify and address critical gaps in accessibility and counteract existing policy implementation gaps.

Finally, health workers such as medical doctors and nurses are not usually trained on disability (Chapter 6). A lack of disability training of health teams was similarly observed in the health policy analysis and was underscored as a barrier for policy implementation. These findings mean that health workers may usually lack the skills to provide appropriate quality services that meet the health needs of people with disabilities, risking effective service coverage. Therefore, it is necessary that health systems intentionally plan and prepare to provide quality care, both during and before people's first contact with health services. Ultimately, mandatory disability training of health workers, including professional, technical, and administrative staff, was deemed a key priority action for disability-inclusive healthcare in Chile (Chapter 6).

7.2.3 Implications for research

The findings of this thesis have implications for research, particularly regarding the framing of disability, the frameworks for assessing access to healthcare among people with disabilities, and the measurement of healthcare access.

Framing disability

Although the framing of disability is transitioning, a medical model of disability may still predominate in many settings, as opposed to the ICF or human rights models promoted in the introduction. The systematic review (Chapter 3) showed a high heterogeneity in the measurement of disability, but most data was collected under a medical model across countries in Latin America and the Caribbean. The predominance of this model was similarly observed in Chile, but in terms of governance and political participation. The health policy analysis (Chapter 5) found that policies were formulated by specific health conditions, rather than broadly targeting certain impairment types or all people with disabilities. A similar fragmentation was observed in the disability movement. People with disabilities were usually grouped under medical diagnoses, with a lack of umbrella Organizations of People with Disabilities cohesively representing and voicing collective needs. In Chile, there is a gradual transition to the current accepted disability frameworks. Transition between models, which started over a decade ago, was reflected in the Chilean health policies (Chapter 5) that had differing terminologies and poor harmonization of disability models. It is then necessary to continue strengthening the uptake of current internationally accepted disability frameworks that consider both the individual and social dimensions of disability. The harmonization is required for both health policy and data collection (e.g. the more widespread use of the Washington Group questions to measure disability), together with the mainstreaming of disability in society. This harmonization will facilitate comparison between countries, within Chile across time, and the increasing recognition of disability in public policy.

Frameworks for assessing access to healthcare among people with disabilities

The Levesque framework on access to healthcare allows a nuanced inspection of the different elements involved in the healthcare journey at the individual level and from the side of service delivery.[38] However, this thesis did not use qualitative approaches, or new quantitative data collection, to address in depth, personal, and individual experiences among people with disabilities and their ability to perceive, seek, reach, pay, and engage with healthcare. It also did not evaluate specific health facilities and their levels of accessibility in terms of approachability, acceptability, availability and accommodation, affordability, and appropriateness of care. Instead, this framework was helpful to interpret some of the findings of the present body of evidence. Namely, in Chapter 4 the barriers in accessing healthcare – as structured by the National Socioeconomic Survey of Chile – were analysed in line with the ability to seek, reach, and pay for care described by Levesque. Nevertheless, the Levesque framework could be useful to examine different individual healthcare seeking journeys across Chile through qualitative methods of research in the future. It also would allow broad consideration of access along the healthcare seeking journey, rather than just at the point of healthcare service delivery. Despite missing a system level perspective, it does consider relevant barriers that can appear before being in contact with health providers, some of which are beyond the health sector alone. For instance, the ability to reach health services, which also depends on the availability of accessible transport. Its strength also lies in the inclusion of the approachability of services (i.e., outreach, information, screening, etc.), as this could facilitate the assessment of health promotion and public heath interventions that require further research.

In this context, the Missing Billion framework enabled an overview of disability inclusion at the system level, integrating the complex interplay between systems and services. It facilitated the collection and analysis of data in a structured approach and can allow international comparison and tracking of health system improvements over time. The framework also addresses crucial aspects that can go beyond the health sector, such as transport subsidy and disability allowance. Consequently, it provides an opportunity for coordination and collaboration across ministries for issues that affect healthcare access and to strengthen mainstreaming of disability in Government. However, some criteria might need revision, as their simple fulfilment could overlook the complexity of health systems, and the further improvement required in certain areas. For example, health financing does not assess budget sufficiency, and the Chilean Ministry of Health scored the highest in disability inclusion budget despite being severely underfunded. Moreover, although nuance can be missed and some of the richness of each context, the Missing Billion framework facilitates setting a benchmark in specific settings and comparison across countries. Thus, its uptake in neighbouring countries in Latin America and the Caribbean could foster the identification of regionally relevant policy solutions, learning, and collaboration.

Measurement of healthcare access

The systematic review (Chapter 3) revealed a high level of heterogeneity in the measurement of healthcare access in Latin America and the Caribbean (i.e. different definitions of access, types of services, period, and data collection methods), thus hampering the comparison across studies. In this context, the Universal Health Coverage framework was useful to frame access to healthcare, and it was also used in the secondary data analysis (Chapter 4). The UHC framework can facilitate consistent assessments and provides some broadly accepted definitions on service coverage, and financial protection. Key tracer indicators are provided, which can be measured through household surveys, administrative system, or facility data depending on the indicator.[34,92,97] Although indicators only represent a selection of essential health services, a richer depth of services can be explored in each setting. Moreover, both unmet needs and forgone care are essential elements to measure in UHC. However, the secondary data analysis (Chapter 4) did not allow assessment of who had not received health check-ups – among those with realised need – nor the reasons for not receiving them, as these aspects were not included in the survey. Instead, they were only evaluated for the overall use of healthcare, without specifying service type, and cancer screening. Nevertheless, there is still no agreed methodology for the measurement of unmet needs and forgone care. Therefore, it is crucial to follow up the upcoming 2025 revision of the UHC indicators, particularly on service coverage, to align the monitoring framework and future studies.[34]

7.3 | Strengths and limitations

This thesis fills in evidence gaps, updates information, and brings novelty to unexplored areas of disability-inclusive health. A relevant strength is the scale and scope of analyses, including a comprehensive overview on access to healthcare in Latin America and the Caribbean, national assessments of health policy and systems in Chile, and the use of a large dataset of 192,666 participants. The secondary data analysis will additionally allow future comparability of evidence from Chile to other countries given the use of the Washington Group Short Set of questions, which is considered one of the gold standard measurements of disability worldwide. Comprehensive analyses of the health policy framework and health system impacting access to general healthcare among people with disabilities were conducted for the first time in Chile, providing novel evidence. These studies included primary data collected and processed by native Spanish speakers familiar with the context, triangulation of sources, and structured tools that allow future international comparisons. Moreover, the participation of diverse and multi-disciplinary teams was another key strength. Teams included both direct representation of people with disabilities and family experiences of disability. Different sectors were represented, integrating the perspectives of academia, government, and civil society. Notably, the health system assessment marked a milestone and enhanced learning in the exchange between the Ministry of Health and Organizations of Persons with Disabilities, which should be leveraged in the future. The establishment of a collaboration with the Ministry of Health required sustained efforts throughout a change of government, which resulted in high ownership of this governing body and the subsequent uptake of the first recommendation drawn from the study. Namely, the Ministry of Health started the formulation of the first National Policy on Inclusive Health for People with Disabilities in Chile.[102]

This thesis also has limitations that should be considered. First, both the systematic review and secondary data analysis were hampered by the availability of data, which was limited in scope and potential generalisability. For instance, for the systematic review most studies were from Brazil and the survey in Chile had a response rate of 69%. Similarly, both studies presented mainly self-reported information that can be subject to information bias. In addition, surveys rely on self-reporting and data collection methods are often not inclusive.[103] Hence, the experiences of people that require accommodations for communication may be underrepresented. Further issues with data pertain to the measurement of disability and the underrepresentation of certain groups of people with disabilities. The review showed a high heterogeneity in disability measurement and an underrepresentation of people with intellectual or learning disabilities as well as those living in institutional settings. Likewise, the Washington Group questions used to determine disabilities in the secondary analysis might have missed people with psychosocial disabilities. In addition, the health policy analysis might have excluded certain groups not explicitly referred to as people with disabilities, such as children with special needs and elderly with dependency. Finally, not all disability groups were directly represented in the task team of the health system assessment, particularly those with intellectual and hearing impairments. Moreover, this thesis did not capture the expressed individual needs of different people with disabilities through in-depth qualitative research. Data was also limited by lack of disaggregated analyses and exploration of intersecting identities with other minority groups, as demonstrated in the systematic review. Similarly, although the secondary data analysis was disaggregated by gender, it was underpowered for a robust analysis on differences by impairment type. Ultimately, the national health system assessment presented a broad overview which may missed nuance by age, gender, sexual orientation, income, residence, impairment type, migration, race, and indigenous populations. Furthermore, even though effective service coverage is an essential UHC dimension, this was not truly captured in this body of evidence.[34,97] The review found only extremely limited evidence on quality of healthcare from one study.[104] The National Socioeconomic Survey dataset used for the secondary data analysis only captured service coverage and did not include quality modules within healthcare. Similarly, the health system assessment corroborated the lack of satisfaction surveys or quality assessments disaggregated by disability existing in Chile. Finally, research plans were affected by the COVID-19 pandemic and new leadership following the change in government. For instance, travel restrictions and public health measures restricting gatherings signified changing some in-person interviews to online. Similarly, focus-groups across the country could not be conducted due to the pandemic as well as due to time and budget constraints.

Lastly, there are both potentially positive and negative impacts related to my positionality, particularly for the health policy analysis (Chapter 5) and health system assessment (Chapter 6). I am a Latina, Chilean woman, trained as an Occupational Therapist and Epidemiologist. The fact that I come from the country where I conducted this research could have acted as a facilitator, as collaborators and participants could have perceived me to be in a “legitimate” position. In addition, being an “insider”, also implied that I was familiar with the context, the culture, and the language of the country. However, I have been living away from Chile in the last years. Therefore, I may have been less connected to the recent social, economic, and political changes. Moreover, I reflect both the perspectives of a researcher and a health worker with previous experience working with people with disabilities, which facilitated my understanding of healthcare service provision in Chile. Furthermore, I have a personal connection to the topic, with a lived family experience of disability, but I am not disabled myself. Instead, I am in a position of a “disability ally” and caregiver. Consequently, I have a personal interest in the improvement of disability-inclusive healthcare in Chile. In addition, I was in an outsider position working with the Ministry of Health. Hence, government officials may have been biased towards giving positive views of their work and may have safeguarded sensitive information. Moreover, many of the interviews conducted could be characterized as “elite” interviews, since participants included high-level government officials and members of parliament.[105] In this context, I could have faced a position of power imbalance as a student, which could have limited an enhanced rapport during some interviews.

7.4 | Recommendations

7.4.1 Recommendation on future research

Future research on healthcare access among people with disabilities should first explore the quality of health services along different patient journeys both in Chile and Latin America and the Caribbean, including effectiveness, patient safety, and responsiveness/people-centredness.[97] Secondly, existing health inequities need to be monitored, particularly after the launch of the upcoming National Policy on Inclusive Health for People with Disabilities in Chile. The implementation of the policy should be also examined. Finally, innovative solutions on the design and organization of disability-inclusive health service provision at health facilities should be pilot-tested and evaluated in participatory research with people with disabilities. Successful protocols could be then upscaled to other primary care centres in Chile

7.4.2 Recommendation on health policy and programs

Some system level elements are crucial to facilitate a successful implementation of the upcoming National Policy on Inclusive Health for People with Disabilities in Chile. The health sector must ensure secured disability financing, clear leadership and accountability mechanisms, and training of health workers, as underscored in the health policy analysis. These key elements align with the second and third recommendations of the health system assessment. Namely, to ensure formal representation of disability in leadership structures and to establish a mandatory disability training program for all health workers. Ultimately, disability inclusion needs to be monitored. The health system assessment using the Missing Billion framework could be reapplied in Chile, with the leadership of the Ministry of Health, and include refined analyses with health outputs and outcomes as more evidence becomes available.

7.5 | Conclusion

People with disabilities can live healthy lives and have the right to the highest attainable standard of health as anyone else.[1] However, many of them experience poorer health, wellbeing, and lack participation in society. This thesis aimed to assess the inclusion of persons with disabilities in the health system of Chile and to provide evidence-based recommendations for improvement. It contributed to the understanding of the level of progress towards universal health coverage and disability-inclusive health in Chile as well as Latin America and the Caribbean. The body of evidence revealed that people with disabilities experience health inequities originating from considerable system level gaps, such as in governance and leadership. Thus, people with disabilities are facing unfair differences compared to the general population that can be avoided in the future. Therefore, gaps need to be closed in health policy and systems as well as at the individual level. Prioritization and mainstreaming of disability in society need to be at the forefront while health systems continue to recover from the COVID-19 pandemic. Chile is starting to build a disability-inclusive system. This journey needs to be accompanied by evidence-informed policymaking and meaningful participation of people with disabilities. Only then, negative health outputs and outcomes among people with disabilities will be improved and universal health care that leaves no one behind realised.

Appendices

| Appendix A. Supplementary material paper one

A.1 | Translated summary

Editor note: *This translation in Spanish was submitted by the authors and we reproduce it as supplied. It has not been peer reviewed. Our editorial processes have only been applied to the original abstract in English, which should serve as reference for this manuscript.*

RESUMEN

Introducción: En el mundo, hay 1.300 millones de personas con discapacidad, incluidos 85 millones en América Latina y el Caribe (ALC). Las personas con discapacidad a menudo enfrentan barreras para acceder a atención de salud y mueren, en promedio, entre 10 y 20 años antes que las personas sin discapacidad. Este estudio tuvo como objetivo revisar sistemáticamente la literatura cuantitativa sobre el acceso a la atención general de salud de personas con discapacidad, en comparación con aquellas sin discapacidad, en ALC.

Métodos: Se realizó una revisión sistemática y síntesis narrativa siguiendo las orientaciones de PRISMA. Se realizaron búsquedas en EMBASE, MEDLINE, LILACS, MedCarib, PsycINFO, SciELO, CINAHL y Web of Science utilizando una estrategia de búsqueda exhaustiva en inglés, español y portugués. Los artículos elegibles debían ser revisados por pares, publicados entre enero de 2000 y abril de 2023, y comparar el acceso general a la atención de salud (utilización, cobertura, calidad, asequibilidad) entre personas con y sin discapacidad en ALC. Dos revisores seleccionaron los estudios de forma independiente, extrajeron los datos y evaluaron el riesgo de sesgo. Esta revisión fue prerregistrada en PROSPERO [CRD42021235797].

Resultados: La búsqueda arrojó 16 538 artículos y se incluyeron 30 estudios, la mayoría con riesgo de sesgo medio o alto (n=23; 76%). La mayoría de los estudios tuvieron un diseño transversal (n=24; 80%), fueron realizados en Brasil (n=19; 63%) y con adultos (n=14; 47%). El tipo de discapacidad fue con mayor frecuencia discapacidad auto informada (n=8; 26%) o limitaciones de funcionamiento (n=8; 26%). En general, los estudios incluidos indicaron que las personas con discapacidad utilizan los servicios de atención de salud más que aquellas sin discapacidad. Hubo cierta evidencia de que las mujeres con discapacidad tenían menos probabilidades de realizarse pruebas de detección del cáncer. Evidencia limitada mostró que la asequibilidad y la calidad de los servicios de salud eran menores entre las personas con discapacidad. No se disponía de datos desglosados por género o etnia.

Interpretación: Las personas con discapacidad parecen experimentar inequidades en salud en ALC, aunque existen grandes brechas en la evidencia actual (por ejemplo, cobertura, calidad, asequibilidad). Se necesita urgentemente armonizar la recopilación de datos sobre discapacidad y acceso a la salud para abordar este problema.

Financiamiento: Este estudio fue apoyado por la Agencia Nacional de Investigación y Desarrollo (ANID); Beca de Doctorado en el Extranjero Becas Chile (Beca 72210471). Hannah Kuper cuenta con el apoyo de una cátedra de investigación global del NIHR (301621); Lena Morgon Banks con la subvención PENDA de FCDO y el Arts and

Humanities Council (subvención 102866EH); y Sara Rotenberg con una beca Rhodes (Rhodes Trust).

A.2 | PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	3
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	4
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	5
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	5
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	5
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	5
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	5
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	5
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	5,6

Section and Topic	Item #	Checklist item	Location where item is reported
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	5
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	5
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	n/a
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	5
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	5
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	n/a
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	n/a
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	5,6
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	5
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	6
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	6
Study characteristics	17	Cite each included study and present its characteristics.	6
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	6,7
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	6,7
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	6,7
	20b	Present results of all statistical syntheses conducted. If meta-analysis was	6

Section and Topic	Item #	Checklist item	Location where item is reported
		done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	6,7
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	n/a
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	6,7
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	6
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	8
	23b	Discuss any limitations of the evidence included in the review.	9
	23c	Discuss any limitations of the review processes used.	9
	23d	Discuss implications of the results for practice, policy, and future research.	9
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	4
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	4
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	n/a
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	2, 6
Competing interests	26	Declare any competing interests of review authors.	10
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	4,5

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

A.3 | EMBASE peer-reviewed search strategy

#	Searches	Annotations
1	((disabilit* or disable* or handicap* or function* limitation* or function* diversit* or dependen* or special need* or rare diseas* or capacit*) adj6 (person* or people or individ* or patient* or subject* or adult* or elderly)).ti,ab.	
2	(Physical* adj5 (impair* or deficienc* or disable* or disabili* or handicap* or incapacit*)).ti,ab.	
3	(Cerebral pals* or Spina bifida or Muscular dystroph* or Arthriti* or Osteogenesis imperfecta or Musculoskeletal abnormalit* or Musculo-skeletal abnormalit* or Muscular abnormalit* or Skeletal abnormalit* or Limb abnormalit* or Amputation* or Clubfoot or Poliomyeliti* or Paraplegi* or Paralys* or Paralyz* or Hemiplegi* or wheelchair user* or wheel chair user*).ti,ab.	
4	exp wheelchair user/	
5	((Hearing or Acoustic or Ear or Ears) adj5 (loss* or impair* or deficienc* or disable* or disabili* or handicap*)).ti,ab.	
6	((Visual* or Vision or Eye or eyes) adj5 (loss* or impair* or deficienc* or disable* or disabili* or handicap*)).ti,ab.	
7	(Deaf* or Blind*).ti,ab.	
8	exp Hearing impairment/	
9	exp vision disorders/	
10	(Schizophreni* or Psychos#s or Psychotic Disorder* or Schizoaffective Disorder* or Schizophreniform Disorder* or Dementia* or Alzheimer* or anxiet* disorder* or depression* or Bipolar Disorder* or personality disorder*).ti,ab.	
11	exp "schizophrenia and disorders with psychotic features"/	
12	exp Dementia/ or exp Alzheimer disease/	
13	((Intellectual* or Mental* or Psychological* or Developmental or cognitive) adj5 (impair* or retard* or deficienc* or disable* or disabili* or handicap* or ill* or dysfunction* or deficit* or incapacit*)).ti,ab.	
14	exp Mentally Disabled Persons/	
15	((communication or language or speech or learning) adj5 (disorder* or disabilit* or impair* or deficit* or deficienc*)).ti,ab.	
16	exp Learning Disorders/	
17	((child* or juvenile or adolescent* or teenager*) adj3 (disable* or handicap* or disabili*)).ti,ab.	
18	exp Disabled Children/	
19	((genetic or hereditary or inherited or congenital) adj3 (disease* or ill* or syndrome or defect* or disorder* or condition* or malformation or anomal* or abnormalit*)).ti,ab.	

20	exp genetic disorder/	
21	or/1-20	Disability
22	(Caribbean or Latin America or Central America or South America).ti,ab.	
23	exp Latin America/ or exp south america/ or exp central america/ or exp caribbean/	
24	(Guadaloupe* or Aruba* or Martinique or Martinican* or "Turks and caicos islands" or Turks Islander* or virgin island* or Peru* or Argentin* or Brazil* or Chile* or Colombia* or Venezuela* or Cayman* or Cayman island* or Puerto Ric* or Saint Barthelem* or ST Barthelemy or Guatemal* or Ecuador* or Bolivia* or Haiti* or Cuba* or Dominican Republic or Dominican* or Hondura* or Paraguay* or Nicaragua* or El Salvador or Salvador* or Costa Rica* or Panama* or Uruguay* or Jamaica* or "Trinidad and Tobago" or Trinidadian* or Tobagonian* or Guyan* or Suriname* or Belize* or Baham* or Barbad* or St Lucia* or Saint Lucia* or Grenad* or St Vincent or "Saint Vincent and the Grenadines" or Saint Vicentian* or St Vicentian* or "Antigua and Barbuda" or Antiguan* or Barbudan* or Dominica* or "Saint Kitts and Nevis" or "St Kitts and Nevis" or Kittitian* or Nevisian* or Mexic* or Curacao).ti,ab.	
25	or/22-24	Latin America and the Caribbean
26	((access* or equal* or inequal* or barrier* or afford* or accept* or avail* or prevent* or treat* or diagn* or us*1 or usage or utili#ation or right* or disparit* or coverage or universal) adj3 (health or healthcare)).mp.	
27	health care delivery/ or exp health care access/ or exp universal health care/	
28	exp health care utilization/	
29	((clinical governance or evaluation* or qualit* or standard* or patient* need* or patient* satisfaction* or experience* or preference* or need* or satisfaction* or people-centredness or patient-centred or patient centered or attitude* or skill* or knowledge or responsiveness) adj3 (health or healthcare)).ti,ab.	
30	exp health care quality/	
31	((plan* or insurance* or program* or benefit* or expenditure* or "out-of-pocket payment*" or "financial risk protection") adj3 (health or medical)).ti,ab.	
32	exp health insurance/	
33	program* acceptabilit*.ti,ab.	
34	exp program acceptability/	
35	or/26-34	Healthcare access - Universal

		Health Coverage
36	((health or healthcare) adj3 (service* or agency or practice* or visiting)).ti,ab.	
37	exp health service/ or exp health care/	
38	((child* or adolescen* or p?ediatric or infant*) adj3 (service or health or healthcare or pneumoni* or lung inflamma* or pulmon* inflamma* or diarrh?ea or rehydration)).ti,ab.	
39	exp child health care/	UHC Tracer area: Child treatment
40	((health or healthcare) adj3 program*).ti,ab.	
41	exp health program/	
42	(palliati* adj3 (care or consultation* or medicine or therap* or surger* or treatment*)).ti,ab.	
43	exp palliative care/	
44	((primary or first) adj3 (health or care or healthcare)).ti,ab.	
45	exp primary health care/	
46	(healthy people or health promotion).ti,ab.	
47	exp health promotion/	
48	((birth interval* or family planning or family building) adj3 (polic* or clinic* or service* or method*)).ti,ab.	
49	exp family planning/	UHC Tracer area: Family planning
50	((matern* or obstetric* or ante natal or antenatal) adj3 (health or healthcare or control*)).ti,ab.	
51	exp maternal health service/	
52	exp maternal care/	
53	obstetric procedure/ or exp intrapartum care/ or exp perinatal care/ or exp postnatal care/ or exp prenatal care/ or exp prepregnancy care/	UHC Tracer area: Pregnancy and delivery care
54	((readaptation or rehabilitation or readjustment) adj3 (functional or medical or program* or treatment* or therap*)).ti,ab.	
55	exp rehabilitation/	
56	(health screening or health screening program* or population screening or mass screening).ti,ab.	
57	exp mass screening/	
58	(hiv treatment* or anti-hiv agent* or anti-retroviral therap* or antiretroviral therap* or antiretroviral treatment* or ART or "anti human immunodeficiency virus agent").ti,ab.	
59	exp anti human immunodeficiency virus agent/	UHC Tracer area: HIV treatment

60	(malaria adj3 (eradication or prevention or prophylaxis or control)).ti,ab.	
61	exp malaria control/	UHC Tracer area: Malaria prevention
62	((impregnated or insecticid* or insecticide treated or insecticide-treated) adj3 (net* or bednet*)).ti,ab.	
63	exp insecticide treated net/	
64	(fluid therap* or parenteral fluid therap*).ti,ab.	
65	exp fluid therapy/	
66	(diagnostic* service* or immuni#ation or immuni#ation program* or preventive service* or preventive health service* or disease prevention or "cardiovascular disease* prevention" or disease prophylaxis or preventive medication* or preventive treatment* or preventive therap* or nicotine abstin* or nicotine cessation or nicotine withdrawal or "abstinence from tobacco" or quit smoking or smoking abstin* or "tobacco use cessation" or cancer prevention or "human papillomavirus vaccine" or "human papilloma virus vaccine" or "papillomavirus vaccine*" or "papilloma virus vaccine*" or "hepatitis b vaccine*" or "hepatitis b virus vaccine*").ti,ab.	
67	prophylaxis/ or exp cancer prevention/ or exp heart infarction prevention/ or exp immunization/ or exp smoking cessation/	UHC Tracer area: Child immunization; Prevention of cardiovascular disease; Tobacco control
68	exp Papillomavirus Vaccines/	
69	exp hepatitis B vaccine/	
70	(sanitation or clean water or sanitary service* or toilet facilit* or hand d#sinfection or hand washing).ti,ab.	UHC Tracer area: Water and sanitation
71	exp hand disinfection/	
72	((cancer or carcinoma or oncological or tumo?r) adj3 (detection or recognition or diagnos#s or cure or healing or remedy or treatment or therapy or screening)).ti,ab.	UHC Tracer area: Cancer detection and treatment
73	exp cancer diagnosis/	
74	exp cancer therapy/	
75	(tuberculosis treatment* or tuberculosis diagnos* or "anti tubercul* drug*" or antitubercul* drug* or antitubercul* agent* or tubercul* drug* or tubercul* therap* or tuberculostatic agent*).ti,ab.	
76	exp tuberculostatic agent/	UHC Tracer area:

		Tuberculosis treatment
77	("anti hypertensi* agent*" or "anti hypertensi* drug*" or antihypertensi* agent* or antihypertensi* drug* or antihypertensi* or hypotensive agent* or hypotensive drug*).ti,ab.	
78	exp antihypertensive agent/	
79	(diabetes management or "diabetes mellitus management" or "diabetes mellitus treatment" or "diabetes mellitus control" or diabetes treatment or diabetes control or "anti diabet* drug*" or antidiabet* drug* or "anti diabet* agent*" or antidiabet* agent* or antidiabetic* or hypoglyc?emic agent* or hypoglyc?emic drug*).ti,ab.	
80	exp antidiabetic agent/	UHC Tracer area: Management of diabetes
81	((healthcare or service or healthcare access or diagnos* or prevention* or vaccine* or immuni#ation*) adj3 ("Human SARS coronavirus" or "SARS associated coronavirus" or SARS cov or SARS virus or SARS coronavirus or "severe acute respiratory syndrome coronavirus" or covid-19 or sars-cov-2)).ti,ab.	
82	exp SARS coronavirus/	
83	((dent* or tooth) adj3 (program* or health or healthcare or service* or treatment*)).ti,ab.	
84	exp dental care/	
85	((bed* or hospital bed*) adj3 (capacity or per capita)).ti,ab.	
86	exp hospital bed capacity/	UHC Tracer area: Hospital access
87	((health worker* or healthcare worker* or "health care worker*" or health professional* healthcare professional or "health care professional" or health personnel or healthcare personnel or "health care personnel" or health practitioner or healthcare practitioner or "health care practitioner" or physician* or psychiatrist* or surgeon* or "skilled health professional*" or nurse) adj3 (density or per capita or ratio)).ti,ab.	
88	exp nurse patient ratio/	UHC Tracer area: Health worker density
89	(essential adj3 (medicine* or drug* or medication*)).ti,ab.	
90	exp essential drug/	UHC Tracer area: Access to essential medicines

91	(IHR or "international health regulation*" or WHO IHR or "IHR core capacity index" or "international health regulation* core capacity index").ti,ab.	
92	exp international health regulation/	UHC Tracer area: Health security
93	or/36-92	Healthcare services
94	**35** and **93**	
95	**21** and **25** and **94**	
96	limit 95 to yr="2000-Current"	

| Appendix B. Supplementary material paper two

B.1 | Supplementary Table S1. National preventive health check-up program

	Target age-group	**National coverage targets**	**Diseases screened**
Child health check-up	0-9 years	Newborn: 100% 3-months: 60% 4 years: 60%	- Newborn: phenylketonuria, hypothyroidism, hip dysplasia. - 3 months old: hip dysplasia - 2-5 years old: overweight and obesity, amblyopia, strabismus and visual acuity defects, bad oral health habits.
Adult health check-up	15-64 years	25%	- Alcoholism, smoking, overweight and obesity, hypertension, diabetes, syphilis, and tuberculosis
Older people health check-up	≥65 years	50%	- Functional autonomy
Pap test	Women, 25-64 years	80%	- Cervical cancer
Mammogram	Women, 50-59 years	25%	- Breast cancer

Note: These free and voluntary health check-ups are part of a funded national health program and are guaranteed by law to people with public or private health insurance (https://bcn.cl/2gx51).

B.2 | Supplementary Table S2. Variable description of disability and level of assistance

Disability People who reported having a lot of difficulty or cannot do at all, in any of the six domains.				
Washington Group Short Set of Questions	**No, no difficulty**	**Yes, some difficulty**	**Yes, a lot of difficulty**	**Cannot do at all**
1. [Seeing] Do you have difficulty seeing, even if wearing glasses?				
2. [Hearing] Do you have difficulty hearing, even if using a hearing aid?				
3. [Mobility] Do you have difficulty walking or climbing steps?				
4. [Cognition] Do you have difficulty remembering or concentrating?				
5. [Self-care] Do you have difficulty (with self-care such as) washing all over or dressing?				
6. [Communicating] Using your usual language, do you have difficulty communicating, (for example understanding or being understood by others)?				

Functional dependence People aged ≥15 years who declare having moderate, severe, or extreme difficulty to perform an activity, and report needing help often or always to carry it out.					
Because of your health:	**None**	**Mild**	**Moderate**	**Severe**	**Extreme**
1. How much difficulty do you have eating?					
2. How much difficulty do you have with self-care or bathing? (washing parts of the body or the whole body and drying)					
3. How much difficulty do you have moving around inside the house?					
4. How much difficulty do you have toileting?					
5. How much difficulty do you have getting in or out of bed?					
6. How much difficulty do you have dressing?					
7. How much difficulty do you have getting out of your home?					
8. How much difficulty do you have doing household tasks?					
9. How much difficulty do you have making or receiving calls or using other means of communication?					
10. How much difficulty do you have shopping or going to the doctor?					
	Never	**Rarely**	**Sometimes**	**Often**	**Always**
Frequency of assistance or help from someone else for any of the 10 items above.					

Level of assistance required (functional dependence) For activities related to severe levels of dependence: eating, self-care/bathing, moving around inside the house, toileting, getting in or out of bed, and dressing.	
Severe	1. **Always** needs help to perform **≥1 activity** related to severe levels of dependence/ 2. **Often** needs help to perform **≥2 activities** related to severe levels of dependence
Moderate	1. **Always** needs help to perform **≥2 activities unrelated** to severe levels of dependence, or 2. **Often** needs help to perform **≥3 activities unrelated** to severe levels of dependence, or 3. **Often** needs help to perform **1 activity** related to severe levels of dependence
Mild	1. **Always** needs help to perform **1 activity unrelated** to severe levels of dependence, or 2. **Often** needs help to perform **1 or 2 activities unrelated** to severe levels of dependency

B.3 | Supplementary Table S3. Variables in the study with missing data

	Missing data, n (%)
Disability	60 (0·04%)
Place of birth	1574 (1·1%)
Schooling	1142 (0·6%)
Income quintile	119 (0·1%)
Health insurance	1587 (0·8%)
Health problem	2288 (1·2%)
Under health treatment	2253 (1·2%)
Child’s nutritional state	68 (0·5%)
Received medical care	29 (0·08%)
General practitioner consultation	762 (0·4%)
Emergency care	601 (0·3%)
Mental health consultation	571 (0·3%)
Specialist consultation	718 (0·4%)
Dental care consultation	684 (0·4%)
Diagnostics	1078 (0·6%)
Hospitalization	632 (0·3%)
Frequency of healthcare	439 (0·5%)
Where received healthcare	1105 (1·0%)
Child health check-up	199 (1·6%)
Adult health check-up	2499 (2·1%)
Older people health check-up	526 (1·7%)
Pap test	2911 (5·7%)
Mammogram	632 (4·9%)
Barrier: Reaching health center	59 (0·3%)
Barrier: Getting an appointment	50 (0·2%)
Barrier: Receiving care	63 (0·3%)
Barrier: Paying for care due to cost	87 (0·3%)
Barrier: Obtaining medications	117 (0·5%)

Note: listed above only variables with missing values. N and percentage considering sample weights and sub-groups/conditions applied for analyses.

B.4 | Supplementary Table S4. Health conditions by sex and disability

	Women			**Men**		
	Women with disabilities, n (%)	**Women without disabilities, n (%)**	**Age-adjusted OR (95% CI) [a]**	**Men with disabilities, n (%)**	**Men without disabilities, n (%)**	**Age-adjusted OR (95% CI) [a]**
Any "health problem" (i.e., disease/accident, in last 3 months) [b]						
Yes	4155 (34%)	13,756 (16%)	2·14 (2·02-2·26)	2612 (31%)	10,794 (14%)	2·32 (2·16-2·50)
Under treatment for selected health conditions (in last 12 months)						
Not treated for any health condition	3378 (28%)	57,753 (68%)	Baseline	3264 (39%)	61,271 (77%)	Baseline
Hypertension	3048 (23%)	9312 (9%)	1·96 (1·82-2·12)	1620 (16%)	6610 (7%)	1·78 (1·63-1·96)
Diabetes	1983 (15%)	5238 (5%)	2·72 (2·49-2·97)	1102 (12%)	3615 (4%)	2·50 (2·24-2·79)
Acute myocardial infarction	106 (0·7%)	149 (0·2%)	3·18 (2·17-4·67)	169 (1·8%)	377 (0·4%)	3·22 (2·48-4·17)
COPD	181 (1·4%)	279 (0·3%)	4·54 (3·58-5·76)	140 (1·6%)	302 (0·3%)	4·82 (3·63-6·43)
Cancer [c]	218 (1·7%)	727 (0·8%)	2·25 (1·82-2·77)	198 (2·1%)	392 (0·4%)	3·64 (2·87-4·61)
Asthma	268 (2%)	1640 (2%)	2·40 (2·02-2·85)	149 (1·9%)	1255 (1·5%)	2·38 (1·87-3·03)
Ischemic stroke	77 (0·6%)	48 (0·04%)	12·44 (7·83-19·78)	109 (1·2%)	48 (0·1%)	19·40 (12·64-29·78)
Other [d]	3459 (27%)	12,868 (15%)	3·00 (2·79-3·23)	2078 (25%)	6925 (9%)	4·45 (4·02-4·92)
Any of above health conditions [e]	9340 (72%)	30,261 (32%)	2·60 (2·44-2·77)	5565 (61%)	19,524 (23%)	3·08 (2·85-3·32)
Child's nutritional state (aged 5-9 years)						
Normal	132 (80%)	4710 (82%)	Baseline	194 (67%)	4681 (79%)	Baseline
Malnourished (or at risk of)	4 (3%)	54 (1%)	3·00 (0·89-10·14)	8 (4%)	64 (1%)	3·99 (1·25-12·76)
Overweight	30 (13%)	937 (15%)	0·89 (0·55-1·46)	62 (25%)	1074 (17%)	1·69 (1·17-2·42)
Obese	7 (3%)	108 (1%)	2·34 (0·96-5·71)	20 (4%)	172 (3%)	1·85 (1·03-3·32)

Note: Sample weights were considered for all analyses. Abbreviation: COPD, Chronic Obstructive Pulmonary Disease. [a] Results of multivariable logistic regression models for the associations between each dependent variables on health conditions and disability, adjusted for age. [b] Including common disease, work-related disease, work/school related accident or any type of accident. [c] Including: Stomach, Cervical, Breast, Testicular, Prostate, Colorectal cancer and Leukaemia. [d] Other includes Renal failure, Lupus, Dental emergency, Depression, Cataracts, Cholecystectomy, Bipolar Disorder and others specified by the informant. [e] Any of the health conditions listed above or reported by the participant versus no reported health condition under treatment.

B.5 | Supplementary Table S5. Healthcare utilization by sex and disability

	Women					**Men**				
	Women with disabilities, n (%)	**Women without disabilities, n (%)**	**Age-adjusted OR (95% CI)**	**Age and sociodemographic-adjusted OR (95% CI)** [a]	**Age and health insurance-adjusted OR (95% CI)**	**Men with disabilities, n (%)**	**Men without disabilities, n (%)**	**Age-adjusted OR (95% CI)**	**Age and sociodemographic-adjusted OR (95% CI)** [a]	**Age and health insurance-adjusted OR (95% CI)**
Received medical care, if had "health problem" [b]	3760 (90%)	12,503 (90%)	1·06 (0·90-1·25)	1·09 (0·93-1·29)	1·06 (0·91-1·25)	2376 (91%)	9623 (89%)	1·30 (1·05-1·59)	1·41 (1·14-1·75)	1·33 (1·08-1·63)
Type of health consultation/service received (in last 3 months)										
General practitioner	5010 (39%)	20,761 (24%)	1·53 (1·44-1·61)	1·54 (1·45-1·63)	1·53 (1·45-1·62)	2983 (34%)	13,495 (17%)	1·85 (1·72-1·99)	1·88 (1·74-2·03)	1·91 (1·77-2·06)
Emergency care	3071 (24%)	11,725 (12%)	2·08 (1·96-2·22)	1·92 (1·80-2·05)	2·01 (1·89-2·14)	1729 (19%)	8644 (10%)	1·99 (1·84-2·15)	1·85 (1·70-2·01)	1·95 (1·80-2·11)
Mental health consultation	1521 (13%)	6380 (8%)	2·12 (1·95-2·30)	2·40 (2·20-2·61)	2·25 (2·07-2·45)	731 (10%)	2864 (4%)	3·55 (3·00-4·20)	4·04 (3·37-4·84)	3·79 (3·18-4·53)
Specialist consultation	3577 (30%)	15,014 (19%)	1·55 (1·46-1·65)	1·88 (1·77-2·01)	1·71 (1·61-1·83)	2441 (30%)	9260 (13%)	2·35 (2·17-2·54)	2·91 (2·66-3·17)	2·64 (2·42-2·87)
Dental care consultation	1564 (13%)	13,211 (16%)	0·95 (0·88-1·03)	1·12 (1·04-1·21)	1·01 (0·93-1·09)	924 (11%)	9288 (13%)	1·03 (0·93-1·13)	1·21 (1·09-1·34)	1·08 (0·98-1·20)
Diagnostics [c]	5785 (45%)	24,024 (28%)	1·50 (1·42-1·58)	1·60 (1·51-1·69)	1·56 (1·48-1·65)	3445 (38%)	15,278 (19%)	1·74 (1·61-1·87)	1·94 (1·79-2·10)	1·84 (1·70-1·98)
Hospitalization (≤12 months)	1645 (13%)	5893 (7%)	1·82 (1·67-1·97)	1·86 (1·71-2·03)	1·88 (1·73- 2·05)	1292 (15%)	4057 (5%)	2·43 (2·12-2·78)	2·57 (2·22-2·97)	2·55 (2·22-2·93)
Number of health consultations (in last 3 months) [d]										
1	3540 (26%)	23,162 (34%)	Baseline	Baseline	Baseline	3517 (25%)	23,076 (34%)	Baseline	Baseline	Baseline
2	2569 (19%)	14,122 (21%)	1·20 (1·11-1·30)	1·21 (1·12-1·32)	1·22 (1·13-1·33)	2555 (19%)	13,964 (21%)	1·21 (1·12-1·32)	1·23 (1·13-1·33)	1·24 (1·14-1·34)
3	2070 (15%)	9822 (15%)	1·35 (1·24-1·47)	1·40 (1·28-1·52)	1·37 (1·26-1·50)	2062 (15%)	9573 (15%)	1·37 (1·26-1·50)	1·43 (1·31-1·56)	1·40 (1·28-1·52)
4	1308 (10%)	5753 (9%)	1·43 (1·30-1·56)	1·46 (1·33-1·60)	1·47 (1·34-1·61)	1291 (10%)	5693 (9%)	1·43 (1·31-1·57)	1·46 (1·33-1·61)	1·47 (1·34-1·61)
>5	3662 (30%)	13,754 (22%)	1·96 (1·81-2·12)	2·10 (1·94-2·28)	2·03 (1·88-2·20)	3656 (30%)	13,667 (22%)	2·02 (1·87-2·18)	2·17 (2·00-2·36)	2·09 (1·93-2·27)
Where received healthcare [e]										
Public health provider	7736 (66%)	34,894 (49%)	Baseline	Baseline	Baseline	4898 (65%)	22,684 (43%)	Baseline	Baseline	Baseline
Private health provider	1505 (17%)	17,586 (38%)	0·48 (0·44-0·52)	0·76 (0·69-0·83)	0·60 (0·55-0·65)	1064 (20%)	15,371 (45%)	0·40 (0·36-0·44)	0·65 (0·55-0·76)	0·46 (0·40-0·54)
Mixed (public or private)	1524 (15%)	7330 (12%)	0·97 (0·89-1·05)	1·17 (1·08-1·28)	0·99 (0·91-1·07)	805 (13%)	4059 (9%)	0·91 (0·80-1·04)	1·11 (0·97-1·28)	0·93 (0·82-1·06)
Other	173 (2%)	698 (1%)	1·20 (0·95-1·51)	1·52 (1·20-1·93)	1·37 (1·08-1·75)	148 (2%)	830 (2%)	0·93 (0·72-1·21)	1·33 (1·01-1·74)	0·99 (0·75-1·30)

Note: Sample weights were considered for all analyses. Adjusted odds ratios were derived from multivariable logistic regression models for the associations between each dependent variables on healthcare utilization and disability. [a] Adjusted for age, place of birth, residence, schooling, and income. [b] Including common disease, work-related disease, work/school related accident, or any type of accident in the last three months. [c] Including laboratory, radiology, and imaging. [d] Among those who received either general practitioner, emergency, mental health, specialist, or dental consultations. [e] Among those who were hospitalised, underwent a medical check-up or diagnostics, or received general medical, emergency, mental health, specialist, or dental consultations.

B.6 | Supplementary Table S6. Type of health provider used among people with public health insurance by disability

	Public health insurance			
	People with disabilities, n (%)	**People without disabilities, n (%)**	**Age and sex-adjusted OR (95% CI)**	**Age, sex, and sociodemographic-adjusted OR (95% CI) [a]**
Public health provider	12,315 (71%)	55,618 (59%)	Baseline	Baseline
Private health provider	1771 (13%)	18,846 (27%)	0·55 (0·51-0·59)	0·76 (0·70-0·82)
Mixed (public or private)	2234 (15%)	10,574 (13%)	0·98 (0·91-1·05)	1·16 (1·08-1·24)
Other [b]	218 (1·4%)	818 (1·1%)	1·53 (1·24-1·88)	1·74 (1·41-2·15)

Note: Sample weights were considered for all analyses. Adjusted odds ratios were derived from multivariable logistic regression models for the associations between type of health provider and disability. [a] Adjusted for age, sex, place of birth, residence, schooling, and income. [b] Including medical/dental services from teaching clinics, student health services, health centres abroad, at home by a family doctor or an acquaintance, or armed forces health centres.

B.7 | Supplementary Table S7. Coverage of preventive health screening services by sex and disability

	People with disabilities, n (%)	People without disabilities, n (%)	Age-adjusted OR (95% CI)	Age and sociodemographic-adjusted OR (95% CI) [a]	Age and health insurance-adjusted OR (95% CI)
Women					
Child health check-up (5-9 years)	76 (51%)	2558 (48%)	1·10 (0·71-1·71)	1·12 (0·72-1·73)	1·18 (0·74-1·89)
Adult health check-up (15-64 years)	901 (16%)	10,671 (19%)	0·73 (0·66-0·81)	0·84 (0·76-0·92)	0·78 (0·70-0·85)
Older people health check-up (≥65 years)	2056 (35%)	3705 (33%)	0·91 (0·83-1·00)	0·93 (0·85-1·02)	0·92 (0·84-1·01)
Men					
Child health check-up (5-9 years)	134 (48%)	2590 (48%)	1·04 (0·76-1·42)	1·01 (0·74-1·38)	1·07 (0·79-1·45)
Adult health check-up (15-64 years)	499 (14%)	7910 (16%)	0·78 (0·69-0·89)	0·93 (0·81-1·07)	0·86 (0·75-0·99)
Older people health check-up (≥65 years)	1204 (32%)	2909 (30%)	0·90 (0·81-1·00)	0·94 (0·84-1·05)	0·93 (0·83-1·03)

Notes: Sample weights were considered for all analyses. These free and voluntary health check-ups are part of a funded national health program and are guaranteed by law to people with public or private health insurance. All in the last 12 months. Adjusted odds ratios derived from multivariable logistic regression models for the associations between each dependent variables on health check-ups and disability. [a] Adjusted for age, place of birth, residence, schooling, and income.

B.8 | Supplementary Table S8. Difficulties presented while accessing healthcare by sex and disability

	Women					Men				
	Women with disabilities, n (%)	**Women without disabilities, n (%)**	**Age-adjusted OR (95% CI)**	**Age and sociodemographic-adjusted OR (95% CI) [a]**	**Age and health insurance- adjusted OR (95% CI)**	**Men with disabilities, n (%)**	**Men without disabilities, n (%)**	**Age-adjusted OR (95% CI)**	**Age and sociodemographic-adjusted OR (95% CI) [a]**	**Age and health insurance- adjusted OR (95% CI)**
Reaching health center [b]	821 (21%)	1340 (9%)	2·14 (1·85-2·46)	1·90 (1·64-2·21)	1·99 (1·73-2·30)	520 (21%)	1027 (10%)	2·07 (1·75-2·45)	1·82 (1·53-2·18)	1·94 (1·64-2·30)
Getting an appointment [c]	1103 (28%)	2645 (20%)	1·47 (1·31-1·66)	1·36 (1·20-1·53)	1·40 (1·24-1·57)	618 (29%)	1721 (17%)	1·84 (1·43-2·36)	1·70 (1·29-2·26)	1·78 (1·36-2·33)
Receiving care [d]	1101 (28%)	2717 (20%)	1·60 (1·43-1·80)	1·41 (1·25-1·59)	1·48 (1·32-1·67)	649 (30%)	1909 (18%)	1·92 (1·52-2·43)	1·74 (1·32-2·29)	1·81 (1·39-2·37)
Paying for care due to cost	467 (13%)	1143 (9%)	1·49 (1·27-1·75)	1·54 (1·31-1·80)	1·48 (1·26-1·74)	268 (11%)	767 (8%)	1·42 (1·15-1·75)	1·36 (1·09-1·69)	1·39 (1·12-1·72)
Obtaining medications [e]	610 (17%)	1380 (11%)	1·72 (1·49-1·98)	1·68 (1·45-1·94)	1·63 (1·41-1·88)	320 (14%)	906 (9%)	1·67 (1·37-2·04)	1·59 (1·30-1·96)	1·58 (1·30-1·93)

Note: Sample weights were considered for all analyses. Difficulties reported in the last three months. Adjusted odds ratios derived from multivariable logistic regression models for the associations between each dependent variables on barriers and disability. [a] Adjusted for age, place of birth, residence, schooling, and income; for the last two difficulties, income was excluded from the model. [b] Distance, transport connectivity, etc. [c] Long waiting times, postponement of appointments, etc. [d] At the health center, e.g., delays, time changes, lack of staff, etc. [e] Including difficulties in obtaining free prescribed medication supplied by health facilities and difficulties for those who must pay for medication out of pocket.

B.9 | Supplementary Table S9. Reasons for not seeking or receiving healthcare among people with and without disabilities

	People with disabilities, n (%)	People without disabilities, n (%)	p-value [a]
Reasons for not seeking/receiving healthcare			
Not necessary	184 (30%)	863 (39%)	p <0·0001
Took homemade remedies instead	124 (20%)	554 (21%)	
Took regular medication instead	86 (14%)	350 (15%)	
Consulted in a pharmacy instead	11 (1·3%)	79 (2·3%)	
Did not have time	23 (3·7%)	77 (3·5%)	
Did not have money	20 (3·1%)	66 (3·1%)	
Difficult to reach health facility	16 (2·1%)	20 (0·5%)	
Could not get an appointment	49 (7·5%)	106 (3·3%)	
Appointment in the next months	14 (2·6%)	42 (1·2%)	
Other reason	84 (14%)	218 (10·2%)	
Reasons for not getting a mammogram [b]			
Does not know where to get it	10 (1·5%)	34 (0·9%)	p = 0·0356
Fear or unpleasant	78 (10%)	333 (10%)	
Forgot to have it	130 (23%)	718 (23%)	
Does not think is needed	101 (17%)	470 (15%)	
Did not know it was needed	20 (2·7%)	52 (1·8%)	
Unsuitable health center timetable	13 (2·2%)	57 (1·9%)	
Does not have time	78 (12%)	591 (20%)	
Could not get an appointment	95 (13%)	432 (12%)	
Does not have money	19 (3·5%)	83 (3·0%)	
Not eligible for the examination	26 (5·1%)	142 (3·8%)	
Other reason	70 (10%)	266 (8·3%)	

[a] Designed-based Pearson chi2. [b] Only among women.

B.10 | Supplementary Table S10. STROBE Statement—Checklist of items that should be included in reports of cross-sectional studies

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	3	State specific objectives, including any prespecified hypotheses	3
Methods			
Study design	4	Present key elements of study design early in the paper	4
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	4
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers· Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement)· Describe comparability of assessment methods if there is more than one group	5
Bias	9	Describe any efforts to address potential sources of bias	6
Study size	10	Explain how the study size was arrived at	4
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	5
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	6
		(*b*) Describe any methods used to examine subgroups and interactions	6
		(*c*) Explain how missing data were addressed	6
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	6
		(*e*) Describe any sensitivity analyses	6
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7
		(b) Give reasons for non-participation at each stage	n/a
		(c) Consider use of a flow diagram	n/a
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7
		(b) Indicate number of participants with missing data for each variable of interest	Table S3
Outcome data	15*	Report numbers of outcome events or summary measures	7-8
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	7-8
		(*b*) Report category boundaries when continuous variables were categorized	7-8
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	7-8
Discussion			
Key results	18	Summarise key results with reference to study objectives	9
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	10-11

Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	11
Generalisability	21	Discuss the generalisability (external validity) of the study results	10
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	11

Note: *Give information separately for exposed and unexposed groups· An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Appendix C. Supplementary material paper three

C.1 | Additional File 1. List of EquiFrame concepts in Spanish

Nº	Concepto Clave	Lenguaje Clave	Pregunta Clave
1	No discriminación	Las personas con discapacidad no son discriminadas en base a sus características distintivas.	¿La política apoya los derechos de las personas con discapacidad con igualdad de oportunidades para recibir atención en salud?
2	Servicios personalizados	Las personas con discapacidad reciben servicios apropiados, efectivos, y comprensibles.	¿La política apoya los derechos de las personas con discapacidad con servicios personalizados para satisfacer sus necesidades y elecciones?
3	Derecho/Garantía	Las personas con discapacidad que tienen escasos recursos, tienen derecho a algunos servicios gratuitos o asignación monetaria de respiro para cuidadores.	¿La política indica como las personas con discapacidad podrían calificar beneficios específicos y relevantes para ellas/os?
4	Servicios basados en competencias	Reconoce a las personas con discapacidad y sus agrupaciones como actor/es relevantes. Por ejemplo, grupos de apoyo de pares entre personas con discapacidad, grupos de abogacía, u organizaciones de personas con discapacidad.	¿La política reconoce las competencias existentes en las personas o grupos de personas con discapacidad?
5	Participación	Las personas con discapacidad puede elegir e influenciar decisiones que afectan sus vidas. Esta consulta puede incluir la planificación, el desarrollo, la implementación, y la evaluación.	¿La política apoya el derecho de personas con discapacidad a participar en las decisiones que afectan a sus vidas y a potenciar su empoderamiento?
6	Coordinación de servicios	Las personas con discapacidad saben cómo los servicios deben interactuar cuando se requiere una colaboración interinstitucional, intrainstitucional, e intersectorial.	¿La política apoya la asistencia a personas con discapacidad para que accedan a los servicios desde un único sistema de prestación (intrainstitucional) o más de un sistema de prestación (interinstitucional) o más de un sector (intersectorial)?
7	Protección contra daños	Las personas con discapacidad están protegidas de daños durante su interacción con el	¿Las personas con discapacidad están protegidas contra daños durante su interacción con el sistema de salud y otros afines?

		sistema de salud y otros sistemas afines.	
8	Libertad	Las personas con discapacidad están protegidas contra el confinamiento físico o de otros tipos injustificado mientras están bajo la custodia del sistema/prestador de servicios.	¿La política apoya el derecho de las personas con discapacidad a estar libres de confinamiento físico o de otro tipo, injustificado?
9	Autonomía	Las personas con discapacidad puede expresar su auto-determinación. Por ejemplo, una persona con discapacidad intelectual podrán recurrir a una tercera persona independiente en cuestiones de consentimiento y elección.	¿La política apoya el derecho de personas con discapacidad a consentir, negar el consentimiento, retirar el consentimiento, o de algún modo controlar o elegir sobre lo que les sucede?
10	Privacidad	La información sobre las personas con discapacidad no debe compartirse con otras personas.	¿La política aborda la necesidad de mantener la privacidad y confidencialidad de la información sobre las personas con discapacidad?
11	Integración	A las personas con discapacidad no se les impide participar en los servicios que se proveen a la población general.	¿La política promueve el uso de los servicios generales por parte de las personas con discapacidad?
12	Contribución	Las personas con discapacidad hacen una contribución significativa a la sociedad.	¿La política reconoce que las personas con discapacidad pueden contribuir de forma productiva a la sociedad?
13	Recurso familiar	La política reconoce el valor de los familiares de las personas con discapacidad como un recurso para abordar las necesidades de salud.	¿La política reconoce el valor de los familiares de las personas con discapacidad en el abordaje de las necesidades de salud?
14	Apoyo familiar	El apoyo/cuidado hacia personas con discapacidad puede tener efectos en el bienestar de otros familiares, de manera que estos mismos familiares requieren apoyo.	¿La política reconoce que las personas con discapacidad pueden tener un impacto en el bienestar de los familiares requiriendo apoyo adicional de los servicios sanitarios?

15	Sensibilidad cultural	i) Las personas con discapacidad son consultadas sobre la aceptabilidad del servicio entregado. ii) Los establecimientos, los bienes y los servicios deben ser respetuosos con los principios éticos y culturalmente adecuados, es decir, respetuosos con la cultura de las personas con discapacidad.	¿La política garantiza que los servicios respondan a las creencias, valores, género, estilos interpersonales, actitudes, aspectos culturales, étnicos o lingüísticos de la persona?
16	Responsabilidad	Las personas con discapacidad tienen acceso a una evaluación profesional interna e independiente o a un procedimiento de salvaguarda.	¿La política especifica ante quién, y para qué son responsables los prestadores de servicios?
17	Prevención		¿La política apoya a las personas con discapacidad en la búsqueda de la prevención primaria, secundaria, y terciaria de las condiciones de salud?
18	Desarrollo de capacidades		¿La política apoya el desarrollo de la capacidad del personal de salud y del sistema donde trabajan, para abordar las necesidades de salud de las personas con discapacidad?
19	Acceso	Las personas con discapacidad tienen establecimientos de salud accesibles (es decir, transporte, estructura física de las instalaciones, asequibilidad e información comprensible en formatos adecuados).	¿La política apoya a las personas con discapacidad en acceso físico, económico y de información a los servicios de salud?
20	Calidad	Las personas con discapacidad tienen garantizada la calidad de los servicios clínicamente adecuados.	¿La política apoya la calidad de los servicios para personas con discapacidad poniendo de relieve la necesidad de una práctica basada en la evidencia y profesionalmente calificada?
21	Eficiencia		¿La política apoya la eficiencia proporcionando una forma estructurada de equiparar los recursos del sistema sanitario con las demandas de servicios para atender las necesidades de salud de las personas con discapacidad?

Note: Concepts adapted from Amin M, MacLachlan M, Mannan H, El Tayeb S, El Khatim A, Swartz L, et al. EquiFrame: a framework for analysis of the inclusion of human rights and vulnerable groups in health policies. Health Hum Rights. 2011;13:1–20, and Wilbur J, Scherer N, Mactaggart I, Shrestha G, Mahon T, Torondel B, et al. Are Nepal's water, sanitation and hygiene and menstrual hygiene policies and supporting documents inclusive of disability? A policy analysis. Int J Equity Health. 2021;20:157.

C.2 | Additional File 2. Aims of health policy documents included

Nº	Year	Title	Type	Health policy aim
1	2016	National Policy on Childhood and Adolescence 2015-2025	Policy	To progressively install an institutional system of rights guarantees for children and adolescents and public policy guidance.
2	2017	National Plan on Dementia	Plan	To address dementias at different levels of healthcare and to reduce its impact on society, as well as to improve the care and quality of life of people living with dementia and their immediate environment.
3	2017	National Plan on Mental Health 2017-2025	Plan	To contribute to improving people's mental health, through sectoral and intersectoral strategies for the promotion of mental health, prevention of mental disorders, guaranteed mental health care and social inclusion, within the framework of the comprehensive health model with a family and community approach.
4	2017	National Policy on Food and Nutrition	Policy	To provide the framework for the development of food and nutrition regulations, strategies, plans, programmes and projects.
5	2018	National Policy on Sexual and Reproductive Health	Policy	To constitute a national reference framework that defines priorities and guides resources for the implementation of sectoral and intersectoral interventions that contribute to improving the sexual and reproductive health of the population.
6	2018	National Plan on Cancer 2018-2028	Plan	To reduce the incidence and morbidity and mortality attributable to cancer through strategies and actions that facilitate the promotion, prevention, early diagnosis, treatment, palliative care and follow-up of people, improving the survival of people with cancer, favouring their quality of life and that of their families and communities.
7	2021	National Health Policy to address Gender-Based Violence	Policy	That the plans, programmes, guidelines, norms and benefits of the different levels of the health system design, implement and sustain strategies for the promotion, prevention, care, provision of support services, recovery and comprehensive rehabilitation of survivors, victims and their families, as well as people at risk of suffering gender-based violence.
8	2021	National Health Plan for the Elderly and its Action Plan 2020-2030	Plan	To improve the functional capacity of the elderly, through a long-term National Integrated Health Plan with Strategic Lines and intervention strategies, thus improving subjective well-being and social participation.
9	2021	National Action Plan on Mental Health 2019-2025	Plan	To strengthen the implementation and management of the National Mental Health Plan 2017-2025, as well as the government's 2018-2022 proposal for mental health,

				providing a consensual route, with defined strategies, actions and indicators, which facilitate the monitoring of mental health actions and their financing.
10	2022	National Health Strategy for the 2030 Health Goals	Strategy	To establish the Health Objectives for the Decade 2021-2030, and its consequent National Health Plan, which seeks to ensure health rights, achieve universal coverage and reduce health inequities in the population, and whose goal is to achieve high levels of health for the entire population.
11	2022	National Plan on Non-Communicable Diseases	Plan	To build a ‘Situation Analysis of Non-Communicable Diseases (NCDs)’, which gathers the updated scientific evidence on NCDs at international and national level and exposes the main epidemiological data, as well as the strategies and policies in place to address NCDs.
12	2022	National Plan on Oral Health 2021-2030	Plan	To improve the oral health status of the population throughout the life course with a focus on health equity.

Note: The documents were published by the Ministry of Health, except for the National Policy on Childhood and Adolescence, which was published by the Ministry General Secretariat of the Presidency, which led a council of ministers, including the Ministry of Health.

C.3 | Additional File 3. Examples of core concepts scored 3 or 4

Nº	Concept	Reference
1	**Non-Discrimination**	**[Score 3, National Plan on Mental Health]** Law 20.584 that Regulates the Rights and Duties of Persons in Relation to Actions Related to their Health Care [...] establishes, among others: The right of every person to "receive health promotion, protection and recovery and rehabilitation actions in a timely manner and without any discrimination, and that the care provided to persons with physical or mental disabilities and those deprived of liberty shall be governed by the rules issued by the Ministry of Health, to ensure that it is timely and of equal quality".
2	**Individualized Services**	**[Score 4, National Action Plan on Mental Health]** Objective: Improve the autonomy and social inclusion of people with mental disorders or disabilities. Initiative on health network management and coordination: Promotion of support services for people with mental disabilities in the health network. Indicator: Number of mental health specialized facilities that incorporate objectives and actions linked to social inclusion in the Comprehensive Care Plans of users/ Total number of facilities in the health network in the country. Goal: 100% by December 2025.
3	**Entitlement**	**[Score 4, National Health Plan for the Elderly and its Action Plan]** Objetive: Audit. Intervention strategies: Generation, systematisation and dissemination of information. Initiatives: Monitoring of compliance with the preferential care regulations associated with Law 21.168. Actions: Monitor the implementation of the Law on Preferential Care to the Elderly and Persons with Disabilities. Indicator: Health centres that comply with the preferential care regulations associated with Law 21.168/health centres audited. Goal: 100% as of March of each year.
4	**Capability-based services**	*None scored 3 or 4.*
5	**Participation**	*None scored 3 or 4.*
6	**Coordination of Services**	**[Score 4, National Health Plan for the Elderly and its Action Plan]** Objective: Reduce waiting times for the elderly. Intervention strategies: Management and coordination of the health network. Initiatives: Implementation of local protocols for the implementation of the Regulation associated with the Law on Preferential Care for the Elderly and Persons with Disabilities. Actions: Monitor and oversee the development and implementation of local protocols for the Preferred Care Act Regulation. Indicator: Number of facilities that develop local preferential care protocol for the implementation of the Regulation associated with Law 21.168 in period t/ Health centres supervised by the Superintendence of Health in period t. Goal: 100% as of December each year.

7	**Protection from Harm**	**[Score 3, National Health Policy to address Gender-Based Violence]** Forced sterilisations: corresponds to the application of sterilisation interventions on a permanent basis and for contraceptive purposes, particularly to children and adolescents in a situation of disability. In this regard, the CEDAW Committee in its Concluding Observations on the Seventh Periodic Report of Chile (2018) recommends the State of Chile to guarantee the full implementation of the national guidelines on fertility regulation (2018) by ensuring that the "informed consent" procedure is requested by medical personnel prior to sterilisation. Practitioners who perform sterilisations without such consent should be sanctioned. Redress and financial compensation should be available to women victims of non-consensual sterilisation (CEDAW/C/CHL/CO/7).
8	**Liberty**	**[Score 4, National Policy on Childhood and Adolescence]** Generate a specific diagnosis of the various forms of violence that occur in our country through the visualisation, quantification and characterisation of the different forms established by the Committee on the Rights of the Child. Similarly, assess the particular forms of violence to which children and adolescents with disabilities may be subjected, such as forced sterilisation, violence inflicted under the guise of medical treatment and deliberate disability to exploit them for purposes of begging. The assessment should incorporate the existing institutional response with an evaluation of its effectiveness and relevance.
9	**Autonomy**	**[Score 3, National Plan on Mental Health]** Strategy: Implementing actions that lead to overcoming the model of substitution of the will of the person with a mental disability by a system of support for the effective exercise of their rights.
10	**Privacy**	*None scored 3 or 4.*
11	**Integration**	**[Score 4, National Plan on Oral Health]** Objective: Strengthening the evaluation stage in the oral health policy cycle. Initiative: Assess the coverage of oral health programmes considering the social determinants of health. Actions: Hold working meetings with the Ministry of Social Affairs to integrate information systems. Process indicators: Report on coverage of oral health programmes implemented in primary healthcare centres, disaggregated by sex, age and disability status.
12	**Contribution**	*None scored 3 or 4.*
13	**Family Resource**	*None scored 3 or 4.*
14	**Family Support**	**[Score 3, National Plan on Mental Health]** Strategy: Generating programmes and actions to support family members and carers of people with mental disabilities, which have a positive impact on them, on the person being cared for and on their family environment.

15	**Cultural responsiveness**	**[Score 3, National Plan on Mental Health]** Strategy: Implementing a mass media plan, including a dedicated website and participation in social media, to disseminate relevant information to users, families and the community in relation to mental health, with special emphasis on the rights of people with mental disabilities, and stigma and mental health.
16	**Accountability**	**[Score 4, National Plan on Mental Health]** Strategic Objective N°3: Maintain current regulatory instruments up to date and develop the necessary regulations to safeguard the rights of people with mental illness, in terms of access to health and social inclusion, incorporating into the legislation considerations regarding human rights and social determinants such as socio-economic level, geographical dispersion, gender, disability, international migrant population and belonging to indigenous peoples, as well as vulnerable populations such as elderly people, children and adolescents at psychosocial risk and in protection systems and people deprived of their liberty.
17	**Prevention**	**[Score 3, National Plan on Mental Health]** In the next 10 years, the number of schools promoting mental health should be increased, with defined strategies to improve school coexistence spaces, early detection of mental problems or disorders and effective linkage flows with the health care network and other existing offers at the community level. For their part, health teams are expected to have a greater presence in schools to carry out promotional and preventive actions in the field of mental health and to be able to provide a more efficient and timely response for assessment and intervention as appropriate. In addition, schools are expected to implement inclusive, non-discriminatory policies and practices towards all children and adolescents, especially those with physical, sensory, intellectual, mental or other disabilities.
18	**Capacity building**	**[Score 4, National Action Plan on Mental Health]** Objective: Develop standards and technical orientations. Initiative: To update policy documents in accordance with the purpose, values, principles and Lines of Action of the National Mental Health Plan 2017-2025. Indicator: By the year 2022 there is a regulation for residential care for people with mental disabilities.
19	**Access**	**[Score 4, National Plan on Oral Health]** Objetive: Assess the coverage of oral health programmes considering the social determinants of health. This initiative considers completing existing health records with variables such as ethnicity, migrant status, disability status and social vulnerability, some of which are available in the National Territorial Information Coordination System (SNIT) of the Ministry of National Assets or in records managed by other ministries. It is proposed to incorporate the geographical distribution and rurality of the beneficiaries, as well as gender, age, ethnicity, migrant status, disability status and social vulnerability in the evaluation of the coverage of oral health programmes.

20	**Quality**	**[Score 4, National Plan on Mental Health]** Strategy: Strengthen links with non-governmental organisations (NGOs) that provide services in agreement with the health sector to people with mental illness and/or disability, especially in the area of social inclusion, through the generation of quality standards for community services and with a rights-based approach, establishing fees in accordance with the services required, generating joint training plans, with full integration into the thematic network of mental health, implementing systems of accompaniment, supervision and monitoring, among other actions.
21	**Efficiency**	**[Score 3, National Action Plan on Mental Health]** In order to advance in the plan to close the gap in mental health services, the Action Plan incorporates actions aimed at implementing the Mental Health Network Management Model: [...] implementation of a system of graduated support for people with disabilities resulting from mental illness; progress in the process of deinstitutionalisation of people in psychiatric hospitals and long-stay clinics in partnership with the Health Services; and implementation of a system for evaluating user satisfaction in mental health, among other actions.

C.4 | Ethical approval

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT
United Kingdom
Switchboard: +44 (0)20 7636 8636

www.lshtm.ac.uk

Observational / Interventions Research Ethics Committee

Mrs Danae Rodriguez
LSHTM

29 September 2022

Dear Mrs Danae Rodriguez

Study Title: Inclusion of persons with disabilities and human rights concepts in Chilean health policy documents: a policy analysis

LSHTM Ethics Ref: 28068

Thank you for responding to the Observational Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Protocol / Proposal	1. Research protocol	29/07/2022	1.0
Protocol / Proposal	Annex 1_EquiFrame_26.07.2022_v1	29/07/2022	1.0
Protocol / Proposal	2. Interview Guide Key Informants	29/07/2022	1.0
Protocol / Proposal	3. Interview Guide OPD representatives	29/07/2022	1.0
Investigator CV	CV_Danae Rodriguez	29/07/2022	1.0
Investigator CV	CV_Hannah Kuper	29/07/2022	1.0
Investigator CV	CV_Pamela Gutierrez	29/07/2022	1.0
Other	Ethics training certificate_Danae Rodriguez	29/07/2022	1.0
Other	Ethics training certificate_Hannah Kuper	29/07/2022	1.0
Information Sheet	4. Participant information sheet Key Informants	29/07/2022	1.0
Information Sheet	5. Participant information sheet OPD representatives	29/07/2022	1.0
Information Sheet	6. Consent form	29/07/2022	1.0
Advertisements	7. Invitation email	29/07/2022	1.0
Local Approval	Research ethics application Chile_project N°152-2022	29/07/2022	1.0
Investigator CV	CV_Morgon Banks	29/07/2022	1.0
Other	Ethics training certificate_Morgon Banks	29/07/2022	1.0
Covering Letter	Cover Letter project 28068	20/09/2022	v1
Information Sheet	4. Participant information sheet Key Informants_20.09.2022_v2	20/09/2022	2.0
Information Sheet	5. Participant information sheet OPD representatives_20.09.2022_v2	20/09/2022	2.0
Information Sheet	6. Consent form_20.09.2022_v2	20/09/2022	2.0

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: http://leo.lshtm.ac.uk

Additional information is available at: www.lshtm.ac.uk/ethics

Yours sincerely,

[redacted]

Professor David Leon and Professor Clare Gilbert
Co-Chairs

ethics@lshtm.ac.uk
http://www.lshtm.ac.uk/ethics/

C.5 | **Participant information sheet:** Key Informant Interviews

Title of Project: "Disability and human rights: Policy Analysis"

Introduction I would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve. I will go through this information sheet with you and answer any questions you may have. Please ask me if there is anything that is not clear or if you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not to take part.

What is the purpose of the study? I want to know to what extent people with disabilities are included in health policies in Chile and the perceptions of key national stakeholders regarding the context, actors and processes of health policies related to disability. This will cover overarching national health policies in place that could impact access to general healthcare (e.g. doctors, hospitals, pharmacy) across all disability groups. This information will be useful to plan and improve healthcare services that are available to and inclusive of people with disabilities.

Why have I been asked to take part? You have been invited because you have been identified by the research team as having an expertise in health policy and/or disability (e.g. policy formulation, implementation).

What is involved in the study? I would like to speak to you (in person – modify as appropriate) for between 60-90 minutes. I will ask you some questions about the context in which policies have been developed, the main stakeholders involved and the key processes of health policy making (e.g. formulation, implementation and evaluation). With your permission, I will record the conversation so that I can accurately recall your responses. You can end this interview at any time or refuse to answer any questions.

Which groups are organising the study? This study is being organised by London School of Hygiene and Tropical Medicine, a university based in London, and supported by University of Chile. Both organizations have responsibility for the project including the analysis of your data, and will act as the data controller for the study. Funding for the study comes from the National Research and Development Agency of Chile.

What are the benefits? The information collected in this interview can help to plan and improve health policies in Chile so that they are inclusive of people with disabilities and positively impact their access to healthcare services.

What are the risks? There are no risks of physical or psychological harm associated with this interview. The questions will take up a bit of your time – about 60-90 minutes. You will not receive a financial or other type of reimbursement for taking part in the study.

What will happen to information I share? I will keep all information private, safe and secure. Only the study staff will be allowed to look at information about you. Audio recordings will be deleted once the transcription of the interview has been verified.

What will happen to the results of this study? The study results will be published in a journal article, reports and in other ways to share findings of this research so that policymakers and practitioners can learn from them. I will not use your name/job title in any of this reporting. However, I may use your organisation/department, unless you request otherwise. If you would like any or all of your answers to be kept fully anonymous (no organisation/department), please let me know

Who has reviewed this study? All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by The London School of Hygiene & Tropical Medicine Research Ethics Committee (<reference number>) and The Faculty of Medicine of University of Chile Research Ethics Committee (<reference number>).

Do I have to take part? No. It is up to you to decide whether or not to take part. If you don't want to take part, that's ok. I will not share your decision with anyone outside the research team. We will discuss the study together and I will give you a copy of this information sheet. If you agree to take part, I will then ask you to agree and sign the terms of a consent form.

Can I change my mind about taking part? Yes. If you agree to take part, you are still free to withdraw from the study at any time and without giving a reason. You just need to tell the researcher that you don't want to be in the study anymore. If you withdraw from the study, I will destroy all audio recorded interviews, and not use any data collected.

Closing remarks Thank you for taking time to read this information sheet. If you think you will take part in the study, please read, and sign the consent form.

If you have any further questions that are not answered here or require any further information or explanation, please contact:

Research Lead: Danae Rodríguez Gatta [danae.rodriguez@lshtm.ac.uk]

C.6 | **Participant information sheet:** Representatives of Organization of Persons with Disabilities (OPDs)

Title of Project: “Disability and human rights: Policy Analysis”

Introduction I would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve. I will go through this information sheet with you and answer any questions you may have (modify as appropriate). Please ask me if there is anything that is not clear or if you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not to take part.

What is the purpose of the study? I want to know to what extent people with disabilities are included in health policies in Chile and the perceptions of key national stakeholders regarding the context, actors and processes of health policies related to disability. This will cover overarching national health policies in place that could impact access to general healthcare (e.g. doctors, hospitals, pharmacy) across all disability groups. This information will be useful to plan and improve healthcare services that are available to and inclusive of people with disabilities.

Why have I been asked to take part? You have been invited because you have been identified by the research team as a leader of a disabled people’s organization in Chile and have lived expertise of disability.

What is involved in the study? I would like to speak to you (in person – modify as appropriate) for between 60-90 minutes. I will ask you some questions about your involvement, if any, in health policy making and your opinion on current health policies. With your permission, I will record the conversation so that I can accurately recall your responses. You can end this interview at any time or refuse to answer any questions.

Which groups are organising the study? This study is being organised by London School of Hygiene and Tropical Medicine, a university based in London, and supported by University of Chile. Both organizations have responsibility for the project including the analysis of your data and will act as the data controller for the study. This means that I am responsible for looking after your information and using it properly. Funding for the study comes from the National Research and Development Agency of Chile.

What are the benefits? The information collected in this interview can help to plan and improve health policies in Chile so that they are inclusive of people with disabilities and positively impact their access to healthcare services.

What are the risks? There are no direct risks of physical or psychological harm associated with this interview. However, you may feel distressed when discussing about disability-inclusive health policy and its implementation. In this situation, Professor Laura Rueda (lrueda@uchile.cl/ +56229786183), an expert in mental health and bioethics from the Faculty of Medicine, University of Chile, will be available to provide initial guidance and support free of charge. The questions will take up a bit of your time – about 60-90 minutes. You will not receive a financial or other type of reimbursement for taking part in the study. However, I will cover for any adaptations required in order to facilitate your participation (e.g. sign language interpretation).

What will happen to information I share? I will keep all information private, safe and secure. Only the study staff will be allowed to look at information about you. Audio recordings will be deleted once the transcription of the interview has been verified.

What will happen to the results of this study? The study results will be published in a journal article, reports and in other ways to share findings of this research so that policymakers and practitioners can learn from them. I will also share the learning with policymakers and practitioners directly. I will not use your name in any of this reporting. However, I may use your organisation/department, unless you request otherwise. If you would like any or all of your answers to be kept fully anonymous (no organisation/department), please let me know.

Who has reviewed this study? All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by The London School of Hygiene & Tropical Medicine Research Ethics Committee (<reference number>) and The Faculty of Medicine of University of Chile Research Ethics Committee (<reference number>).

Do I have to take part? No. It is up to you to decide whether or not to take part. If you don't want to take part, that's ok. Your decision to participate or not participate will have no effect on any health and social services you receive. I will not share your decision with anyone outside the research team. We will discuss the study together and I will give you/read out to you (modify as appropriate), a copy of this information sheet. If you agree to take part, I will then ask you to agree the terms of a consent form, signing or taking oral consent which will be recorded.

Can I change my mind about taking part? Yes. If you agree to take part, you are still free to withdraw from the study at any time and without giving a reason. You just need to tell the researcher that you don't want to be in the study anymore. This will make no difference to any health or social services you receive. If you withdraw from the study, I will destroy all audio recorded interviews, and not use any data collected.

Closing remarks Thank you for taking time to read to this information sheet (modify as appropriate). If you think you will take part in the study, please read and sign the consent form (modify as appropriate).

If you have any further questions that are not answered here or require any further information or explanation, please contact: Research Lead: Danae Rodríguez Gatta [danae.rodriguez@lshtm.ac.uk]

C.7 | Consent form for participant

Title of Project: “Disability and human rights: Policy analysis”

- ☐ I confirm that I have read the information sheet for the “Disability and human rights: Policy Analysis” study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- ☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected [delete as applicable].
- ☐ I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.
- ☐ I agree to take part in the above study.
- ☐ I agree to this interview being recorded.

Printed name of participant	Signature of participant [state full name orally for remote interviews]	Date [state orally for remote interviews]

Printed name of person obtaining consent	Signature of person obtaining consent [state full name orally for remote interviews]	Date [state orally for remote interviews]

C.8 | Información para participantes

Proyecto de Investigación: “Inclusión de personas con discapacidad y enfoque de derechos en políticas de salud chilenas”

Invitación a participar: Le invito a participar como informante en una investigación. Antes de que decida, tiene que entender por qué se hace la investigación y en qué consiste. Revisará esta hoja informativa y responderé a cualquier pregunta que pueda tener. Por favor, pregunte si hay algo que no está claro o si desea más información. Si lo desea, puede hablar con otras personas sobre el estudio. Tómese su tiempo para decidir si quiere participar o no.

¿Cuál es el objetivo del estudio? Esta investigación busca evaluar la inclusión de las personas con discapacidad en los documentos de política de salud de Chile y explorar las percepciones de los principales actores nacionales sobre el contexto, los actores y los procesos de las políticas sanitarias relacionadas con discapacidad. Esto abarcará las políticas nacionales de salud vigentes que podrían repercutir en el acceso a la atención general de salud en todos los grupos de discapacidad.

¿Por qué se me ha pedido que participe? Se le ha invitado porque el equipo de investigación ha considerado que tiene experiencia en política de salud y/o discapacidad (por ejemplo, en la formulación de políticas o su implementación).

¿Qué grupos organizan el estudio? Este estudio está organizado por London School of Hygiene and Tropical Medicine, una universidad con sede en Londres, Reino Unido, y cuenta con el apoyo de la Facultad de Medicina, Universidad de Chile. Ambas organizaciones son responsables del proyecto, incluido el análisis de sus datos, y actuarán como responsables del estudio. La financiación del estudio procede de la Agencia Nacional de Investigación y Desarrollo de Chile.

Nombre del Investigador principal: Danae Rodríguez Gatta,

Institución: International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine

Correo electrónico: danae.rodriguez@lshtm.ac.uk

Nombre del Co-investigador: Pamela Gutiérrez Monclus,

Institución: Facultad de Medicina, Universidad de Chile

Teléfono: 22978 6545 (oficina) – 229786183 (secretaría)

¿En qué consiste la participación? Si usted acepta participar, se le invitará a una entrevista individual. En esta actividad le haré preguntas sobre los procesos clave de las políticas sanitarias relacionadas con discapacidad (por ejemplo, formulación, implementación y evaluación), el contexto en el cual se han desarrollado y los principales actores involucrados. Además, le preguntaré su opinión sobre la inclusión de las personas con discapacidad en las políticas de salud chilenas en general. La duración estimada de esta actividad será de 60 a 90 minutos. Esta entrevista será grabada, con su permiso, y se realizará de forma presencial, por ejemplo, en su lugar de trabajo, en la Facultad de Medicina de la Universidad de Chile o en un lugar público, según sus preferencias. Se le podría invitar a más de una entrevista y de forma excepcional, la entrevista podrá ser remota (por ejemplo, debido a viajes, emergencia sanitaria, etc.).

¿Cuáles son los riesgos? La existencia de riesgos es inherente a todas las investigaciones en que participen seres humanos. Sin embargo, las conversaciones con un profesional tienen un riesgo de daño físico o psicológico mínimo. Si usted considera que le afectan de alguna manera estas actividades, deberá hablar con la Profesora Terapeuta Ocupacional, especialista en salud mental y ética, Laura Rueda (lrueda@uchile.cl; número secretaría +56229786183), quien le ofrecerá una orientación inicial y red de apoyo. El apoyo que reciba no tendrá costo para usted.

¿Cuáles son los costos? La participación en las actividades de la investigación no tiene costos para usted. Las preguntas le llevarán entre 60 y 90 minutos de su tiempo. No recibirá ningún reembolso económico o de otro tipo por participar en el estudio.

¿Cuáles son los beneficios? La información recopilada en esta entrevista podrá ayudar a mejorar el conocimiento y la forma en que se incluye a las personas con discapacidad en las políticas de salud chilenas, para que tengan un impacto positivo en su acceso a atención de salud.

¿Qué pasará con la información que comparta? Toda la información sobre su participación en esta investigación será guardada en forma de estricta confidencialidad. Sólo los investigadores del estudio podrán ver la información sobre usted. Ninguna publicación de los resultados incluirá su nombre o cargo. Sin embargo, se utilizará su organización o departamento, a menos que usted solicite lo contrario. Si desea que alguna o todas sus respuestas sean totalmente anónimas (sin organización o departamento), hágamelo saber. Mantendré toda la información privada, segura y protegida. Se reemplazará el nombre de las personas por un número y este solo será conocido por los investigadores. Toda la información de la investigación será guardada en un estante con llave en la oficina del investigador principal. Los documentos digitales se guardarán en un servidor de la universidad, con encriptación de datos y clave secreta. Las grabaciones de audio se eliminarán una vez que se haya verificado la transcripción de la entrevista.

¿Qué pasará con los resultados de este estudio? Los resultados del estudio se publicarán en un artículo de revista científica, en informes y a través de divulgación (anonimizada) en redes sociales, de modo que los responsables políticos y los profesionales puedan aprender de ellos.

¿Quién ha revisado este estudio? Todas las investigaciones con participantes humanos son examinadas por un grupo independiente de personas, llamado Comité de Ética de la Investigación, para proteger sus intereses. Este estudio ha sido revisado y aprobado por el Comité de Ética de la Investigación de

London School of Hygiene and Tropical Medicine (Nº28068) y el Comité de Ética de la Investigación en Seres Humanos de la Facultad de Medicina de la Universidad de Chile (Nº152-2022).

¿Estoy obligado a participar? No. Usted decide si quiere participar o no. Su participación en esta investigación es totalmente voluntaria. Si usted decide no participar en esta investigación, esto no tendrá consecuencias negativas para usted. No compartiré su decisión con nadie ajeno al equipo de investigación.

¿Puedo cambiar de opinión sobre mi participación? Sí. Si acepta participar, es libre de retirarse del estudio en cualquier momento y sin necesidad de dar una razón. Sólo tiene que decir al investigador que no quiere seguir participando en el estudio. Si se retira del estudio, destruiré todas las entrevistas grabadas y no utilizaré los datos recogidos.

Derechos del participante: Usted recibirá una copia íntegra y escrita de este documento firmado. Si necesita más información, puede comunicarse con la investigadora principal. En caso de duda sobre sus derechos debe comunicarse con el presidente del Comité de Ética de Investigación en Seres Humanos, Dr. Manuel Oyarzún Gómez (Teléfono: 22978 9536, Email: ceish.med@uchile.cl), cuya oficina se encuentra ubicada a un costado de la Biblioteca Central de la Facultad de Medicina, Universidad de Chile en Av. Independencia 1027, Comuna de Independencia.

Observaciones finales Gracias por tomarse el tiempo de leer esta hoja informativa. Si cree que va a participar en el estudio, lea y firme el siguiente formulario de consentimiento.

C.9 | Formulario de consentimiento

Proyecto de Investigación: "Inclusión de personas con discapacidad y enfoque de derechos en políticas de salud chilenas"

- ☐ Confirmo que he recibido y comprendido la información de este documento y que he tenido la oportunidad de hacer preguntas y aclarar todas mis dudas.
- ☐ Entiendo que mi participación es voluntaria y que soy libre de retirarme en cualquier momento sin dar ninguna razón.
- ☐ Entiendo que la información recopilada se utilizará para apoyar otras investigaciones en el futuro y puede ser compartida de forma anónima con otros investigadores.
- ☐ Otorgo mi consentimiento para participar como informante en el proyecto "Inclusión de personas con discapacidad y enfoque de derechos en políticas de salud chilenas".
- ☐ Acepto que se grabe esta entrevista.

Nombre del participante / Rut	Firma	Fecha

Danae Rodríguez Gatta – Investigadora Principal	Firma	Fecha

C.10 | INTERVIEW GUIDE FOR KEY INFORMANTS

Note 1: These will be adapted based on the background of the key informant and, ideally, the specific health policy in which the person has been involved.

Note 2: These questions should be used to guide discussion but do not have to be used in the sequence listed below. The interviewer should follow up on any additional issues that may arise and seem important in relation to the issues above.

Interview registration

Code	
Interview date and time	
Interview location	
Interviewer	
Interviewee	
Job title	
Organization	

Interview topics

1	Key informant background
2	Health policy and disability
3	Policy context
4	Key stakeholders
5	Policy processes (agenda setting, policy formulation, implementation and evaluation)

Introduction

Good morning/afternoon/evening, it is a pleasure to meet you. Thank you very much for your time. I am [interviewer’s name] from...

1. Advise once again of the issue of confidentiality and anonymity.
2. Mention again that the interview will be audio-recorded.
3. Check if they have any questions about the research.
4. Remind them that they are free to decline to answer any of the questions or stop the interview at any time.

Section 1: Key informant background

1. Please, tell me more about your role as [job title]. Probes: What activities do you do in this role?
2. Has your organization been involved in health policy (e.g. formulation, planning, implementation, consultancy)?
    a. If yes: In what ways? In which capacity? In which policies?
    b. If no: why / why not?

Section 2: Health policy and disability

[Note to interviewers: focus on the specific health policy in which the key informant has been directly involved. If the informant has not been directly involved, focus on the health policy most relevant to the informant's area of expertise or one disability inclusive health policy]

3. How would you generally describe the current governance (e.g. laws, policies, programmes) on health and disability in Chile?
4. Have people with disabilities been included in health policy? Probes: Specific provisions? Consultations?
    a. If yes: how? In which capacity? In which policies? Which provisions?
    b. If not: why/ why not?
5. What do you think about the health policies in place [if possible, focus on one specific policy]?
    a. What does it cover/what does it **not** cover?
    b. What is the quality of the provisions?

Section 3: Policy context

[Note to interviewers: refer to the policy(ies) discussed, the National Law on Preferential Access to Healthcare for People with Disabilities or the disability-related goals within the current and past National Health Strategies]

6. What led to the inclusion of disability in the health policies that you described? Probes: What were the main reasons? Any socio-economic and political contextual factors?
7. What role, if any, has played the international and regional developments in health policy? Probes: Any influence of regional policies or international policy documents?

Section 4: Key stakeholders

8. Which have been the main stakeholders involved in the development of this disability-inclusive health policy [name policy/ies discussed]?
9. Have people with disabilities taken part in health policy making?

    a. If yes: how? In which instance? Who participated? Which was their level of engagement? Which role have played disabled people organizations? How, if at all, could involvement of people with disabilities be improved?
    b. If no: Why/why not? What do you think would be helpful in addressing this?

Section 5: Policy processes

[Note to interviewers: focus on key informant's area of expertise and refer to the policies discussed, particularly to the ones that impact access to healthcare for people with disabilities]

10. Please describe to me how people with disabilities began to be considered in public health policy. Probes: were any problems identified? Did any relevant event happen?
11. How did the topic get onto the policy agenda? Probes: when did that happen? How did that come about?
12. How were these disability-inclusive policies formulated? Probes: under which theoretical frameworks and principles?
13. What has been the level of implementation of these policies? Probes: Any facilitators/barriers? What could help advance in implementation?
14. How have things changed since these policies were published? Probes: how are policies monitored and evaluated?
15. What are the key policy gaps, if any, that impact access to healthcare for people with disabilities? Probes: in implementation? in evaluation?
    a. What needs to be done from a policy perspective? Probes: new policy? Implementation/modification of existing policy?
16. What, if any, are the needs of people with disabilities in Chile regarding health access?
    a. How have these needs been reflected in health policies?
    b. How have the needs of people with disabilities been considered by the government/program implementers during the COVID-19 epidemic?

C.11 | INTERVIEW GUIDE FOR REPRESENTATIVES OF ORGANIZATIONS OF PEOPLE WITH DISABILITIES

Note 1: These will be adapted based on the background of the key informant.

Note 2: These questions should be used to guide discussion but do not have to be used in the sequence listed below. The interviewer should follow up on any additional issues that may arise and seem important in relation to the issues above.

Interview registration

Code	
Interview date and time	
Interview location	
Interviewer	
Interviewee	
Role	
Organization	

Interview topics

1	Key informant background
2	Health policy and disability
3	Policy context
4	Key stakeholders
5	Policy processes (agenda setting, policy formulation, implementation and evaluation)

Introduction

Good morning/afternoon/evening, it is a pleasure to meet you. Thank you very much for your time. I am [interviewer's name] from...

1. Advise once again of the issue of confidentiality and anonymity.
2. Mention again that the interview will be audio-recorded.
3. Check if they have any questions about the research.
4. Remind them that they are free to decline to answer any of the questions or stop the interview at any time.

Section 1: Key informant background

1. Please, tell me more about your role as [job title] in the organization. Probes: What activities do you do in this role? Since when?
2. What is the main focus of the work of your organization?

Section 2: Health policy and disability

I'm now going to ask you some questions about public health policies in Chile and your experiences as DPO.

3. How would you generally describe the existing disability-inclusive health policies in Chile? Probes: for example, the disability-related goals within the National Health Strategy or the National Policy of the Social Inclusion of Persons with Disabilities (2013-2020)?
4. Have you or your organization been involved in health policy making (e.g. formulating, advising, implementing)? If yes: In what ways? In which capacity? In which policies? If no: Why/why not?
5. How have people with disabilities been considered in health policy documents? Probes: In which type of policies? All groups of disabilities or certain types/groups?
    a. What do you think about the health policies in place [focus on the policy in which the DPO has been involved or one known to the informant]? Probes: Strengths/ weaknesses? Areas for improvement?
    b. Do these policies adequately reflect the needs of the group you represent? If yes: How? Which needs? Any areas for improvement? If no: Why/why not? What, if anything, could help improve those policies?

Section 3: Policy context

6. What led to the inclusion of disability in the health policies that you described? Probes: What were the main reasons? Any socio-economic and political contextual factors?
7. What role, if any, has played the international and regional developments in health policy? Probes: Any influence of regional policies or international policy documents?
8. What role, if any, has the disability rights movement played in shaping these policies?

Section 4: Key stakeholders

9. In general, how would you describe the participation/engagement of people with disabilities/DPOs in health policy making? Probes: in which role, if any? How often? If participation is minimal, what would be helpful to improve it?
10. Which, if any, people with disabilities were key actors?

Section 5: Policy processes

[Note to interviewers: refer to those disability-inclusive health policy/ies discussed, known to the informant or in which the person was involved]

11. Please describe to me how people with disabilities began to be included in public health policy. Probes: were any problems identified? Did any relevant event happen? How did that come about?
12. How did the topic get onto the policy agenda? Probes: when did that happen? How did that come about?
13. What has been the level of implementation of these policies? Probes: Any facilitators/barriers?
    a. Do these policies translate into practice? If not, why not?
    b. What could help advance in implementation?
14. How have things changed since these disability-inclusive policies were published? Probes:
    a. How have these policies been monitored and evaluated?
    b. What parts of the policy and their implementation, if any, need to be changed?
15. How have your needs been considered in health policy during the COVID-19 epidemic?
    a. What, if any, policies are being implemented to address this?

D.1 | Additional Table 1. Civil society representation by type of organization and impairment group (n=8)

	Type of organization[*]			
Impairment type or disease	**Of people with disabilities (n=2)**	**For people with disabilities (n=2)** [†]	**Of and for people with disabilities (n=1)**	**Patients' association (n=3)**
Any	+	−	+	−
Visual	−	+	−	−
Hearing	−	−	−	−
Deafblindness	−	+	−	−
Physical	−	−	−	−
Intellectual	−	−	−	−
Psychosocial	+	+	−	−
Disease[‡]	−	−	−	+

[*] According to the National Registry of and for People with Disabilities of the National Disability Agency (http://externos.senadis.cl/catastro/) and the National Registry of Health-related Organizations (https://www.minsal.cl/wp-content/uploads/2021/08/Consolidado-pagina-web-28-04-2021.pdf) .

[†] One organization represented both visual disability and deafblindness.

[‡] Patient associations were grouped by Fibromyalgia, Rare diseases, and Lupus.

D.2 | Additional Table 2. List of indicators, metric and scoring logic

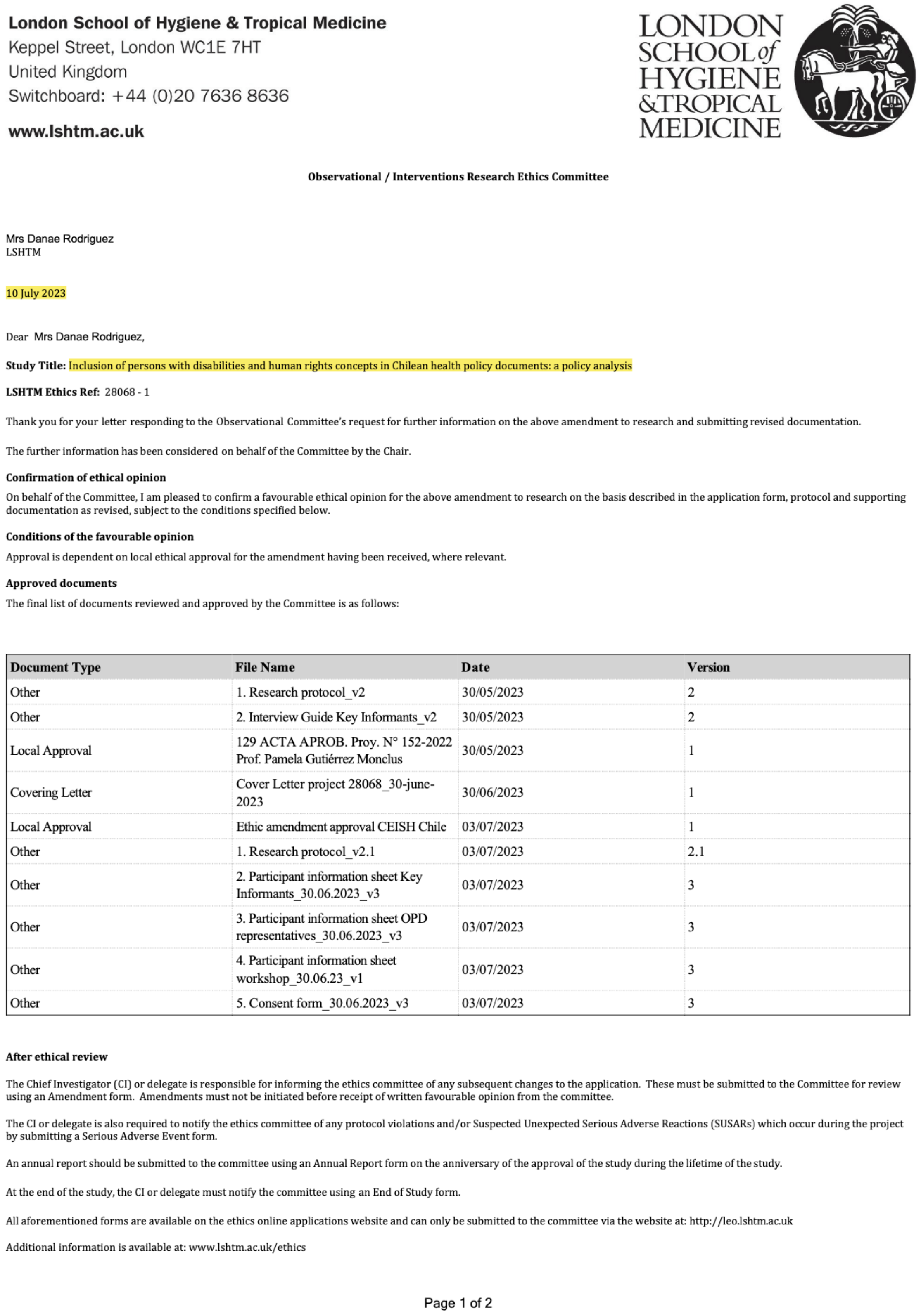
	Metric and scoring logic		
Indicator	**Basic/Maximum score**	**Mid-points / additional sub-criteria**	**Lowest score**
1.1 UNCRPD	Yes, ratified and adopted (1)	a) Ratified with no evidence of action (0.5)	No (0)
1.2 National Law	Yes, it protects the right to health for people with disabilities (0.33)	a) Prohibits discrimination (+0.33) and b) requires reasonable accommodations (+0.33)	No (0)
1.3 National Health Policy or Decree	Yes, national policy on health for people with disabilities exists (0.25)	a) General healthcare services (+0.25) b) Rehabilitation, AT, and specialist services (+0.25) c) Measures to implement these services (+0.25)	No (0)
1.4 National Health Sector Plan(s)	Yes, it includes people with disabilities (0.2)	a) Actions and targets for general healthcare (+0.2) and b) specialist services (+0.2) c) Basic statistics on disability and health (+0.2) d) Monitoring and evaluation of indicators (+0.2)	No (0)
1.5 National Disease Plan(s)	Yes, people with disabilities are included, and testing, treatment, and information programs are ensured (1)		No (0)
1.6 Cross ministry governance	Yes, structure exists to coordinate work on disability inclusion (0.5)	a) MoH is included (+0.5)	No (0)
2.1 MoH leadership	A focal point/team is responsible for ensuring health access for people with disabilities (1)		No (0)
2.2 National health sector coordination	Yes, with formal representation of persons with disabilities (individual or OPDs) in highest-level (1)		No (0)
2.3 Pandemic preparedness structures	Yes, with formal representation of people with disabilities (individuals or OPDs) in national taskforce (1)		No (0)
3.1 Disability inclusion budget	Yes, in MoH (or devolved levels) for department working on disability inclusion (1)		No (0)
3.2 Reimbursement adjustments	Yes, there is a national health insurance reimbursement or there is adjusted capitation rates for services provided to some patients with disabilities (1)		No (0)
3.3 Rehabilitation/AT budget	Yes, in MoH (or devolved levels) (1)		No (0)
4.1 Maturity of disability and health data collection	Health information records tag people with disabilities (electronic integrated system) (1)	a) National register for people with disabilities connected to health data (0.67) b) National survey/census asks disability questions (0.33)	Not collected (0)
4.2 Quality of disability and health data collection method	All criteria fulfilled (1)	a) Valid method (0.25) and b) recent data collection (in <10 years) (0.25) c) Data is nationally representative (0.25)	No criteria fulfilled (0)

		d) 5+ impairment types are covered (0.25)	
4.3 Maturity of disability and health data usage	Data collected is analysed, published, and used to direct policy change (1)	a) Data is analysed and published (0.5)	Neither (0)
4.4 Quality of disability and health data usage method	All criteria fulfilled (1)	a) Method is transparent and valid (0.25) b) Data is analysed and published within three years of collection (0.25) and c) the analysis is nationally representative (0.25) d) Publications and raw data are easily accessible (0.25)	No criteria fulfilled (0)
5.1 OPDs advocacy	Yes, OPDs advocate on the right to health and have been engaged in advisory roles/partnerships with the MoH (1)		No (0)
5.2 Autonomy and awareness	In the last 10 years, people with disabilities were asked about autonomy and awareness about health in a quantitative survey or qualitative data was published in a peer-reviewed journal (1)		Not reported (0)
5.3 Accessibility of health information	Yes, health information is available in two or more accessible formats (1)		<2 accessible formats (0)
6.1 Health coverage	Yes, people with disabilities are fully covered for free healthcare (1)	a) Healthcare is partially covered (0.5)	No (0)
6.2 Transport subsidy	Yes, available for people with disabilities including travel to medical care (1)	a) Subsidized transport but not facility dedicated services (0.5)	No (0)
6.3 Disability allowance	Yes, available to cover healthcare fees not covered by existing insurance or tax-based systems to people with moderate to severe disabilities (1)	a) Disability allowance available for some people with disabilities in the country (0.5)	No (0)
6.4 Co-payments	Yes, co-pays for services in either health insurance or taxation-based systems are waived for people with disabilities (1)		No (0)
7.1, 7.2 & 7.3 Training of medical doctors, nurses, and CHWs	Yes, information about disability is delivered as part of their national curricula (0.33)	a) Training content covers medical and non-medical modules (+0.33) and b) is part of the core curriculum (+0.33)	No (0)
7.4 Representation of people with disabilities in health workforce	Yes, representation is in line with or greater than disability prevalence of the working age population (2% for LMICs, 4% HICs) (1)		No (0)
7.5 Satisfaction	In the last 10 years, people with disabilities were asked about satisfaction with health services in a quantitative survey or qualitative data was published in a peer-reviewed journal (1)		No (0)

8.1 National accessibility standards	Yes, national accessibility standards exist for healthcare facilities (1)		No (0)
8.2 Accessibility audit	Yes, accessibility audit of health facilities has been undertaken (in <10 years) (0.33)	a) Results published in government report or peer-reviewed journal (+0.33) and b) is mandatory for all facilities to meet the accessibility standards (+0.33)	No (0)
9.1 National assessments of rehabilitation/AT	Yes, conducted in the last 10 years (1)		No (0)
9.2 Cross-ministry coordination for rehabilitation and AT	Yes, where more than one ministry is involved (1)		No (0)
9.3 Trained workforce for rehabilitation and AT	Above 300 physiotherapists/1,000,000 population for high-income countries (1)		Below the threshold (0)

Abbreviations: Assistive Technology (AT), Community Health Workers (CHWs), High-Income Countries (HIC), Low- and Middle-Income Countries (LMICs) Ministry of Health (MoH), United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

D.3 | Ethical approval



London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT
United Kingdom
Switchboard: +44 (0)20 7636 8636

www.lshtm.ac.uk

Observational / Interventions Research Ethics Committee

Mrs Danae Rodriguez
LSHTM

10 July 2023

Dear Mrs Danae Rodriguez,

Study Title: Inclusion of persons with disabilities and human rights concepts in Chilean health policy documents: a policy analysis

LSHTM Ethics Ref: 28068 - 1

Thank you for your letter responding to the Observational Committee's request for further information on the above amendment to research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above amendment to research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval for the amendment having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Other	1. Research protocol_v2	30/05/2023	2
Other	2. Interview Guide Key Informants_v2	30/05/2023	2
Local Approval	129 ACTA APROB. Proy. N° 152-2022 Prof. Pamela Gutiérrez Monclus	30/05/2023	1
Covering Letter	Cover Letter project 28068_30-june-2023	30/06/2023	1
Local Approval	Ethic amendment approval CEISH Chile	03/07/2023	1
Other	1. Research protocol_v2.1	03/07/2023	2.1
Other	2. Participant information sheet Key Informants_30.06.2023_v3	03/07/2023	3
Other	3. Participant information sheet OPD representatives_30.06.2023_v3	03/07/2023	3
Other	4. Participant information sheet workshop_30.06.23_v1	03/07/2023	3
Other	5. Consent form_30.06.2023_v3	03/07/2023	3

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: http://leo.lshtm.ac.uk

Additional information is available at: www.lshtm.ac.uk/ethics

Yours sincerely,

[redacted]

Professor David Leon and Professor Clare Gilbert
Co-Chairs

ethics@lshtm.ac.uk
http://www.lshtm.ac.uk/ethics/

D.4 | Participant information sheet: Key Informant Interviews

Title of Project: “Disability and human rights: Policy Analysis”

Introduction I would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve. I will go through this information sheet with you and answer any questions you may have. Please ask me if there is anything that is not clear or if you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not to take part.

What is the purpose of the study? I want to know to what extent people with disabilities are included in health policies in Chile and the perceptions of key national stakeholders regarding the context, actors and processes of health policies related to disability. This will cover overarching national health policies in place that could impact access to general healthcare (e.g. doctors, hospitals, pharmacy) across all disability groups. I also want to understand disability inclusion in other important aspects of the health system and co-develop recommendations with the disability community in Chile. This information will be useful to plan and improve healthcare services that are available to and inclusive of people with disabilities.

Why have I been asked to take part? You have been invited because you have been identified by the research team as having an expertise in health policy and/or disability (e.g. policy formulation, implementation).

What is involved in the study? I would like to speak to you (in person – modify as appropriate) for between 60-90 minutes. I will ask you some questions about: the context in which policies have been developed, the main stakeholders involved and the key processes of health policy making (e.g. formulation, implementation and evaluation) / the inclusion of people with disabilities in your area of the health system (e.g. health financing, health facilities, etc.) [select as appropriate]. With your permission, I will record the conversation so that I can accurately recall your responses. You can end this interview at any time or refuse to answer any questions.

Which groups are organising the study? This study is being organised by London School of Hygiene and Tropical Medicine, a university based in London, and supported by University of Chile. Both organizations have responsibility for the project including the analysis of your data, and will act as the data controller for the study. Funding for the study comes from the National Research and Development Agency of Chile.

What are the benefits? The information collected in this interview can help to plan and improve health policies in Chile so that they are inclusive of people with disabilities and positively impact their access to healthcare services.

What are the risks? There are no risks of physical or psychological harm associated with this interview. The questions will take up a bit of your time – about 60-90 minutes. You will not receive a financial or other type of reimbursement for taking part in the study.

What will happen to information I share? I will keep all information private, safe and secure. Only the study staff will be allowed to look at information about you. Audio recordings will be deleted once the transcription of the interview has been verified.

What will happen to the results of this study? The study results will be published in a journal article, reports and in other ways to share findings of this research so that policymakers and practitioners can learn from them. I will not use your name/job title in any of this reporting. However, I may use your organisation/department, unless you request otherwise. If you would like any or all of your answers to be kept fully anonymous (no organisation/department), please let me know

Who has reviewed this study? All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by The London School of Hygiene & Tropical Medicine Research Ethics Committee (<reference number>) and The Faculty of Medicine of University of Chile Research Ethics Committee (<reference number>).

Do I have to take part? No. It is up to you to decide whether or not to take part. If you don't want to take part, that's ok. I will not share your decision with anyone outside the research team. We will discuss the study together and I will give you a copy of this information sheet. If you agree to take part, I will then ask you to agree and sign the terms of a consent form.

Can I change my mind about taking part? Yes. If you agree to take part, you are still free to withdraw from the study at any time and without giving a reason. You just need to tell the researcher that you don't want to be in the study anymore. If you withdraw from the study, I will destroy all audio recorded interviews, and not use any data collected.

Closing remarks Thank you for taking time to read this information sheet. If you think you will take part in the study, please read, and sign the consent form.

If you have any further questions that are not answered here or require any further information or explanation, please contact:

Research Lead: Danae Rodríguez Gatta [danae.rodriguez@lshtm.ac.uk]

D.5 | Participant information sheet: Representatives of Organization of Persons with Disabilities (OPDs)

Title of Project: “Disability and human rights: Policy Analysis”

Introduction I would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve. I will go through this information sheet with you and answer any questions you may have (modify as appropriate). Please ask me if there is anything that is not clear or if you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not to take part.

What is the purpose of the study? I want to know to what extent people with disabilities are included in health policies in Chile and the perceptions of key national stakeholders regarding the context, actors and processes of health policies related to disability. This will cover overarching national health policies in place that could impact access to general healthcare (e.g. doctors, hospitals, pharmacy) across all disability groups. I also want to understand disability inclusion in other important aspects of the health system and co-develop recommendations with the disability community in Chile. This information will be useful to plan and improve healthcare services that are available to and inclusive of people with disabilities.

Why have I been asked to take part? You have been invited because you have been identified by the research team as a leader of a disabled people’s organization in Chile and have lived expertise of disability.

What is involved in the study? I would like to speak to you (in person – modify as appropriate) for between 60-90 minutes. I will ask you some questions about your involvement, if any, in health policy making and your opinion on current health policies, health information, and health worker attitudes. With your permission, I will record the conversation so that I can accurately recall your responses. You can end this interview at any time or refuse to answer any questions.

Which groups are organising the study? This study is being organised by London School of Hygiene and Tropical Medicine, a university based in London, and supported by University of Chile. Both organizations have responsibility for the project including the analysis of your data and will act as the data controller for the study. This means that I am responsible for looking after your information and using it properly. Funding for the study comes from the National Research and Development Agency of Chile.

What are the benefits? The information collected in this interview can help to plan and improve health policies in Chile so that they are inclusive of people with disabilities and positively impact their access to healthcare services.

What are the risks? There are no direct risks of physical or psychological harm associated with this interview. However, you may feel distressed when discussing about disability-inclusive health policy and its implementation. In this situation, Professor Laura Rueda (lrueda@uchile.cl/ +56229786183), an expert in mental health and bioethics from the Faculty of Medicine, University of Chile, will be available to provide initial guidance and support free of charge. The questions will take up a bit of your time – about 60-90 minutes. You will not receive a financial or other type of reimbursement for taking part in the study. However, I will cover for any adaptations required in order to facilitate your participation (e.g. sign language interpretation).

What will happen to information I share? I will keep all information private, safe and secure. Only the study staff will be allowed to look at information about you. Audio recordings will be deleted once the transcription of the interview has been verified.

What will happen to the results of this study? The study results will be published in a journal article, reports and in other ways to share findings of this research so that policymakers and practitioners can learn from them. I will also share the learning with policymakers and practitioners directly. I will not use your name in any of this reporting. However, I may use your organisation/department, unless you request otherwise. If you would like any or all of your answers to be kept fully anonymous (no organisation/department), please let me know.

Who has reviewed this study? All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by The London School of Hygiene & Tropical Medicine Research Ethics Committee (<reference number>) and The Faculty of Medicine of University of Chile Research Ethics Committee (<reference number>).

Do I have to take part? No. It is up to you to decide whether or not to take part. If you don't want to take part, that's ok. Your decision to participate or not participate will have no effect on any health and social services you receive. I will not share your decision with anyone outside the research team. We will discuss the study together and I will give you/read out to you (modify as appropriate), a copy of this information sheet. If you agree to take part, I will then ask you to agree the terms of a consent form, signing or taking oral consent which will be recorded.

Can I change my mind about taking part? Yes. If you agree to take part, you are still free to withdraw from the study at any time and without giving a reason. You just need to tell the researcher that you don't want to be in the study anymore. This will make no difference to any health or social services you receive. If you withdraw from the study, I will destroy all audio recorded interviews, and not use any data collected.

Closing remarks Thank you for taking time to read to this information sheet (modify as appropriate). If you think you will take part in the study, please read and sign the consent form (modify as appropriate).

If you have any further questions that are not answered here or require any further information or explanation, please contact:

Research Lead: Danae Rodríguez Gatta [danae.rodriguez@lshtm.ac.uk]

D.6 | Participant information sheet: Participatory workshop

Title of Project: “Disability and human rights: Policy Analysis”

Introduction I would like to invite you to take part in a workshop. Before you decide, you need to understand why this activity is being done and what it would involve. I will go through this information sheet with you and answer any questions you may have. Please ask me if there is anything that is not clear or if you would like more information. Please feel free to talk to others about the workshop if you wish. Take time to decide whether or not to take part.

What is the purpose of the workshop? The purpose is to discuss the findings of the study about the inclusion of people with disabilities in Chilean health policy and across the healthcare system. Then, to develop altogether recommendations and key priority areas for improving healthcare services that are available to and inclusive of people with disabilities.

Why have I been asked to take part? You have been invited because you have been identified by the research team as having an expertise in health policy and/or disability (e.g. policy formulation, implementation); as a leader of an organization of people with disabilities and/or have lived expertise of disability; and/or your role is key in the wider inclusion of people with disabilities in the health system.

What is involved in the activity? You would be invited to take part in an in-person workshop that will last half a day. With your permission, I will record the workshop so I can accurately recall your responses.

Which groups are organising the workshop? The workshop is being organised by London School of Hygiene and Tropical Medicine, a university based in London, and the Department of Disability and Rehabilitation of the Ministry of Health of Chile. Funding for the workshop comes from the Ministry of Health of Chile.

What are the benefits? The information collected in this workshop can help to plan and improve health policies in Chile so that they are inclusive of people with disabilities and positively impact their access to healthcare services. You will be provided with compensation for your travel costs and any adaptations required in order to facilitate your participation (e.g. sign language interpretation) will be covered.

What are the risks? There are no risks of physical or psychological harm associated with this workshop. The questions will take up a bit of your time – approximately half a day.

What will happen to information I share? Recommendations and key priority areas for improving healthcare services that are available to and inclusive of people with disabilities will be co-developed based on your feedback. These recommendations will be shared with key stakeholders in Chile and also internationally. The recording of the workshop will be only shared with the research team and will be kept secure, safe.

Confidentiality I would like to list your name and organization in the recommendations developed. However, if you would prefer not to be named in that list, please let me know and I will exclude your name and organization from the dissemination materials.

Do I have to take part? No. It is up to you to decide whether or not to take part. If you don't want to take part, that's ok. I will not share your decision with anyone outside the research team. We will discuss the workshop together and I will give you a copy of this information sheet. If you agree to take part, I will then ask you to agree and sign the terms of a consent form.

Closing remarks Thank you for taking time to read this information sheet. If you think you will take part in the workshop, please read and sign the consent form.

If you have any further questions that are not answered here or require any further information or explanation, please contact:

Research Lead: Danae Rodríguez Gatta [danae.rodriguez@lshtm.ac.uk]

LONDON
SCHOOL of
HYGIENE
&TROPICAL
MEDICINE

FACULTAD DE MEDICINA
UNIVERSIDAD DE CHILE

D.7 | Consent form for participant

Title of Project: “Disability and human rights: Policy analysis”

☐ I confirm that I have read the information sheet for the “Disability and human rights: Policy Analysis” study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected [delete as applicable].

☐ I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.

☐ I agree to take part in the interview for the above study.

☐ I agree to take part in the workshop for the above study.

☐ I agree to this interview being recorded.

Printed name of participant	Signature of participant [state full name orally for remote interviews]	Date [state orally for remote interviews]

Printed name of person obtaining consent	Signature of person obtaining consent [state full name orally for remote interviews]	Date [state orally for remote interviews]

D.8 | Información para participantes

Proyecto de Investigación: "Salud inclusiva para personas con discapacidad en Chile"

Invitación a participar: Le invito a participar como informante en una investigación. Antes de que decida, tiene que entender por qué se hace la investigación y en qué consiste. Revisará esta hoja informativa y responderé a cualquier pregunta que pueda tener. Por favor, pregunte si hay algo que no está claro o si desea más información. Si lo desea, puede hablar con otras personas sobre el estudio. Tómese su tiempo para decidir si quiere participar o no.

¿Cuál es el objetivo del estudio? Esta investigación busca:

1. Evaluar la inclusión de las personas con discapacidad en los documentos de política de salud de Chile y explorar las percepciones de los principales actores nacionales sobre el contexto, los actores y los procesos de las políticas sanitarias relacionadas con discapacidad.
2. Evaluar la inclusión de personas con discapacidad en el sistema de salud chileno y entregar recomendaciones basadas en la evidencia y desarrolladas en conjunto con organizaciones de personas con discapacidad.

¿Por qué se me ha pedido que participe? Se le ha invitado porque el equipo de investigación ha considerado que tiene experiencia en política de salud y/o discapacidad (por ejemplo, en la formulación de políticas o su implementación).

¿Qué grupos organizan el estudio? Este estudio está organizado por London School of Hygiene and Tropical Medicine (LSHTM), una universidad con sede en Londres, Reino Unido, y cuenta con el apoyo de la Facultad de Medicina, Universidad de Chile. Ambas organizaciones son responsables del proyecto, incluido el análisis de sus datos, y actuarán como responsables del estudio. También co-lideran el proyecto el Departamento de Discapacidad y Rehabilitación del Ministerio de Salud y organizaciones de personas con discapacidad. La financiación del estudio procede de la Agencia Nacional de Investigación y Desarrollo de Chile y de LSHTM.

Nombre del Investigador principal: Danae Rodríguez Gatta,

Institución: International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine

Correo electrónico: danae.rodriguez@lshtm.ac.uk

Nombre del Co-investigador: Pamela Gutiérrez Monclus, Institución: Facultad de Medicina, Universidad de Chile

Teléfono: 22978 6545 (oficina) – 229786183 (secretaría)

¿En qué consiste la participación? Si usted acepta participar, se le invitará a una entrevista individual. En esta actividad le haré preguntas sobre la inclusión de las personas con discapacidad en el sistema de salud de Chile, según su área de experiencia. La duración estimada de esta actividad será de 45 a 60 minutos. Esta entrevista será grabada, con su permiso, y se realizará de forma presencial, por ejemplo, en su lugar de trabajo, en la Facultad de Medicina de la Universidad de Chile o en un lugar público, según sus preferencias. Se le podría invitar a más de una entrevista y de forma excepcional, la entrevista podrá ser remota (por ejemplo, debido a viajes, emergencia sanitaria, etc.).

¿Cuáles son los riesgos? La existencia de riesgos es inherente a todas las investigaciones en que participen seres humanos. Sin embargo, las conversaciones con un profesional tienen un riesgo de daño físico o psicológico mínimo. Si usted considera que le afectan de alguna manera estas actividades, deberá hablar con la Profesora Terapeuta Ocupacional, especialista en salud mental y ética, Laura Rueda (lrueda@uchile.cl; número secretaría +56229786183), quien le ofrecerá una orientación inicial y red de apoyo. El apoyo que reciba no tendrá costo para usted.

¿Cuáles son los costos? La participación en las actividades de la investigación no tiene costos para usted. Las preguntas le llevarán entre 45 a 60 minutos de su tiempo. No recibirá ningún reembolso económico o de otro tipo por participar en el estudio.

¿Cuáles son los beneficios? La información recopilada en esta entrevista podrá ayudar a mejorar el conocimiento y la forma en que se incluye a las personas con discapacidad en las políticas y sistema de salud de Chile, para que tengan un impacto positivo en su acceso a atención de salud.

¿Qué pasará con la información que comparta? Toda la información sobre su participación en esta investigación será guardada en forma de estricta confidencialidad. Sólo los investigadores del estudio podrán ver la información sobre usted. Ninguna publicación de los resultados incluirá su nombre o cargo. Sin embargo, se utilizará su organización o departamento, a menos que usted solicite lo contrario. Si desea que alguna o todas sus respuestas sean totalmente anónimas (sin organización o departamento), hágamelo saber. Mantendré toda la información privada, segura y protegida. Se reemplazará el nombre de las personas por un número y este solo será conocido por los investigadores. Toda la información de la investigación será guardada en un estante con llave en la oficina del investigador principal. Los documentos digitales se guardarán en un servidor de la universidad, con encriptación de datos y clave secreta. Las grabaciones de audio se eliminarán una vez que se haya verificado la transcripción de la entrevista.

¿Qué pasará con los resultados de este estudio? Los resultados del estudio se publicarán en un artículo de revista científica, en informes y a través de divulgación (anonimizada) en redes sociales, de modo que los responsables políticos y los profesionales puedan aprender de ellos.

¿Quién ha revisado este estudio? Todas las investigaciones con participantes humanos son examinadas por un grupo independiente de personas, llamado Comité de Ética de la Investigación, para proteger sus intereses. Este estudio ha sido revisado y aprobado por el Comité de Ética de la Investigación de

London School of Hygiene and Tropical Medicine (Nº28068) y el Comité de Ética de la Investigación en Seres Humanos de la Facultad de Medicina de la Universidad de Chile (Nº152-2022).

¿Estoy obligado a participar? No. Usted decide si quiere participar o no. Su participación en esta investigación es totalmente voluntaria. Si usted decide no participar en esta investigación, esto no tendrá consecuencias negativas para usted. No compartiré su decisión con nadie ajeno al equipo de investigación.

¿Puedo cambiar de opinión sobre mi participación? Sí. Si acepta participar, es libre de retirarse del estudio en cualquier momento y sin necesidad de dar una razón. Sólo tiene que decir al investigador que no quiere seguir participando en el estudio. Si se retira del estudio, destruiré todas las entrevistas grabadas y no utilizaré los datos recogidos.

Derechos del participante: Usted recibirá una copia íntegra y escrita de este documento firmado. Si necesita más información, puede comunicarse con la investigadora principal. En caso de duda sobre sus derechos debe comunicarse con el presidente del Comité de Ética de Investigación en Seres Humanos, Dr. Manuel Oyarzún Gómez (Teléfono: 22978 9536, Email: ceish.med@uchile.cl), cuya oficina se encuentra ubicada a un costado de la Biblioteca Central de la Facultad de Medicina, Universidad de Chile en Av. Independencia 1027, Comuna de Independencia.

Observaciones finales Gracias por tomarse el tiempo de leer esta hoja informativa. Si cree que va a participar en el estudio, lea y firme el siguiente formulario de consentimiento.

D.9 | Formulario de consentimiento

Proyecto de Investigación: "Salud inclusiva para personas con discapacidad en Chile"

☐ Confirmo que he recibido y comprendido la información de este documento y que he tenido la oportunidad de hacer preguntas y aclarar todas mis dudas.

☐ Entiendo que mi participación es voluntaria y que soy libre de retirarme en cualquier momento sin dar ninguna razón.

☐ Entiendo que la información recopilada se utilizará para apoyar otras investigaciones en el futuro y puede ser compartida de forma anónima con otros investigadores.

☐ Otorgo mi consentimiento para participar como informante en el proyecto "Salud inclusiva para personas con discapacidad en Chile".

☐ Acepto que se grabe esta entrevista.

Nombre del participante / Rut	Firma	Fecha

Danae Rodríguez Gatta – Investigadora Principal	Firma	Fecha

D.10 | Información para participantes: Workshop

Proyecto de Investigación: "Salud inclusiva para personas con discapacidad en Chile"

Invitación a participar: Le invito a participar en un workshop. Antes de que decida, tiene que entender por qué se hace esta actividad y en qué consiste. Revise esta hoja informativa y responderé a cualquier pregunta que pueda tener. Por favor, pregunte si hay algo que no está claro o si desea más información. Si lo desea, puede hablar con otras personas sobre el workshop. Tómese su tiempo para decidir si quiere participar o no.

¿Cuál es el objetivo del workshop? Este workshop busca (1) discutir los principales resultados de la investigación en base al primer borrador del reporte, (2) dialogar recomendaciones en conjunto y definir prioridades de acción para la mejora del sistema de salud y (3) conocer las trayectorias de salud y ajustes razonables requeridos por organizaciones de personas con discapacidad.

¿Por qué se me ha pedido que participe? Se le ha invitado porque el equipo de investigación ha considerado que tiene experiencia en política de salud y discapacidad (por ejemplo, en la formulación de políticas o su implementación), liderazgo en una organización de personas con discapacidad, expertiz por experiencia y/o un rol clave en la inclusión de personas con discapacidad en el sistema de salud.

¿Qué grupos organizan el workshop? Este workshop está organizado por London School of Hygiene and Tropical Medicine (LSHTM), una universidad con sede en Londres, Reino Unido, y cuenta con el soporte de la Facultad de Medicina, Universidad de Chile. El apoyo para la implementación del workshop procede del Departamento de Discapacidad y Rehabilitación del Ministerio de Salud, mediante la disposición de profesionales, instalaciones, materiales y coffee break.

¿En qué consiste la participación? Se le invita a participar de un workshop presencial que durará aproximadamente media mañana. Durante la actividad, se espera que usted revise los resultados de la investigación y las recomendaciones iniciales, y luego dialogue y acuerde recomendaciones finales y prioridades de acción junto con otros participantes del workshop. Con su permiso, el audio del workshop será grabado, para luego recordar con precisión sus respuestas.

¿Cuáles son los riesgos? La existencia de riesgos es inherente a todas las investigaciones en que participen seres humanos. Sin embargo, la participación en un workshop tiene un riesgo de daño físico o psicológico mínimo. Si usted considera que le afecta de alguna manera esta actividad, deberá hablar con la Profesora Terapeuta Ocupacional, especialista en salud mental y ética, Laura Rueda (lrueda@uchile.cl; número secretaría +56229786183), quien le ofrecerá una orientación inicial y red de apoyo. El apoyo que reciba no tendrá costo para usted.

¿Cuáles son los costos? La participación en el workshop le tomará aproximadamente entre 3 a 4 horas de su tiempo. No recibirá ningún reembolso económico o de otro tipo por participar en esta actividad.

¿Cuáles son los beneficios? La información recopilada en este workshop podrá ayudar a planificar y mejorar las políticas sanitarias y sistema de salud de Chile, para que incluyan a las personas con discapacidad e incidan positivamente en su acceso a servicios de salud. Además, contribuirá a la construcción de conocimiento y evidencia en este ámbito en nuestro país. Para facilitar su participación, se dispondrá de los apoyos necesarios que usted requiera (por ejemplo, interpretación de lengua de señas, lenguaje fácil, etc.)

¿Qué pasará con la información que comparta? En base a su participación y comentarios, se desarrollarán de manera conjunta las recomendaciones finales y prioridades de acción. Esta información se compartirá con actores claves en Chile y también a nivel internacional. Se incluirá su nombre y el de su organización en la información elaborada. No obstante, si prefiere no figurar en esa lista, hágamelo saber y excluiré su nombre y organización de los materiales de difusión. La grabación del workshop se mantendrá segura y protegida, y solo se compartirá con el equipo de investigación. Las grabaciones de audio se eliminarán una vez que se haya verificado la transcripción del workshop.

¿Qué pasará con los resultados de este workshop? Los resultados del workshop se publicarán en un reporte, un artículo científico revisado por pares y a través de divulgación en redes sociales, de modo que los responsables políticos y la sociedad civil puedan aprender de ellos.

¿Quién ha revisado este estudio? Todas las investigaciones con participantes humanos son examinadas por un grupo independiente de personas, llamado Comité de Ética de la Investigación, para proteger sus intereses. Este estudio ha sido revisado y aprobado por el Comité de Ética de la Investigación de London School of Hygiene and Tropical Medicine (Nº28068) y el Comité de Ética de la Investigación en Seres Humanos de la Facultad de Medicina de la Universidad de Chile (Nº152-2022).

¿Estoy obligado a participar? No. Usted decide si quiere participar o no. Su participación en este workshop es totalmente voluntaria. Si usted decide no participar en ese workshop, esto no tendrá consecuencias negativas para usted.

¿Puedo cambiar de opinión sobre mi participación? Sí. Si acepta participar, es libre de retirarse del workshop en cualquier momento y sin necesidad de dar una razón. Sólo tiene que decir al investigador que no quiere seguir participando en el workshop.

Derechos del participante: Usted recibirá una copia íntegra de este documento firmado. Si necesita más información, puede comunicarse con la investigadora principal. En caso de duda sobre sus derechos debe comunicarse con el presidente del Comité de Ética de Investigación en Seres Humanos, Dr. Manuel Oyarzún Gómez (Teléfono: 22978 9536, Email: ceish.med@uchile.cl), cuya oficina se encuentra ubicada a un costado de la Biblioteca Central de la Facultad de Medicina, Universidad de Chile en Av. Independencia 1027, Comuna de Independencia.

Observaciones finales Gracias por tomarse el tiempo de leer esta hoja informativa. Si cree que va a participar en el workshop, lea y firme el siguiente formulario de consentimiento.

D.11 | Formulario de consentimiento

Proyecto de Investigación: “Salud inclusiva para personas con discapacidad en Chile”

☐ Confirmo que he recibido y comprendido la información de este documento y que he tenido la oportunidad de hacer preguntas y aclarar todas mis dudas.

☐ Entiendo que mi participación es voluntaria y que soy libre de retirarme en cualquier momento sin dar ninguna razón.

☐ Entiendo que la información recopilada se utilizará para apoyar otras investigaciones en el futuro y puede ser compartida de forma anónima con otros investigadores.

☐ Otorgo mi consentimiento para participar en el workshop del proyecto de investigación “Salud inclusiva para personas con discapacidad en Chile”.

☐ Acepto que se grabe este workshop.

Nombre del participante / Rut	Firma	Fecha

Danae Rodríguez Gatta – Investigadora Principal	Firma	Fecha

D.12 | INTERVIEW GUIDE FOR KEY INFORMANTS

Note 1: These will be adapted based on the background of the key informant and, ideally, the specific health policy in which the person has been involved.

Note 2: These questions should be used to guide discussion but do not have to be used in the sequence listed below. The interviewer should follow up on any additional issues that may arise and seem important in relation to the issues above.

Interview registration

Code	
Interview date and time	
Interview location	
Interviewer	
Interviewee	
Job title	
Organization	

Introduction

Good morning/afternoon/evening, it is a pleasure to meet you. Thank you very much for your time. I am [interviewer's name] from...

5. Advise once again of the issue of confidentiality and anonymity.
6. Mention again that the interview will be audio-recorded.
7. Check if they have any questions about the research.
8. Remind them that they are free to decline to answer any of the questions or stop the interview at any time.

Section 1: Key informant background

17. Please, tell me more about your role as [job title]. Probes: What activities do you do in this role?

Section 2: Disability inclusive health

[Note: the following questions are phrased specifically for each key informant. During each consultation, focus on the specific health system area in which the key informant has been directly involved. If the informant has not been directly involved, focus on the area most relevant to the informant]

CONSULTATION 1

Component: Governance – National health sector plan

Key informant: *Disability Liaison or Health Equity, National Health Strategy, Ministry of Health*

1. How was disability included in the national strategy?
2. How were these disability-related goals prioritized?
3. Which are the main actions and targets? (Probe: General healthcare, specialized services, etc.)
4. Monitoring and evaluation indicators on disability have not been published. How is it planned to be measured? Why did the last health strategy not measure the progress within disability even if it had goals related to it?
5. How do you involve Organizations of People with Disabilities (OPDs) in drafting/monitoring the national health strategy?

CONSULTATION 2

Component: Governance – National HIV plan | Effective service coverage – ARTs coverage | Health status - HIV

Key informant: *HIV, AIDS and STI Prevention and Control department, Ministry of Health*

1. Are people with disabilities considered in the plan? Yes/No
    a. Why? Why not? How could this be improved?
2. Which are the main actions and targets? (Probe: General healthcare, specialized services, etc.)
3. What evidence, statistics exists on HIV and disability in Chile? (Probe: disease prevalence, ART coverage, etc.)
4. How will you plan to monitor and evaluate indicators on HIV amongst people with disabilities?

CONSULTATION 3

Component: Leadership – MoH leadership & National health sector coordination & Global Fund CCM | Rehabilitation services and AT - Coordination

Key informant: *National Disability Agency* **or** *Disability department, Ministry of Health*

1. Who is responsible for disability inclusion and rehabilitation?
2. Is there representation of persons with disabilities (individual, or OPDs) in highest-level health sector coordination structure? Yes/no? Why/ Why not?
3. Are people with disabilities represented in the Global Fund CCM? Yes/no? Why/ Why not?
4. Is there a coordination mechanism cross-Ministry for rehabilitation services and assistive technology (AT)? (E.g., Between MoH and Ministry of Social Affairs?)

CONSULTATION 4

Component: Leadership – Pandemic preparedness structures

Key informant: *National Pandemic Response-taskforce* ***or*** *National COVID-19 Epidemic Disability taskforce*

1. Were people with disabilities represented in the taskforce?
    a. If yes, who? In which capacity?
    b. If not, why? How could participation improve?

CONSULTATION 5

Component: Health financing – Assistive Technology/Rehabilitation budget & Disability inclusion budget

Key informant: *Ministry of Finance;* ***or*** *Disability department, MoH;* ***or*** *Association of Municipalities;* ***or*** *National disability agency*

1. What is the funding for AT/rehabilitation in MoH (or devolved levels) budget?
2. Which of the annual MoH budget or absolute amount contributed from other Ministries as % MoH budget?
3. What is the Budget (MoH or devolved levels) for role/department in MoH working on disability inclusion? Probes:
    a. Nationwide? Amount in USD?
    b. Decentralized level? Amount in USD?

CONSULTATION 6

Component: Health financing – Reimbursements | Affordability – Disability allowance

Key informant: *Ministry of Finance;* ***or*** *National health insurer;* ***or*** *National private insurer;* ***or*** *GES programme, MoH;* ***or*** *National Disability Agency;* ***or*** *Association of municipalities;* ***or*** *Disability department, MoH;* ***or*** *Unit of disability and social benefits, MoH*

1. What type of disability-related health services are covered through [main health insurance plans in Chile]? Probes:
    a. If yes, for which conditions? Which types of rehabilitation services, AT etc.? What services are not covered?
2. What are typical contributions people enrolled in [main health insurance plans in Chile] pay (e.g., insurance premiums, at point of use)?
    a. Are there subsidies/exemptions for people with disabilities?
    b. If no adjustments exist. Why? How could it be improved?
3. Is there a disability allowance available to cover healthcare fees not covered by existing insurance or tax-based systems, e.g., travel to clinics, assistive technologies?
    a. If yes, which ones? Which % of population is covered? (Amount per person per time unit in USD)
    b. If not, why not? How could it be improved?
4. Is there a transport subsidy for people with disabilities? If yes, how does it work?

5. Are people with disabilities fully covered for free healthcare through social health insurance, tax-based system, provision as part of disability allowance or any other stipulations? Yes/no? Why/ why not?
6. Do any co-pays exist for services in either health insurance or taxation-based systems are waved for persons with disabilities? Yes/no? Why/ why not?

CONSULTATION 7

Component: Data and Evidence – Routine health data

Key informant: *Department of statistics, Ministry of Health;* ***or*** *Disability identification cards, National Disability Agency;* ***or*** *Department of Disability, Ministry of Health*

1. How is disability monitored through routine health data?
   a. If yes, which data is available? How is it collected?
   b. If not, how could data be disaggregated by disability? What opportunities exist to expand data collection on disability?

CONSULTATION 8

Component: Leadership – National health sector coordination & Global Fund CCM | Autonomy and Awareness – OPD advocacy & Accessibility of health information | Human resources – Satisfaction & Representation in the health workforce

Key informant: *National Organization of People with Disabilities (OPD)*

1. Are you or other OPDs participating in the highest-level health sector coordination structure? Yes /No? Why? Why not? How could it be improved?
2. Are you or other OPDs participating in the Global Fund CCM? Yes /No? Why? Why not? How could it be improved?
3. How relevant is the advocacy for the right to health for the disability community? Probe: collaboration with government and NGO delivery partners?
4. Do you think lack of autonomy and awareness about health access is an issue for the disability community? Yes /No? Why? Why not?
5. How accessible is health information? For instance, simple language, sign interpretation of video/tv messages, braille, information for caregivers?
6. What is the attitude of health workers towards people with disabilities? What is the overall level of satisfaction of the disability community?

CONSULTATION 9

Component: Human Resources – Training of medical doctors, nurses, and community health workers & Representation in the health workforce | Rehabilitation services and AT – trained workforce available

Key informant: *National society of medicine;* ***or*** *National society of nurses;* ***or*** *Dean of medicine faculty, University of Chile;* ***or*** *Primary care services, MoH;* ***or*** *Department of training, human resources development and continuing education, MoH*

1. Is disability training part of the national curricula for **medical schools/colleges**?
    a. If yes, what is the number of hours training? Curriculum? Type of training?
    b. If not, why not? How could it be improved?
2. Is disability training part of the national curricula for **nurses/nursing schools/colleges**?
    a. If yes, what is the number of hours training? Curriculum? Type of training?
    b. If not, why not? How could it be improved?
3. Is disability training part of the national curricula for **community health workers**?
    a. If yes, what is the number of hours training? Curriculum? Type of training?
    b. If not, why not? How could it be improved?
4. Are people with disabilities represented in the health workforce? If yes, what % of medical doctors have disability?
5. What trained workforce is available to provide rehabilitation services and AT? For example, number of physiotherapists/10,000 population?

CONSULTATION 10

Component: Health facilities – National accessibility standards and accessibility of facilities

Key informant: *Disability department, MoH;* ***or*** *National Disability Agency;* ***or*** *Ministry of Housing and Urban planning*

1. Are there any national accessibility standards? If yes, which ones? How are they implemented and monitored? Audit of health facilities? For instance, in the last 10 years?

Closing

I'm aware of the time and now we are approaching the end of this interview. I will now stop the recording. It has been a pleasure to meet you. Thank you so much for your time and participation in this study!

References

1. World Health Organization. Global report on health equity for persons with disabilities [Internet]. Geneva; 2022 [cited 2023 Jun 13]. Available from: https://www.who.int/publications/i/item/9789240063600
2. Kuper H, Heydt P. The Missing Billion: Access to health services for 1 billion people with disabilities [Internet]. London; 2019 [cited 2023 Jun 29]. Available from: https://www.lshtm.ac.uk/research/centres/international-centre-evidence-disability/missing-billion
3. Missing Billion Initiative, Clinton Health Access Initiative. Reimagining health systems that expect, accept and connect 1 billion people with disabilities [Internet]. 2022 [cited 2023 Jun 29]. Available from: https://www.themissingbillion.org/the-reports
4. Office of the High Commissioner for Human Rights. OHCHR Training Package on the Convention on the Rights of Persons with Disabilities [Internet]. 2024 [cited 2024 Aug 14]. Available from: https://www.ohchr.org/en/disabilities/ohchr-training-package-convention-rights-persons-disabilities
5. World Health Organization. International Classification of Diseases Eleventh Revision (ICD-11) [Internet]. Geneva; 2022 [cited 2024 Aug 19]. Available from: https://icd.who.int/browse11/l-m/en
6. Lundberg DJ, Chen JA. Structural ableism in public health and healthcare: a definition and conceptual framework. The Lancet Regional Health - Americas. 2024 Feb;30:100650.
7. World Health Organization. International Classification of Functioning, Disability and Health (ICF) [Internet]. 2001 [cited 2024 Aug 14]. Available from: https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health
8. United Nations. Convention on the Rights of Persons with Disabilities—Articles. [Internet]. 2006 [cited 2023 Jul 19]. Available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html
9. World Health Organization, World Bank. World report on disability 2011 [Internet]. 2011 [cited 2023 Jul 19]. Available from: https://apps.who.int/iris/handle/10665/44575

10. GBD 2019 Diseases and Injuries Collaborators. Global burden of 369 diseases and injuries in 204 countries and territories, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. Lancet. 2020 Oct 17;396(10258):1204–22.

11. United Nations. World Social Report 2023: Leaving No One Behind In An Ageing World [Internet]. 2023 [cited 2024 Aug 21]. Available from: https://desapublications.un.org/publications/world-social-report-2023-leaving-no-one-behind-ageing-world

12. Patwardhan V, Gil GF, Arrieta A, Cagney J, DeGraw E, Herbert ME, et al. Differences across the lifespan between females and males in the top 20 causes of disease burden globally: a systematic analysis of the Global Burden of Disease Study 2021. Lancet Public Health. 2024 May;9(5):e282–94.

13. Cieza A, Causey K, Kamenov K, Hanson SW, Chatterji S, Vos T. Global estimates of the need for rehabilitation based on the Global Burden of Disease study 2019: a systematic analysis for the Global Burden of Disease Study 2019. The Lancet. 2020 Dec;396(10267):2006–17.

14. UN Women. Progress on the Sustainable Development Goals, the gender snapshot 2023 [Internet]. 2023 [cited 2024 Aug 21]. Available from: https://www.unwomen.org/en/digital-library/publications/2023/09/progress-on-the-sustainable-development-goals-the-gender-snapshot-2023

15. World Health Organization. World mental health report: transforming mental health for all [Internet]. Geneva; 2022 [cited 2024 Aug 20]. Available from: https://www.who.int/publications/i/item/9789240049338

16. Steinmetz JD, Seeher KM, Schiess N, Nichols E, Cao B, Servili C, et al. Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021. Lancet Neurol. 2024 Apr;23(4):344–81.

17. World Health Organization. World report on hearing [Internet]. Geneva; 2021 [cited 2024 Aug 20]. Available from: https://www.who.int/publications/i/item/9789240020481

18. Haile LM, Kamenov K, Briant PS, Orji AU, Steinmetz JD, Abdoli A, et al. Hearing loss prevalence and years lived with disability, 1990–2019: findings from the Global Burden of Disease Study 2019. The Lancet. 2021 Mar;397(10278):996–1009.

19. Burton MJ, Ramke J, Marques AP, Bourne RRA, Congdon N, Jones I, et al. The Lancet Global Health Commission on Global Eye Health: vision beyond 2020. Lancet Glob Health. 2021 Apr;9(4):e489–551.

20. World Health Organization and the United Nations Children’s Fund (UNICEF). Global report on children with developmental disabilities: from the margins to the mainstream [Internet]. Geneva; 2023 [cited 2024 Aug 20]. Available from: https://www.who.int/publications/i/item/9789240080232

21. Moodley J, Ross E. Inequities in health outcomes and access to health care in South Africa: a comparison between persons with and without disabilities. Disabil Soc. 2015 Apr 21;30(4):630–44.

22. Ko KD, Lee KY, Cho B, Park MS, Son KY, Ha JH, et al. Disparities in Health-Risk Behaviors, Preventive Health Care Utilizations, and Chronic Health Conditions for People With Disabilities: The Korean National Health and Nutrition Examination Survey. Arch Phys Med Rehabil. 2011 Aug;92(8):1230–7.

23. Reichard A, Stolzle H. Diabetes Among Adults With Cognitive Limitations Compared to Individuals With No Cognitive Disabilities. Intellect Dev Disabil. 2011 Jun 1;49(3):141–54.

24. Schwartz N, Buliung R, Wilson K. Disability and food access and insecurity: A scoping review of the literature. Health Place. 2019 May;57:107–21.

25. Solar O, Irwin A. A conceptual framework for action on the social determinants of health. Social Determinants of Health Discussion Paper 2 (Policy and Practice) [Internet]. Geneva; 2019 [cited 2024 Mar 28]. Available from: https://www.who.int/publications/i/item/9789241500852

26. Banks LM, Kuper H, Polack S. Poverty and disability in low- and middle-income countries: A systematic review. 2017 [cited 2023 Jun 15]; Available from: https://doi.org/10.1371/journal.pone.0189996

27. United Nations Children’s Fund. Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities [Internet]. New York; 2021 [cited 2024 Aug 14]. Available from: https://data.unicef.org/resources/children-with-disabilities-report-2021/

28. OECD. Disability, Work and Inclusion: Mainstreaming in All Policies and Practices. Paris; 2022.

29. García Mora ME, Schwartz Orellana S, Freire G. Disability Inclusion in Latin America and the Caribbean: A Path to Sustainable Development [Internet]. Washington, DC; 2021 [cited 2023 Jul 19]. Available from: https://documents1.worldbank.org/curated/en/099015112012126833/pdf/P17538305622600c00bf3f09659df1f2f79.pdf

30. World Health Organization. Universal health coverage [Internet]. 2024 [cited 2024 Aug 23]. Available from: https://www.who.int/health-topics/universal-health-coverage#tab=tab_1

31. Papanicolas I, Rajan D, Karanikolos M, Soucat A, Figueras J, editors. Health system performance assessment: a framework for policy analysis [Internet]. Geneva; 2022 [cited 2024 Aug 22]. Available from: https://www.who.int/publications/i/item/9789240042476

32. European Observatory. Health Systems in Transition: template for authors 2019 [Internet]. Copenhagen; 2019 [cited 2024 Aug 23]. Available from: https://iris.who.int/handle/10665/333262

33. United Nations. Political declaration of the high-level meeting on universal health coverage [Internet]. Oct 16, 2023. Available from: https://documents.un.org/doc/undoc/gen/n23/306/84/pdf/n2330684.pdf

34. World Health Organization and International Bank for Reconstruction and Development / The World Bank. Tracking universal health coverage: 2023 global monitoring report [Internet]. Geneva; 2023 [cited 2024 Aug 23]. Available from: https://www.who.int/publications/i/item/9789240080379

35. Bright T, Kuper H. A systematic review of access to general healthcare services for people with disabilities in low and middle income countries. Int J Environ Res Public Health. 2018 Sep 1;15(9).

36. Bright T, Wallace S, Kuper H. A systematic review of access to rehabilitation for people with disabilities in low-and middle-income countries. Int J Environ Res Public Health. 2018 Oct 2;15(10).

37. UHC2030. UHC2030 Social Media Toolkit [Internet]. 2024 [cited 2024 Sep 8]. Available from: https://www.uhc2030.org/what-we-do/voices/advocacy/uhc2030-social-media-toolkit/

38. Levesque JF, Harris MF, Russell G. Patient-centred access to health care: conceptualising access at the interface of health systems and populations. Int J Equity Health. 2013;12(1):18.

39. Doherty AJ, Atherton H, Boland P, Hastings R, Hives L, Hood K, et al. Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: an integrative review. BJGP Open. 2020 Aug;4(3):bjgpopen20X101030.

40. Nguyen TV, King J, Edwards N, Pham CT, Dunne M. Maternal Healthcare Experiences of and Challenges for Women with Physical Disabilities in Low and Middle-Income Countries: A Review of Qualitative Evidence. Sex Disabil. 2019 Jun 1;37(2):175–201.

41. Matin BK, Williamson HJ, Karyani AK, Rezaei S, Soofi M, Soltani S. Barriers in access to healthcare for women with disabilities: a systematic review in qualitative studies. BMC Womens Health. 2021 Dec 30;21(1):44.

42. Banks LM, Hameed S, Abu Alghaib O, Nyariki E, Olenja J, Kulsum U, et al. “It Is Too Much for Us”: Direct and Indirect Costs of Disability Amongst Working-Aged People with Disabilities in Dhaka, Bangladesh and Nairobi, Kenya. J Human Dev Capabil. 2022 Apr 3;23(2):228–51.

43. Reichenberger V, Corona AP, Ramos VD, Shakespeare T, Hameed S, Penn-Kekana L, et al. Access to primary healthcare services for adults with disabilities in Latin America and the Caribbean: a review and meta-synthesis of qualitative studies. Disabil Rehabil. 2024 Mar 3;1–10.

44. Gréaux M, Moro MF, Kamenov K, Russell AM, Barrett D, Cieza A. Health equity for persons with disabilities: a global scoping review on barriers and interventions in healthcare services. Int J Equity Health. 2023 Nov 13;22(1):236.

45. Ganle JK, Baatiema L, Quansah R, Danso-Appiah A. Barriers facing persons with disability in accessing sexual and reproductive health services in sub-Saharan Africa: A systematic review. PLoS One. 2020 Oct 12;15(10):e0238585.

46. Hashemi G, Wickenden M, Bright T, Kuper H. Barriers to accessing primary healthcare services for people with disabilities in low and middle-income countries, a Meta-synthesis of qualitative studies. Disabil Rehabil. 2020;44(8):1207–20.

47. Kuper H, Rotenberg S, Azizatunnisa’ L, Banks LM, Smythe T. The association between disability and mortality: a mixed-methods study. Lancet Public Health. 2024 May;9(5):e306–15.

48. Purohit BM, Singh A. Oral health status of 12-year-old children with disabilities and controls in Southern India. WHO South East Asia J Public Health. 2012;1(3):330–8.

49. Lee JY, Lim KC, Kim SY, Paik HR, Kim YJ, Jin BH. Oral health status of the disabled compared with that of the non-disabled in Korea: A propensity score matching analysis. PLoS One. 2019;14(1):e0208246.

50. Anders PL, Davis EL. Oral health of patients with intellectual disabilities: a systematic review. Spec Care Dentist. 2010;30(3):110–7.

51. World Health Organization. Health equity for persons with disabilities: a guide for action [Internet]. 2024 Jan [cited 2024 Jul 29]. Available from: https://cdn.who.int/media/docs/default-source/ncds/sdr/disability/info-sheet-disability-guide-for-action.pdf?sfvrsn=23bc00fa_4&download=true

52. United Nations. Political declaration of the high-level meeting on universal health coverage [Internet]. Oct 18, 2019. Available from: https://documents.un.org/doc/undoc/gen/n19/311/84/pdf/n1931184.pdf

53. World Health Assembly. Resolution EB148.R6 "The highest attainable standard of health for persons with disabilities" [Internet]. 2021 [cited 2023 Jun 29]. Available from: https://apps.who.int/gb/ebwha/pdf_files/WHA74/A74_R8-en.pdf

54. Kuper H, Azizatunnisa' L, Rodríguez Gatta D, Rotenberg S, Banks LM, Smythe T, et al. Building disability-inclusive health systems. Lancet Public Health. 2024 May;9(5):e316–25.

55. Instituto Nacional de Estadísticas. Proyecciones de población [Internet]. 2024 [cited 2024 Jan 9]. Available from: https://www.ine.gob.cl/estadisticas/sociales/demografia-y-vitales/proyecciones-de-poblacion

56. Biblioteca del Congreso Nacional de Chile. Chile Nuestro País [Internet]. 2024 [cited 2024 May 31]. Available from: https://www.bcn.cl/siit/nuestropais/index_html

57. World Bank. World Bank Open Data [Internet]. 2024 [cited 2024 Jul 17]. Available from: https://data.worldbank.org

58. Observatorio Social. Encuesta de Caracterización Socioeconómica Nacional [Internet]. 2022 [cited 2024 Jan 19]. Available from: https://observatorio.ministeriodesarrollosocial.gob.cl/encuesta-casen-2022

59. OECD. OECD Reviews of Public Health: Chile. Paris: OECD Publishing; 2019.

60. Sánchez M. Análisis Estadístico del Sistema Isapre con Perspectiva de Género [Internet]. Santiago; 2022 [cited 2024 Jan 18]. Available from: https://www.superdesalud.gob.cl/app/uploads/2023/11/articles-24054_recurso_1.pdf

61. Missoni E, Solimano G. Towards Universal Health Coverage: The Chilean experience [Internet]. 2010 [cited 2024 Jan 18]. Available from: https://cdn.who.int/media/docs/default-source/health-financing/technical-briefs-background-papers/4chile.pdf?sfvrsn=2a6c48a1_3&download=true

62. Aguilera I, Infante A, Ormeño H, Urriola C. Chile, implementation of the Universal Access with Explicit Guarantees (AUGE) reform [Internet]. Geneva; 2015 [cited 2024

Dec 6]. Available from: https://www.who.int/publications/i/item/WHO-HIS-HGF-CaseStudy-15.3#:~:text=In%202005%2C%20a%20reform%20known,public%20or%20private%20insurance%20status.

63. FONASA. Cuenta Pública Participativa 2022 [Internet]. Santiago; 2022 [cited 2024 Jan 10]. Available from: https://www.fonasa.cl/sites/fonasa/noticia/cuenta_publica

64. Fondo Nacional de Salud. Tramos de FONASA [Internet]. 2024 [cited 2024 Dec 6]. Available from: https://www.fonasa.cl/sites/fonasa/tramos#:~:text=Fonasa%20no%20excluye%20a%20nadie,pagan%20extra%20por%20carga%20familiar.

65. Gobierno de Chile. Copago 0 – Red Pública de Salud Gratuita [Internet]. 2022 [cited 2024 Jan 19]. Available from: https://www.gob.cl/copagocero/

66. North J. Private Health Insurance. Thomson S, Sagan A, Mossialos E, editors. Cambridge University Press; 2020.

67. Sanhueza R, Ruiz-Tagle J. Choosing Health Insurance in a Dual Health Care System: The Chilean Case. J Appl Econ. 2002 May 21;5(1):157–84.

68. Superintendencia de Salud. Resolución exenta IF/Nº46, Rechaza y acoge parcialmente los recursos de reposición en contra de la Circular IF/N°354 del 18 de junio de 2020, que imparte instrucciones respecto a la no declaración de enfermedades o condición de salud al nacer. [Internet]. Santiago; Feb 3, 2021. Available from: https://www.superdesalud.gob.cl/normativa/resolucion-exenta-if-n-46/

69. Superintendencia de Salud. Circular IF/Nº396, imparte instrucciones acerca de las coberturas y acceso para las atenciones de salud mental en ISAPRES conforma a la ley 21.331 [Internet]. Santiago; Nov 8, 2021. Available from: https://www.superdesalud.gob.cl/normativa/circular-if-n396/

70. Ministerio de Salud. Decreto 22 aprueba Garantías Explícitas en Salud del Régimen General de Garantías en Salud [Internet]. Santiago; Jul 1, 2019. Available from: https://bcn.cl/2gx51

71. Paraje G, Vásquez F. Health equity in an unequal country: the use of medical services in Chile. Int J Equity Health. 2012;11(1):81.

72. Bitran R. Explicit Health Guarantees for Chileans: The AUGE Benefits Package [Internet]. Washington DC; 2013 Jan [cited 2024 Dec 7]. Available from:

https://documents1.worldbank.org/curated/zh/308611468014981092/pdf/749580NWP0CHIL00Box374316B00PUBLIC0.pdf

73. Frenz P, Delgado I, Kaufman JS, Harper S. Achieving effective universal health coverage with equity: evidence from Chile. Health Policy Plan. 2014 Sep;29(6):717–31.

74. Alvear-Vega S, Vargas-Garrido H. Social determinants of the non-use of the explicit health guarantees plan (the GES plan). BMC Health Serv Res. 2023 Oct 19;23(1):1129.

75. World Bank. Chile - Program for Universal Primary Healthcare Coverage and Resilience Program (English) [Internet]. Washington, D.C.; 2023 Nov [cited 2024 Jul 19]. Available from: http://documents.worldbank.org/curated/en/099111523171017639/BOSIB0332f964b038094ce055086eb6a6b8

76. Observatorio Social M de DS y F. Encuesta de Discapacidad y Dependencia 2022 [Internet]. 2022 [cited 2024 Jan 19]. Available from: https://observatorio.ministeriodesarrollosocial.gob.cl/endide-2022

77. Rozas Assael F, González Olave F, Cerón Cañoles G, Guerrero Hurtado M, Vergara Henríquez R, Pinto Mora S. III Estudio Nacional de la Discapacidad 2022. Santiago; 2023.

78. Sakellariou D, Rotarou ES. Utilisation of cancer screening services by disabled women in Chile. PLoS One. 2017 May 1;12(5):e0176270.

79. Fuentes-López E, Fuente A. Access to healthcare for deaf people: a model from a middle-income country in Latin America. Rev Saude Publica. 2020 Jan 27;54:13.

80. Rotarou ES, Sakellariou D. Inequalities in access to health care for people with disabilities in Chile: the limits of universal health coverage. Crit Public Health. 2017 Oct 20;27(5):604–16.

81. Ministerio de Relaciones Exteriores. Decreto 201 promulga la Convención de las Naciones Unidas sobre los Derechos de las personas con Discapacidad y su protocolo facultativo . 2008.

82. Ministerio de Planificación. Ley Nº20.422 Establece normas sobre Igualdad de Oportunidades e Inclusión Social de Personas con Discapacidad [Internet]. Santiago: Cámara de Diputados; Feb 10, 2010. Available from: https://bcn.cl/2irkh

83. Ministerio de Salud. Decreto 2 aprueba reglamento que regula el derecho a la atención preferente dispuesto en la ley Nº20.584 [Internet]. Santiago: Cámara de Diputados; Jan 21, 2020. Available from: https://bcn.cl/2mggp

84. Ministerio de Salud. Resolución 54 exenta, Modifica Resolución Exenta No 277/2011 del Ministerio de Salud, que aprobó las normas técnico administrativas para la aplicación del arancel del régimen de prestaciones de salud del Libro II DFL Nº1 de 2005, del Ministerio de Salud en la modalidad de libre elección [Internet]. Santiago; Feb 18, 2020. Available from: https://bcn.cl/2mbk6

85. SENADIS. Diagnóstico del Plan Nacional de Calificación y Certificación [Internet]. Santiago; 2020 Mar [cited 2024 Aug 27]. Available from: https://www.senadis.gob.cl/pag/579/1901/diagnostico_del_plan_nacional_de_calificacion_y_certificacion

86. Symbolon Consultores, Subsecretaría de Redes Asistenciales. Brechas en atención de salud de personas en situación de discapacidad en atención primaria [Internet]. Santiago; 2018 Feb [cited 2024 Jan 19]. Available from: http://www.symbolon.cl/uploads/7/5/2/8/75280781/sintesis_resultados_psd_en_aps_2018.pdf

87. United Nations. CRPD/C/CHL/QPR/2-4. List of issues prior to submission of the combined second to fourth reports of Chile. [Internet]. Geneva; 2020 Oct [cited 2024 Mar 28]. Available from: https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Countries.aspx

88. Campillay-Campillay M, Calle-Carrasco A, Dubo P, Moraga-Rodríguez J, Coss-Mandiola J, Vanegas-López J, et al. Accessibility in People with Disabilities in Primary Healthcare Centers: A Dimension of the Quality of Care. Int J Environ Res Public Health. 2022 Sep 29;19(19):12439.

89. Ozawa S, Pongpirul K. 10 best resources on … mixed methods research in health systems. Health Policy Plan. 2014 May 1;29(3):323–7.

90. Gilson L. Health Policy and Systems Research: A Methodology Reader [Internet]. Geneva; 2012 [cited 2024 Dec 5]. Available from: https://iris.who.int/bitstream/handle/10665/44803/9789241503136_eng.pdf?sequence=1

91. Johnson RB, Onwuegbuzie AJ. Mixed Methods Research: A Research Paradigm Whose Time Has Come. Educational Researcher. 2004 Oct 1;33(7):14–26.

92. World Health Organization, International Bank for Reconstruction and Development / The World Bank. Tracking Universal Health Coverage: 2021 Global monitoring report [Internet]. Geneva; 2021 [cited 2024 Aug 28]. Available from: https://www.who.int/publications/i/item/9789240040618

93. Andiwijaya FR, Davey C, Bessame K, Ndong A, Kuper H. Disability and Participation in Breast and Cervical Cancer Screening: A Systematic Review and Meta-Analysis. Int J Environ Res Public Health. 2022 Aug 1;19(15).

94. Wilbur J, Scherer N, Mactaggart I, Shrestha G, Mahon T, Torondel B, et al. Are Nepal's water, sanitation and hygiene and menstrual hygiene policies and supporting documents inclusive of disability? A policy analysis. Int J Equity Health. 2021 Dec 8;20(1):157.

95. Scherer N, Mactaggart I, Huggett C, Pheng P, Rahman M ur, Biran A, et al. The Inclusion of Rights of People with Disabilities and Women and Girls in Water, Sanitation, and Hygiene Policy Documents and Programs of Bangladesh and Cambodia: Content Analysis Using EquiFrame. Int J Environ Res Public Health. 2021 May 11;18(10):5087.

96. Scherer N, Mactaggart I, Huggett C, Pheng P, Rahman M ur, Wilbur J. Are the rights of people with disabilities included in international guidance on WASH during the COVID-19 pandemic? Content analysis using EquiFrame. BMJ Open. 2021 Jul 13;11(7):e046112.

97. World Health Organization, International Bank for Reconstruction and Development / The World Bank. Tracking universal health coverage: 2017 global monitoring report [Internet]. 2017 [cited 2023 Jul 19]. Available from: https://apps.who.int/iris/bitstream/handle/10665/259817/9789241513555-eng.pdf

98. Morgon Banks L, Kuper H, Shakespeare T. Social health protection to improve access to health care for people with disabilities. Bull World Health Organ. 2021 Aug 1;99(08):543-543A.

99. Banks LM, Mearkle R, Mactaggart I, Walsham M, Kuper H, Blanchet K. Disability and social protection programmes in low- and middle-income countries: a systematic review. Oxford Development Studies. 2017 Jul 3;45(3):223–39.

100. Booth A. Chile abolishes copayments in step towards UHC. The Lancet. 2022 Sep;400(10356):877.

101. Mitra S, Palmer M, Kim H, Mont D, Groce N. Extra costs of living with a disability: A review and agenda for research. Disabil Health J. 2017 Oct;10(4):475–84.

102. Ministerio de Salud. Hacia una Política de Salud Inclusiva para Personas con Discapacidad [Internet]. 2024 [cited 2024 Jul 16]. Available from: https://rehabilitacion.minsal.cl/hacia-una-politica-de-salud-inclusiva-para-personas-con-discapacidad/

103. United Nations Children's Fund. Producing Disability- Inclusive Data: Why it matters and what it takes [Internet]. New York; 2020 [cited 2024 Sep 10]. Available from: https://www.unicef.org/thailand/reports/producing-disabilityinclusive-data-why-it-matters-and-what-it-takes

104. Kuper H, Mactaggart I, Dionicio C, Cañas R, Naber J, Polack S. Can we achieve universal health coverage without a focus on disability? Results from a national case-control study in Guatemala. PLoS One. 2018 Dec 27;13(12):e0209774.

105. Green J. Qualitative methods for health research. 4th edition. Thorogood N, editor. Los Angeles: SAGE; 2018. (Introducing qualitative methods).