

Interview of María Soledad Cisternas Reyes and Rosa Kornfeld-Matte

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Résumé de l'article

This interview was prepared, conducted, and reviewed by Marion Scheider-Yilmaz, post-doctorate researcher at PACTE, University of Grenoble Alpes and Jean-Philippe Viriot Durandal, Professor at the University of Lorraine and "Inclusive society and ageing" chairholder. The aim was to hear from María Soledad Cisternas Reyes, Special Envoy on Disability and Accessibility for the UN (2017 – June 2023), and Rosa Kornfeld-Matte, Independent Expert on the enjoyment of all human rights by older persons by the UN Human Rights Council (2014 – 2020), about their commitment to the inclusion and promotion of the rights of persons with disabilities and older persons. Throughout the discussion, the process that led to the promulgation of the Convention on the Rights of Persons with Disabilities is presented. Based on this historical example, the ongoing challenges in the process in favor of a Convention on the rights of older people are then outlined.

Interview of María Soledad Cisternas Reyes and Rosa Kornfeld-Matte

MARÍA SOLEDAD CISTERNAS REYES¹, ROSA KORNFELD-MATTE²

- 1- *Ms. Cisternas Reyes was involved in the committee that drafted the Convention on the Rights of Persons with Disabilities and served as the chairperson on the Committee on the Rights of Persons with Disabilities. In 2017 she was appointed as Special Envoy on Disability and Accessibility for the UN (2017 – June 2023).*
- 2- *Ms. Kornfeld-Matte was a Professor at the Pontifical Catholic University and served as the National Director of the Chilean National Service of Ageing. She was the first Independent Expert on the enjoyment of all human rights by older persons by the UN Human Rights Council (2014 – 2020)*

Entrevue • Interview



Abstract: This interview was prepared, conducted, and reviewed by Marion Scheider-Yilmaz, post-doctorate researcher at PACTE, University of Grenoble Alpes and Jean-Philippe Viriot Durandal, Professor at the University of Lorraine and “Inclusive society and ageing” chairholder. The aim was to hear from María Soledad Cisternas Reyes, Special Envoy on Disability and Accessibility for the UN (2017 – June 2023), and Rosa Kornfeld-Matte, Independent Expert on the enjoyment of all human rights by older persons by the UN Human Rights Council (2014 – 2020), about their commitment to the inclusion and promotion of the rights of persons with disabilities and older persons. Throughout the discussion, the process that led to the promulgation of the Convention on the Rights of Persons with Disabilities is presented. Based on this historical example, the ongoing challenges in the process in favor of a Convention on the rights of older people are then outlined.



Having both received mandates from the UN, one related to disability and the other related to aging, could you describe and analyze how the UN has organized the discourse and efforts toward a convention for persons with disabilities and for older persons?

María Soledad Cisternas Reyes, Special Envoy on Disability and Accessibility for the UN (2017 – June 2023)

Before the Convention, there were two models for individuals with disabilities: the benefit model and the medical model. In both models, the participation and input of individuals with disabilities in society were not central. Consequently, during the 1980s and 1990s, disability rights movements established the social model for individuals with disabilities. This new model recognized that interactions with various societal barriers - not just impairments - were crucial to understanding the restrictions faced by individuals with disabilities in fully accessing social, political, and economic participation in society.

In line with this rationale, at the beginning of the 21st century, the goal was to create an International Convention for individuals with Disabilities. Mexico proposed this idea on the international stage. The project of Convention aimed to promote the rights and inclusion of individuals with disabilities on a global scale.

As a result, the United Nations established an Ad Hoc Committee for the development of the Convention on the Rights of Persons with Disabilities (CRPD). During these 8 sessions, which included the participation from delegations of the States, individuals with disabilities, and United Nations staff, we had the opportunity to exchange experiences and knowledge.

We focused on two significant pillars. The first pertained to addressing discrimination, and the second concerned the diversification in the exercise of the rights of individuals with disabilities. In the latter point, the key issue was that individuals with disabilities have all the same rights as others, in accordance with the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights.

Based on this foundation, we developed the draft of the Convention.

The Convention finally developed and fostered new concepts and frameworks. For example, universal accessibility. The convention on the rights of persons with disabilities is the first international instrument that mentions the right of universal accessibility. Or the right for independent living and inclusion in society, or the right of reasonable accommodations and the possibility to acknowledge



discrimination when services, or institutions, do not provide reasonable accommodation.

You can witness the innovations brought about by the Convention on the Rights of Persons with Disabilities. Undoubtedly, the pivotal element in this achievement was the full participation of civil society representatives of individuals with disabilities. This enabled us to articulate our perspectives on the social model and specific aspects related to different articles through discussions with the delegations of the States' parties. They, in turn, committed to diverse approaches in the exercise of the rights of individuals with disabilities. We encountered various complex issues along the way. However, the leadership of the Ad Hoc committee chair was a significant factor in our success. I'd like to emphasize this as the second key element: the competence and ability of the chair of the Ad Hoc committee. We had two chairs during this process. The first chair, for five sessions, was the Ambassador of Ecuador. For the final three sessions, we were led by the Ambassador of New Zealand. The concluding phase was challenging because, until that point, there were differences on various topics. These differences stemmed from the cultural perspectives of different groups within the committee.

It's worth noting that our sessions involved nearly 2000 participants in each meeting.

I'd like to add that we conducted various meetings with ambassadors and engaged with the diplomatic community, creating different documents and opportunities for direct expression within the sessions. "Nothing about us without us" became a powerful motto within the United Nations. This entire process was remarkable, and it's crucial to emphasize that we achieved consensus on most articles, with only one aspect being decided by a vote among the delegations.

When I say "we", I'm referring to individuals with disabilities and their representative organizations, the delegations of the state parties, and the United Nations staff – these three groups played crucial roles. However, the driving force behind this initiative undeniably came from individuals with disabilities and their organizations. In this context, as individuals with disabilities, we actively propelled the process, assuming various roles. For instance, organizations representing individuals with disabilities were at the forefront, but there were also experts, such as myself, who were part of our country's delegation.

In some cases, particularly in developed countries, the practice of including experts with disabilities within the state parties' delegations was employed. In my case, the embassy representative assured me, "I will be alongside you, but you possess the expertise and the right to speak at these meetings". This was a fantastic opportunity for me because I had invested significant effort in studying the subject matter thoroughly. I held diverse opinions on various articles and had the

chance to make a specific contribution, such as proposing an article on access to justice. The Convention's initial draft did not include an article on access to justice, and I proposed this addition during a plenary session. Fortunately, they accepted the inclusion of this article.

The time frame for this Convention appears to be relatively rapid when compared to conventions projects currently in progress, such as the project for a convention toward older persons.

María Soledad Cisternas Reyes, Special Envoy on Disability and Accessibility for the UN (2017 – June 2023)

In 2001, Mexico proposed the convention. It took five years for its adoption, and the Ad Hoc committee convened for four years.

The Convention was adopted in 2006, opened for ratification in 2007, and came into force in 2008. At that time, the United Nations organized the first conference of the States' parties, during which experts were elected to form the Committee on the Rights of Persons with Disabilities. This election occurred in 2008.

During this initial election, the committee was composed of twelve members, and I was elected as one of its members. After four years, the second round of elections took place. As the number of ratifications increased, so did the number of experts, and at that point, we had 18 experts. I participated in the reelection, and following this reelection, I served as the chairperson of the committee for four years, in line with the rule that allowed only one reelection. During my first term, I was Vice-chairperson and Rapporteur for the Optional Protocol. During my second term I was Chairperson of the Committee CRPD.

In 2017, the Secretary-General of the United Nations appointed me as the Special Envoy of the UN Secretary-General on Disability and Accessibility.

All things considered, the Convention on the Rights of Persons with Disabilities saw a swift ratification process, with nearly universal support. Since 2007, we have witnessed almost universal ratification, with 186 state parties having ratified it to date.

During the process of elaborating the Convention, did you encounter opposition, opponents, or specific obstacles?

Maria Soledad Cisternas Reyes, Special Envoy on Disability and Accessibility for the UN (2017 – June 2023)

We faced various challenges. For instance, from a religious perspective, there were disagreements, particularly regarding the right to life for all individuals. The issue of women's reproductive choice was a point of contention, as some countries supported abortion rights while others did not. This pertained to sexual and reproductive rights, viewed through a religious lens. Additionally, the debate extended to the right to form a family, with some countries insisting that interpersonal relationships should only occur within marriage.

Another major challenge was related to legal capacity, which is a specific topic tied to civil legislation within individual countries. Some countries opposed the concept of legal capacity, while others were in favor of it. Towards the end of the drafting process, some countries raised reservations concerning the article on legal capacity. Legal capacity was a particularly complex issue.

In the economic realm, certain countries were hesitant to include aspects of international cooperation, whereas developing countries were generally supportive of this effort.

Another area that posed difficulties was the establishment of an international mechanism for monitoring compliance with the Convention and the measure of the fulfillment of this Convention. Ultimately, we recognized the need for such a mechanism at the international level. A second point related to the committee's ability to receive individual or group communications concerning human rights violations. This matter was addressed through the creation of an optional protocol, which included conditions and procedures for individual communications.

The optional protocol also allowed for the initiation of inquiries by the committee in response to reports of widespread human rights violations received from individuals with disabilities. During my tenure on the committee, we received two requests for inquiries, and this process sometimes involved conducting on-site visits to countries.

I would like to emphasize that all these aspects had to be balanced, considering the diversity of disabilities and the specific concerns emphasized within the Convention. However, it's worth noting that disability organizations and experts with disabilities worked in a unified manner.

It's essential to acknowledge the contributions of international disability organizations, such as the World Blind Union, the World Federation of the Deaf, Inclusion International for individuals with intellectual disabilities, and Survivors of Psychiatry, which focuses on psychosocial disability. These organizations played a crucial role in the process.

Representatives of civil society were actively engaged in the process, and this working methodology had a significant impact on the composition of the committee. Many of the experts on the first committee had participated in drafting the Convention.

Consequently, we were acutely aware of the importance of full participation by civil society organizations representing individuals with disabilities in the committee's work. For instance, civil society took part in closed-door meetings to discuss complex issues related to human rights violations against persons with disabilities.

With such a high level of engagement, we were able to formulate guidelines for the participation of individuals with disabilities in specific facets of the committee's activities, especially when it came to assessing the initial reports submitted by States' parties or their periodic reports. This process encompassed both written submissions and direct meetings, which also included online discussions.

I would also like to mention another aspect. The process of involving persons with disabilities in the Convention was quite challenging because we lacked the resources to travel to New York. This made it difficult for us as we had to raise funds and often pay from our own pockets to attend meetings in New York. This posed a significant challenge, especially for individuals in developing countries. I express this point because it may also apply to the participation of older persons in certain processes.

In both fields of disability and aging, could you provide more insight on the structuration of the United Nations to open discussions and encourage actions on behalf of these populations?

María Soledad Cisternas Reyes, Special Envoy on Disability and Accessibility for the UN (2017 – June 2023)

Firstly, I consider that persons with disabilities and older persons constitute legal categories that are distinct, even though there is some intersection between these two groups: Some older persons may have a disability. They are not the same, persons with disabilities and older persons, and it's essential to recognize this distinction.



Consequently, I believe it's crucial to have a Convention on the rights of older persons.

As far as individuals with disabilities are concerned, the United Nations has a well-defined structure. Within the Convention, there are two primary mechanisms. The first is the Committee on the Rights of Persons with Disabilities, responsible for reviewing the reports submitted by States' parties. This committee also makes recommendations on individual or group communications for human rights violations, in relation to persons with disabilities.

Additionally, it plays a key role in providing guidance to States' parties on the interpretation and implementation of specific articles of the Convention, as well as collaboration with disability organizations. This committee is a very robust mechanism.

The second mechanism is the Conference of the States' parties, serving as a forum for States and civil society to exchange experiences related to legislation, public policies, and good practices.

There's also the Rapporteur on disability, a role under the Human Rights Council. This Rapporteur is responsible for producing reports annually in relation to specific countries and on specific topics. The Rapporteur conducts interviews and research during visits to the countries.

Lastly, the Special Envoy of the Secretary-General of the United Nations, a role I held (2017 - June 2023), is tasked with raising awareness about the rights of persons with disabilities and connecting the CRPD with the 2030 Agenda on Sustainable Development. In this capacity, my work focused on sustainable development and the Convention on the Rights of Persons with Disabilities. I developed various campaigns, including audiovisual materials and guidelines for the police and schools on topics such as accessibility and the proper treatment of children and adolescents with disabilities.

At times, Special Envoys of the UN can collaborate on joint statements. In my case, I collaborated with other mandates, such as Rosa Kornfeld-Matte, on a joint COVID statement.

In the structure of the United Nations, I also see the significance of the Independent Expert for older persons. Unlike individuals with disabilities, the United Nations lacks a convention or similar mechanisms for older persons, or conferences of States' parties. The Open-Ended Working Group for older persons serves as an important forum for exchanging experiences and attempting to move the process forward. However, in my opinion, it lacks the necessary strength to drive the system effectively. Nonetheless, figures like Rosa Kornfeld-Matte, in her role as Independent Expert, brought significant energy to the table and helped raise various issues. For

this reason, I believe the figure of the Independent Expert is highly important within the United Nations.

Rosa Kornfeld-Matte, Independent Expert on the enjoyment of all human rights by older persons by the UN Human Rights Council (2014 – 2020)

The insights of María Soledad Cisternas Reyes on her field are of great importance to all of us who are dedicated to the Convention. Her work serves as an exemplary model. In the field of aging, we face different sets of challenges.

Initially, when we looked at Conventions for Women, Persons with Disabilities, and Children, we realized there was no equivalent for Older Persons. Therefore, we initiated an Open-Ended group in New York, aiming to work collectively on a Convention. We collaborated with other countries, but after about five or six years of work with little progress, the Open-Ended group proposed to create an Independent Expert under the United Nations Human Rights Council. The Independent Expert's mission was to expedite the process. Initially, it was challenging to gain the United Nations' agreement on this proposal, but ultimately, it was accepted. I was selected by vote to become the first Independent Expert on the Rights of Older Persons, and I served in this role for two mandates totaling six years. During this time, I worked tirelessly to understand the needs and rights of older persons. As María Soledad Cisternas Reyes knows, this population is often misunderstood, and even ambassadors from countries visited during my state visits lacked a comprehensive understanding of older persons' rights. This is a complex issue, and as awareness grows, some minor changes occur, but we lack the powerful advocacy organizations that individuals with disabilities have, which María Soledad Cisternas Reyes mentioned. In the field of aging, civil society lacks this level of influence. I made efforts to strengthen civil society's role, particularly in Europe. Latin America, in particular, has more advocacy strength than Europe or African nations. Latin America is the only region with a Convention for the rights of older persons: the Inter-American Convention on the Protection of the Human Rights of Older Persons. This is unique globally because the civil society in Latin America is robust and has worked actively for this cause.

I would like to emphasize that when I attended meetings at the United Nations in New York, Geneva, or other places, there was often insufficient drive to establish a Convention for Older Persons. In Europe, some governments and decision makers questioned the need for such a Convention when Conventions already existed for Persons with Disabilities, Poverty, and Women. They failed to recognize the unique challenges, like age discriminations, and



difficulties faced by older persons, which can be vastly different. My role was to educate and convince assemblies, ambassadors, and countries of the necessity of a specific Convention. This is exceptionally vital in a world with an increasingly aging population. Not having a Convention for the human rights of older persons, would be a grave oversight. The COVID-19 pandemic and its impact on the elderly serve as a stark example. Older persons were among the most affected by this global crisis.

I believe the reluctance to establish such a Convention stems primarily from economic reasons. Adopting an international Convention necessitates changes in many laws and policies within countries, and countries may be unwilling to bear the associated costs.

Nevertheless, we must remain optimistic and continue our work. We need to start by recognizing the common rights shared by persons with disabilities and then focus on specific rights for older persons. For example, we must address the heterogeneity among older persons themselves, the prejudices they face, their vulnerability to abuse, and the aging process. Persons with disabilities also encounter similar challenges or situations. Therefore, we must work together to support each other and help the fight against discrimination in the field of aging.

About the main differences with the field of disability I have observed in the Open-Ended group and as Independent Expert, I would firstly underline that it's important to remember the complexity and diversity of the link between aging and disabilities in a life course perspective. This viewpoint is crucial because many older persons with disabilities start experiencing disabilities later in life, without having had their entire lives to prepare for them. This situation is fundamentally different from individuals with disabilities who have lived with them throughout their lives. Consequently, we cannot solely rely on the Convention on the Rights of Persons with Disabilities, as these situations require different approaches.

Secondly, not all older persons have disabilities. There is a significant difference between aging with a pre-existing disability and becoming disabled due to aging. Many older persons face multiple disabilities in their later years. I have a graph depicting the percentages of different types of disabilities experienced by older persons aged over 66 in various countries. Some older persons may walk or eat more slowly than others, but this should not necessarily be considered a disability. Such situations create gaps in rights because older persons who are not considered disabled are not covered by the Convention on the Rights of Persons with Disabilities. Therefore, it is essential to work towards addressing these gaps. We need to include disabled persons, as well as women, in the process of developing a Convention on the rights of older persons. This is critical because

currently, these older persons are denied their rights. COVID-19 revealed the dire situation of the elderly in nursing homes, particularly concerning hospital triage practices. Many countries failed to provide adequate assistance, making it imperative to work toward a Convention. Aging should be viewed as a human right, not merely as assistance for persons. A paradigm shift is needed in how we perceive older persons and respond to their needs. Presently, older persons are often seen primarily through a biomedical lens, but they are individuals with rights. While progress is being made, it is not sufficient. Adequate social protection for older persons is crucial, given the negative stereotypes associated with aging. Ageism is pervasive, with assumptions made about older persons walking too slowly or forgetting things. These biases need to be challenged. We require robust human rights protections specifically tailored to older persons.

Additionally, older persons face various forms of abuse, including economic, psychological, and physical abuse. Many older persons are abandoned in hospitals or nursing homes, and their families may take advantage of the situation by accessing their pensions or selling family properties, without adequately caring for them. This is an example of economic abuse against older persons. Therefore, there is a pressing need to establish social protection measures that cater to the unique needs of older persons. We must prepare for aging because disability often becomes a part of life as persons grow older. While not always the case, it happens frequently. We need to ensure equal rights for all older persons, considering their diverse living situations and needs. Education about older persons is vital, including the use of appropriate language because discrimination based on language is pervasive, affecting both older persons and individuals with disabilities.

So, there is much work to be done. To achieve our goals, we can draw inspiration from María Soledad Cisternas Reyes and the Convention on the Rights of Persons with Disabilities, as well as the Convention related to the rights of older persons in the Organization of American States. However, we need the support of civil society. For this reason, I called upon civil society to assist us during the 6th International Congress of REIACTIS in Metz in 2020, particularly those in Europe. Convincing European representatives and citizens of the need for a specific Convention is crucial. Civil society's involvement is paramount because experts and human rights workers can accomplish much, but we need civil society's support to advocate for a Convention.



How would you explain the difference of involvement between organizations for disabled persons and those for older persons?

María Soledad Cisternas Reyes, Special Envoy on Disability and Accessibility for the UN (2017 – June 2023)

I don't have a deep understanding of the reality regarding organizations for older persons. My familiarity lies more with organizations for persons with disabilities. At the international level, these organizations work diligently on fundraising efforts to collect funds to support their activities and members.

I'd like to mention that international organizations played a significant role, but the contributions of other independent experts were also crucial. In some cases, these independent experts were highly educated individuals or researchers, and with their qualifications, experts with disabilities were able to make substantial contributions to the process.

Another vital aspect was the involvement of persons with disabilities in different parts of the world, within various countries, advocating with their respective governments. This advocacy extended to ministers, presidents, first ladies, and other key figures in order to secure agreements within their countries regarding the rights of persons with disabilities. In my view, this grassroots effort by persons with disabilities, not just by large organizations, was instrumental. I remember, for instance, in Chile, we worked diligently with the executive branch, Congress, and lawmakers to expedite the ratification within the country. I believe that similar experiences at the local level within various countries were equally significant.

Rosa Kornfeld-Matte, Independent Expert on the enjoyment of all human rights by older persons by the UN Human Rights Council (2014 – 2020)

I believe there is a distinction, primarily because disabled persons are often younger than the elderly. Many of them are employed in significant roles within companies, and persons readily perceive their ability to work and contribute to the workforce throughout their lives. They are visible and actively participating in the workforce. In contrast, older persons retire, and they can sometimes become less visible in society.

I agree with María Soledad Cisternas Reyes about the importance of advocacy on both levels in the highest scales of deciding process within the UN or at the diplomatic level and also on a more local level with the role of the grassroots organizations. I had the opportunity to

work on the International Convention on the Rights of Older Persons. I collaborated on this effort because the President of Senama (Chilean National Service of Ageing) was involved. This required me to travel to Washington and engage in discussions there. It's worth noting that every country puts in a significant amount of work at the local level, working closely with local communities. The expert on older persons who went to Washington collaborated with the government.

In many countries, activists often struggle to find the resources and support needed to advocate effectively for their causes.

Moreover, the universities in these countries may not prioritize human rights issues. There is a significant potential for collaboration between organizations and universities, which could yield substantial results.

For this reason, I proposed to Jean-Philippe Viriot Durandal, the former President of REIACTIS, that we initiate a substantial and practical research project named RIDPA. RIDPA, which stands for "Research on the Impact of COVID-19 Pandemics on the Respect for Human Rights of Older persons", is an international undertaking. This extensive study spans 18 countries across Asia, Africa, Europe, and the Americas, with a specific focus on the challenges older persons faced during the COVID-19 pandemic in relation to human rights issues.

The research project involves collaboration between university researchers and local stakeholders, as well as government participation. It's an example among others but I believe Europe could benefit from similar initiatives, as we have seen the positive outcomes of such collaboration in Latin America, where universities, governments, and civil society work closely together.

And in my opinion, it is also crucial to stress the importance of the direct participation of older persons as stakeholders in the research process. The research is important, but the presence of older persons directly aware of what aging represents in their everyday life is important too. This point is also made by María Soledad Cisternas Reyes, in her experience in the disability field is of outmost importance.



What is the impact of the Open-Ended Group, and what results or advancements has this group achieved in the development of the convention project for older persons?

Rosa Kornfeld-Matte, Independent Expert on the enjoyment of all human rights by older persons by the UN Human Rights Council (2014 – 2020)

The Open-Ended Group certainly put in significant effort, but progress towards the Convention on the Rights of Older persons has been slow. Consequently, they decided to introduce the role of the Independent Expert, hoping that this status would provide better support to the cause. The group continues to be active and engaged, with participants from around the world who are eager to contribute. Representatives from European countries, including France, are attending meetings in New York on a regular base. I have had the opportunity to participate in this group three times, and it has been an immersive and engaging experience. Each meeting spans three days, with a sole focus on aging-related issues. It's worth noting that Latin American countries have been at the forefront of advocating for the International Convention on the Rights of Older persons.

Returning to what María Soledad Cisternas Reyes mentioned about the role of civil society in the process, she emphasized several times that civil society played a pivotal role. However, from my perspective at the United Nations, I did not witness a comparable level of influence from civil society in the context of older persons' rights. While there were European NGOs present in Geneva, they did not possess significant influence. What are the causes of this weak influence? The difference lies in the approach taken by NGOs in Latin America, where they have established connections with the government, conducted research, and engaged with universities. It is through this collective effort that they advocate for a Convention. Research is vital in informing decision-making, but researchers must also have close ties to the field and collaborate with civil society.

When advocating for the rights of older persons, including the right to age gracefully, protection against mistreatment, access to culture, education, and improved social conditions, governments often perceive it as an expensive endeavor. However, it may not necessarily require increased financial investment but a structural reorganization of public responses to aging. Achieving a holistic response to aging necessitates cross-ministerial coordination within governments. This approach emphasizes collaboration between ministries, the elderly population, civil society, and researchers, all grounded in a human rights-based framework, rather than a focus solely on costs.

However, it's important to note that the convention for older persons is still not on the international agenda, unfortunately. I believe that COVID-19 has brought many issues faced by older persons and their families to light, but I don't see enough momentum from organizations to push in this direction. Governments continue to be convinced that such a convention would come with a high cost, particularly in terms of supporting pensions and healthcare systems. As a result, governments recommend using existing international conventions instead.

