**Remarks by**

**Gerard Quinn**

**UN Special Rapporteur on the rights of persons with disabilities**

**COFACE Disability Platform**

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Thank you.

My name is Gerard Quinn and I am the UN Special Rapporteur on the rights of persons with disabilities.

*As I am not sure I can join you on time tomorrow, I am taking the precaution of preparing this short video.*

At the outset let me congratulate all the COFACE team on a great initiative.

Let me confine my thoughts to three things as you open up the discussion today:

First, let me say something about the **human rights framing on disability** – its twin building blocks – the individual and the social self.

**Secondly, let me say a few words about families** and their place in the human rights firmament. This is complex – but it is also crucial.

**Thirdly, let me say a few words on the service paradigm** – and why it needs to radically change – and can change – in the 21st century. This is equally relevant to the individual as it is to families.

1. **On the human rights framing let me just say this.**

Rights define your ground as an individual – and they define the right relationship between people. The set the terms of co-existence.

From time immemorial there has been a debate about the nature of the ideal person inherent in human rights: is it the atomistic individual or is it the social self, bounded by and organically connected to the community?

There is a deeply embedded assumption that the individual -all individuals – can image their own conception of the good and all are due an equal right to pursue it (provided it does not inhibit the pursuit of the good for others). There is nothing inherently wrong with this emphasis on autonomy – indeed key elements of it are emblazoned on the UN CRPD.

Yet, it is fairly plain, the UN CRPD also supports the view that the person is social – that we become human through our interactions with others. So the CRPD does not just genuflect to autonomy and to equality – but also to inclusion, belonging and participation.

The social self is just as important as the individual self in human rights – and nowhere more so than under the CRPD. After all, one of the biggest contributions of the disability field to the broader human rights field is against segregation in all its forms and including especially its most extreme form which is institutionalisation.

1. **Secondly, this brings me on to families**. I recently did a thought piece for COFACE on this subject. And it was very much linked to the above – the notion of the social self.

Viewed through the prism of an individualistic conception of rights, family rights can be reduced to a right to form one’s own family, a right to have children or to adopt, a right to participate in family life, etc.

Viewed slightly more broadly, this entails a recognition that the quality of family life is crucial in enabling self-development: protecting, nurturing and empowering the human spirit. You might say our family environment constitutes the ecosystem or political economy of our rights. Family support is therefore crucial in providing an enabling and nurturing environment by which we become free agents in our own right. Here I am not making an ideological point – I’m simply acknowledging reality.

1. **Thirdly, it is fairly obvious that the mid-20th century conception of services and support has to change.**

Whenever Governments want to defend lack of progress on deinstitutionalisation they always point to the lack of development of community-based services. Services are hardly ever based on the voice, choice and control of the person. Budgets remain largely un-devolved to the person. The business models of service providers need to change. Many of them try but are stuck in funding arrangements (set by States) that do not incentivise innovation. Everyone knows this needs to change. Maybe the advent of electronic platform based services will requires drastic change. One of my thematic priorities as SR is to reimagine the service paradigm – maybe even change the vocabulary.

One thing that has remained largely hidden in our service debates has been the easy default in nearly all systems that families can and will pick up the pieces. That is to say, families are the ‘natural’ default for informal caring when services give out.

Translated, this means an excessive load placed on women and especially middle aged married women to care of their disabled son or daughter or older parent. Apart from anything else, this leads to physical and mental strain, high opportunity costs in their own lives and in the labour market and possible poverty in later years due to the lack of adequate pension entitlements. The astute among you will have noted that the CERDAW Committee has recently found this to amount to direct discrimination on the ground of gender. I agree. To me family support and especially the plight of informal carers worldwide this has to be part of the debate about change.

It is obvious we need a new social contract – based on human rights but also extending to families and connected with the paradigm shift needed in services. The time is right. Taking intersectionality seriously must mean broadening our focus. We should never accept gains for one group to be achieved to the detriment of another.

I see SHIFT as part of that re-alignment. I welcome it and I look forward to your deliberations.

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