INTERVIEW

# are as a right. Reflecting on care from a perspective of redistribution and recognition Mariela Serey, Member of the Constitutional Convention - District 6

*Por Carlos Andrade Guzmán*[1]

> ***"Today we are not alone. When we realised that we were not alone, when we realised that we needed each other to generate strength, and when we realised that this individualistic society that had been put into our heads which was supposedly the right way to achieve our objectives, was not the right one, we recognised that redistribution logically goes hand in hand with social justice".***

In this issue dedicated to the struggle for redistribution and recognition, we share this interview conducted by Carlos Andrade Guzmán, academic of the Department of Social Work at the University of Chile, with Mariela Serey, representative of District 6 at the Constitutional Convention and founder of the Organization "Yo Cuido", an association oriented to the struggle for the protection and safeguarding of the rights of caregivers and people with disabilities. Mariela left the presidency of "Yo Cuido" to become a member of the Convention and to include the issue of care in the text of the new Constitution put to a plebiscite on 4 September 2022. We hope you enjoy this conversation that puts the issue of care at the centre, from a perspective of recognition and redistribution. Thanks go to Mariela and Carlos for sharing this conversation with our readership.

**Carlos:** Mariela, thank you very much for attending on a Saturday, knowing that your agenda is very busy with the work you are doing at the Convention. To begin with, I wanted to ask you, how did you become involved in the struggle for redistribution and recognition in terms of care?

**Mariela:** Because of an experience. Well, all this started in my life, in 2014. That's when I found myself, in inverted commas, "confronted" with the problem of care,

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[1] PhD en Trabajo Social, Boston College, Estados Unidos y Doctor en Trabajo Social y Políticas de Bienestar de la Universidad Alberto Hurtado, Chile. Académico del Departamento de Trabajo Social de la Universidad de Chile. Contacto: carlos.andrade@uchile.cl

which to this day continues to be a problem. In 2014 my daughter was born, she swallowed meconium in childbirth and this caused severe cerebral palsy, severe swallowing disorders and a refractory epilepsy that was very difficult to manage. These were the three main diagnoses. That led to a series of other conditions that made her 100% dependent. She required constant suction machines; she had to be fed, first by a nasogastric tube, then by a gastric button. That was from day one. In other words, she was born and immediately came with all these diagnoses as a result of what happened to her in childbirth. Up to that point, I was working as a primary school teacher. I was working in an establishment in Peñablanca, and of course, I went with the pre-natal period thinking that after the post-natal period I was going to start working immediately, after the legal six months, but all that came crashing down with what happened to us. And that's when I was faced with this situation where, of course, with all her health complications, I couldn't go back to my profession and I had to dedicate myself 100% to looking after her to keep her alive. That's the picture. My daughter required this care 24 hours a day, which obviously has an impact on the caregiver, which in this case was me: the mother. But it doesn't only affect the direct caregiver, who in this case is the main caregiver, it affects the whole environment. This is a situation that I always describe as a "nuclear bomb" that falls within the whole family circle but also extends far beyond. It falls on you as a person, then it spreads to your partner, to your family, to your closest circle, to your work, to your community. In other words, the issue begins to expand. It becomes a problem and when it becomes a problem, you are left alone. This is because, unfortunately, we have been made to see, feel and take comfort in the fact that we don't need anyone else, but simply ourselves, our capacities, and in this way we stop living in society. From one moment to the next we forget about each other. And we forget much more easily when there is some kind of serious problem. So, it is at that moment that I am confronted with this situation, which is, as I said, a "nuclear bomb". You are left alone in the end, for all that it means, and that loneliness means that you obviously can't work in a paid job because you are caring all day long. You are impoverished by 100% care, and it is not only an economic impoverishment, but an impoverishment in all aspects of your life; and society and the State, the community and every space forces you to transform yourself into this dyad, one that hopefully is enclosed within its walls, and that nobody sees, nobody listens and nobody is in charge. Only you.

**Carlos:** This dyad, is it the caregiver/ person in need of care?

**Mariela:** Yes. Unfortunately the rights of the person in need of care are not respected: that person does not exist. And you - the caregiver- cease to exist too..

**Carlos:** Mariela, and what are you doing there? At that moment, when you are confronted with this "nuclear bomb", as you call it. Otherwise, how does it all start?

**Mariela:** In 2014, I was able to, in inverted commas, "subsist" until my leave lasted. This was because I had been on leave since my daughter's first year, due to her medical condition. Then I was on psychiatric leave. So I was able to be, quote unquote, "calm" for a year and a half after she was born. After that year and a half I had to take over the economic stability of the family. This was because my husband is an entrepreneur, so he didn't have anything stable either, and I, as a teacher, was the one who had a stable salary. When all that came to an end, we had to go and live with my in-laws, which was in 2015. Around 2017 I reinvented myself again. I started to support my husband in entrepreneurship and I dedicated myself 100% to the care of Amelia, my daughter. Then, that same year, I separated, and with my daughter we went to my parents' house. That's when I said: "we've hit rock bottom, I don't know what to do". I was a bit paralysed. I said to myself: "I have two possibilities: either I stay here locked up and sink with my daughter, or I try to do something". The answer was, of course, "I'm going to try to do something" and that "try to do something", I think, was a product of desperation. As a result of this, of this desperation, I started to look for answers on social networks and Google. I asked myself: "How can we be the only ones"; "Doesn't anyone else go through this? That's how I came to the concept of "caregiver", of "care", I came to the dependency law in Spain. I also searched here in Chile, I started looking to see if there were other people in a similar situation. For example, I came across Sonia Castro, from the association "Mamá Terapeuta". The people from "Mamá Terapeuta" were very generous with me, but I was with the issue of "care". Even today they ask me: "why did you do what you did?" To tell you the truth, I have no idea. I remember that through social networks I reached a councillor from Villa Alemana and I said "how social he is". The thing is that I spoke to him and he received me in his office, and of course, I go with this entire question that "I am a teacher, I can't work". During the time I had been at my parents' house, I had dedicated myself to scribbling on sheets of paper (which I still have) with red marker pens: "This is what they have to solve for me... if all this is sorted out, my daughter's life and mine would be better off". And with that I went to talk to the councillor. There, on the one hand, I told him: "I feel that as a woman, this right, this other right, is being violated", and on the other hand, "I think that these things have to be fixed at the system level so that our lives are better". So I created a programme, very handmade, which had ten points: I talked about work flexibility, that there had to be centres close to my work where my daughter was, for any kind of health complication, among other issues that were common sense to me. I put it down on paper and with that I went to talk to the councillor. My position was to give him that information and let him do his job. He told me: “Mariela, you know, it’s the first time I’ve heard something like this, I’m super surprised, it’s incredible”, but then, “you know what Mariela, I can’t do anything, you’re the one who has to do something”. And that’s when the whole thing started. So it was like a snowball: they were situations that I wasn’t looking for but that came to me. What this councillor did was to open up the possibilities for me to meet with politicians and explain my situation, this, approximately in 2018. Now, obviously I didn’t have a political vision. I always thought that the meeting was between the councillor, me and a couple of other people who were going to be MPs. The thing is that a couple of days before the meeting, the councillor goes to me and says, “Mariela, how many people do we have for the meeting?” And I say, “Just me”. He says to me: “Mariela, the place for the meeting has to be filled, because if not, the politicians who are going to go are not going to give you any importance”. And I had about five days left before the meeting and I said: “Where can I find people if I’ve been locked up in my house for more than two years, with my daughter, and I don’t know anyone?” So I published a post on social networks. It said: “I’m looking for women to take care of people with disabilities”. The thing is that it was done in a centre for the physically disabled in Villa Alemana, where the people who participated in that centre went. They also invited the members, the mothers who took care of them, and I had a lot of support from that place. And it was full. So, of course, when I made the presentation, the room was full and the parliamentarians were very impressed. And that’s how it started.

**Carlos:** Mariela, what is “Yo Cuido”?

**Mariela:** “Yo Cuido” started as an organisation that allowed us to make ourselves visible, to unite, to fight, to no longer feel alone. It opened paths for us, it allowed us to empower ourselves as women, as leaders, as a family, and for many of us it has also meant and given us a meaning to continue. Many of those in need of care have died along the way as a result of their diagnoses, which is my case. For me, “Yo Cuido” allowed me to continue. To continue, knowing that I could not detach myself from a reality that no one seemed to care about until that moment, one that no one was taking care of, and for which I felt responsible. I felt responsible for what we had achieved, I also felt responsible for my daughter who had brought me to this. Thus, “Yo Cuido” became a fighting family, with very clear convictions and, on the personal side, my healing as well.

**Carlos:** And why did you organise through “Yo Cuido”?

**Mariela:** It was from the experience with the councillor, to understand that "they won't listen to you alone, you have to organise yourself". But it wasn't just because we wanted to, but because it was necessary. And none of us had any experience in that either. So it was all new, but we did it. And we did it with the conviction that we had already found each other, and we would do it because what we were going through seemed like nobody cared and we were going to have to take care of it ourselves.

**Carlos:** Mariela, how did you get to the Convention? Did anyone say to you: "you have to go in"?

**Mariela:** No, nobody told me anything. Look, we at "Yo Cuido" have been working with parliamentarians since 2018. Besides, I have never been an activist, but we have always been close to a sector, working on the creation of public policies. In other words, we already had that path with a party that had supported us from the beginning. Before that, the social outburst came and we as an organisation decided to get involved, because we were involved in politics from day one. That's how we said: "Our human rights are being violated", isn't that politics? So, with that conviction we said: "You know what, let's go for the new constitution". Because we also understood as an organisation that everything we had done since we started had been our struggle, a product of the model that was the basis of the current Constitution. We managed to understand that we needed a much more profound change so that our demands could come to fruition. That is why we got involved as an organisation in the "I Approve New Constitution". Then, the campaign for the new constitution came out and this election came along, where many different positions were being elected at the same time. At that time, I don't really remember very well, but I think I was asked for a meeting by the party we had been working with from the beginning. They said to me: "Mariela, maybe you would like to be a councillor, something like that"... And I said: "Never". I said: "The only thing I could go for is the new constitution", and "I would do it because we are going to enshrine the right to care". And that was my immovable position. So that's how I came to this.

**Carlos: :** Mariela, and today, what are the struggles you are fighting for from your position in the Convention?

**Mariela:** As I am not participating in any commission after the work of the permanent commissions (Harmonisation, Transitional Standards and Preamble), we went to the territories. We are going out to talk to people, providing information, answering questions, etc. This is also to fight against false information and misinformation about the constitutional process. So, we are in this period of active listening, but also of saying from the first voices: “this is what was worked on”, “this is what is written and not what is being said by some parties and which has no validity whatsoever”. That is the work we have been doing these last few weeks. What we have achieved in these last meetings is a revitalisation of the movement. As well as: “these guys played 100% inside, now we as a society have to take responsibility for participating”. And that has been very nice.

**Carlos:** Mariela, thinking back to day one, when you entered the Convention, what were the struggles you had to put up?

**Mariela:** Well, what happened is that I feel that we as an organisation did a very good job from the outside, in the sense that I didn’t have to make much effort; I wore the “Yo Cuido” T-shirt and many of the constituents who were inside already knew about the organisation. They knew about our struggle, they knew where we came from. It was something very organic. I don’t know how to explain it very well, but, for example, we entered with two very crucial processes. On the one hand, the issue of the pandemic, which highlighted the care crisis, and on the other hand, all the presidential speeches, in an extremely transversal way, were talking about care. With these two extremely important events, we entered the constituent process. As an organisation we were already “recognised” among the social movements and that made the conversation very easy. There was a lot of respect. The truth is that on the issue of care, inclusion, non-discrimination and disability, there was a lot of respect.

**Carlos:** Mariela, and if we think about how the state has operated throughout history, how has it operated in terms of recognition and redistribution of rights in relation to care?

**Mariela:** With total abandonment. Absolute neglect. That is my main diagnosis from the beginning until today. Now the issue is on the table, we are thinking about a comprehensive care system, where there is going to be funding. In other words, we are only now at a good place to talk about redistribution, co-responsibility, all the wonderful words that we have been using for several years now. But, until now, it has been completely neglected by all the authorities on duty..

**Carlos:** And on the part of civil society and business?

**Mariela:** We, for example, from the organisation, and obviously having a strong political stance, we have not had any luck with companies, but on the public sector side and with civil society, from the "Yo Cuido Organisation", we have. That is, for example, we have worked on the creation of public policies and on political advocacy, and we have managed to make progress. We have managed, for example, to work with other state bodies. Now, all those instances in which it was previously impossible to think that women carers could participate, are being used 100%. Before, we were left out because, for example, everything was done in person, and it was impossible for a caregiver to go every day from 9 a.m. to 1 p.m. to such and such a place. That was impossible. But now, because of the pandemic, most things are done online and at times when they can participate, so we have been able to occupy those spaces. .

**Carlos:** Mariela, and if you could answer in broad terms, why is it that today, as a country, we are talking about care in terms of recognition and redistribution?

**Mariela:** I think that everything that has happened since the social outburst, and this, without taking away the weight of anything that happened previously, I feel that it showed a lot of unhappiness on the part of the population. It showed that everyone had their own ordeals in their own places: dissatisfaction as a result of poor health, poor education, and so on. In other words, it was as if we all felt very similar things, but until then we hadn't had the capacity to express them. And for me, at least, that was the social explosion. It was like realising that today we are not alone. So, when we realised that we were not alone, when we realised that we needed each other to generate strength, and when we realised that this individualistic society that had been put into our heads... which was supposedly the right way to achieve our goals, was not the right way, we recognised ourselves. That's when we started to talk about care, about this care economy, about this care society, about a "care state". We understood that we have to take care of each other, and not only of people, but also of our environment, to take care of our nature, to take care of water. We realised the responsibility we have, but it is a collective responsibility, not an individualistic one, typical of this model that was imposed on us. And redistribution logically goes hand in hand with social justice. This whole struggle has to do with that, with the idea of social justice.

**Carlos:** I think that everything that has happened since the social outburst, and this, without taking away the weight of anything that happened previously, I feel that it showed a lot of unhappiness on the part of the population. It showed that everyone had their own ordeals in their own places: dissatisfaction as a result of poor health, poor education, and so on. In other words, it was as if we all felt very similar things, but until then we hadn't had the capacity to express them. And for me, at least, that was the social explosion. It was like realising that today we are not alone. So, when we realised that we were not alone, when we realised that we needed each other to generate strength, and when we realised that this individualistic society that had been put into our heads... which was supposedly the right way to achieve our goals, was not the right way, we recognised ourselves. That's when we started to talk about care, about this care economy, about this care society, about a "care state". We understood that we have to take care of each other, and not only of people, but also of our environment, to take care of our nature, to take care of water. We realised the responsibility we have, but it is a collective responsibility, not an individualistic one, typical of this model that was imposed on us. And redistribution logically goes hand in hand with social justice. This whole struggle has to do with that, with the idea of social justice

**Mariela:** On the issue of redistribution, in concrete terms: more crèches, more work flexibility, more specialised rehabilitation centres, more opportunity for what I once dreamed of: having workplaces closer to the centres where people who require specific care can be. Also more specialisation for the professionals who are going to fulfil this care role. The care profession should also be dignified, a career in care should be created at the institutional level, and a low salary should not continue to be perpetuated for a person who fulfils the role of caring for someone else. So, I believe that we must also move forward along these lines. Care must be collectivised. We must also create an awareness from the earliest years of life that both men and women have the same capacity to care for others, and that we must have the same responsibility to care for others, and to care for ourselves as well. What do I hope for? A profound change in the way we relate to each other, in the way we understand how each family functions. That we become more generous, that we show more solidarity. And that there really is this caring society where we have the capacity to no longer shut ourselves away, but to talk, because that also helps us with our mental health, which today is really affected. In terms of recognition, it is about seeing the diversity of realities. For example, we were very concerned that people simply talked about paying women who were carers in the home, but without seeing everything that goes with it. It is important that the person who, for whatever reason, is going to be paid a salary, it should be fair, and it should be by choice and not by imposition, which is what happens now. By being by decision and not by imposition, it promotes that there is no violation of rights. In other words, it is a question of not truncating the life projects of those who today, many times, have to assume care. This is about recognition.

**Carlos:** Mariela, and finally, what do you feel we need as a country in terms of conditions for this to be sustainable?

**Mariela:** Look, I think there is a different way of doing things, and this is what happened in the constituent process, at least in the commission where I worked, which was the "Fundamental Rights" commission. There, many of the issues we worked on: the rights of the elderly, the rights of people with disabilities, the issue of care, the issue of health, education, etc., were worked on directly with organisations. This has to be done in this way. I really believe that this is the way to do politics. Sitting down, talking, listening to each other, reaching agreements. With the issue of care, with the issue of redistribution, with the issue of recognition, it has to be the same way. What I would not like here, and this is what has happened so far in many issues, is for things to be done behind closed doors, where there is no participation of the population that lives with the problem, and that, in doing so, in the end, things are done that do not work. So, what I hope, from what is coming now and with what we are leaving at the base of this draft Constitution, is that we can work in a cross-cutting, inter-ministerial, inter-sectoral way, and hand in hand with civil society and with the people who live with the problems. For me, this is the new creation of policy, this is the new way of creating programmes and public policies, because otherwise, it is useless. And it should be progressive, because it would be an illusion to think that from one day to the next everyone is going to have crèches, that there will be thousands of rehabilitation centres, it is not like that. Let's start, but let's start. Because we already know what the needs are.

**Carlos:** Mariela, anything else you want to add?

**Mariela:** No, nothing.

**Carlos:** Mariela, thank you very much for this conversation.

**Mariela:** No, thank you very much Carlos

## Find out more about Mariela's work, Constitutional Convention Member for District 6.

https://www.chileconvencion.cl/constituyentes/mariela-serey/

http://www.nomasviolenciacontramujeres.cl/mariela-serey-de-asociacion-yo-cuido-el-cuidado-tiene-que-quedar-en-la-nueva-constitucion-tiene-que-ser-un-derecho-el-cuidar-y-el-ser-cuidado/

*Mariela Serey is the founder of "Yo Cuido", an association formed by women caregivers of family members with dependency due to illness, severe disability and/or chronic condition, who joined together to fight for the rights of both. Until July 4, she served as Conventional for District 6 in order to install the issue of the right to care as an integral part of the text of the New Constitution.*