

# Parliamentary Assembly of the Council of Europe

Committee on Social Affairs, Health and Sustainable Development.

## Public Hearing on De-institutionalisation of Persons with Disabilities

16 March, 2021

Remarks by Gerard Quinn,

UN Special Rapporteur on the rights of persons with disabilities.

I thank the Parliamentary Assembly of the Council of Europe for the opportunity to address you today on Deinstitutionalisation and I greatly welcome this initiative by Ms. De Brijn-Wezeman, especially as we move toward a ten-year strategy in the UN system to end institutionalisation worldwide.

I like to think of the Council of Europe as Europe's premiere human rights organisation. This makes it all the more important that the Council of Europe sends a strong unified message in favour of de-institutionalization.

More positively, it is why the Council of Europe should send a strong unified message in favour of independent living, being included in the community with the necessary build-up of community-based supports to make this a reality.

In the time available, and to answer the perceptive questions of Ms de Brijn-Wezeman, I just want to do three things.

**First of all, I want to reflect a bit on the ideas driving change.** I want to peer behind the legalise to identify the key values at stake – and why these values matter to us especially in Europe.

**Secondly, I want to reflect on change in the context of the Recovery following the pandemic.** We are at a crucial inflection point. A resilient and inclusive recovery cannot and must not mean restoring or investing in an old model whose time has come and gone.

**Lastly, I want to reflect on the intersectional lessons learned.** Most of the people who have died in the pandemic have been older persons with disabilities or prior medical conditions. DI must mean something for them too.

## **1. Ideas: Home.**

First if all – what’s really at stake?

Human rights doctrine since the Second World War has focused on controlling public power and expanding the possibilities for free interaction in civil society. Rightly so. Left curiously out of that imagination are entities in between – like the core idea of *home* – which is both public and private.

Let’s start with the private side. We humans are probably unique – our physical environment does more than just shield us from the elements. Our homes are echoes of who we are. We see ourselves mirrored in our surroundings – the small things like a picture, a cup or a flower vase. Through time, our surroundings are reflective of who we are as well as constitutive of who we are.

You don’t always have to be capable of remembering to have memories etched into your being. And so home, in this private sense, is central to human personality. Do we stop developing as humans because we have a disability? I don’t think so.

And what of home in the public sense? Humans are social. Our sense of self is a complex function of how we interact, of who we interact with and on what terms. Our ‘homes’ are typically spatially connected to the community. Much more importantly. Our homes open us up to human interaction. Our front doors announce us to passers’ by. When we pass a

nice garden our minds turn to thinking ‘what a nice way to live and to connect, I wonder who lives there.’ We don’t think ‘ahh, she lives there because she has a disability like the others.’ We naturally *intuit the person behind the garden* – and not the trait like disability that connects the residents of an institution.

If placed in an institution – and I count a group home as a mini institution - I see three distinct sets of losses for the person (any person).

**First, in an institution you lose that intimate bond between self and place** – a uniquely human experience, the mystic cords of memory that hold our sense of self together. This is important in itself. But is also important because it is a portal to other things. It is well known that to move people from this kind of environment into a more anonymous congregated setting accelerates medical decline. Mind and body do matter.

**Second, in an institution you lose voice, choice and control.** Put another way, when de-institutionalised, it is important to restore voice, choice and control. That’s why the fight over autonomy and legal capacity is closely tied to the right to live independently and be in the community.

Curiously enough, it’s the small decisions that count the most like when to have breakfast or turn out the lights.

**Third, your relationship with the community fundamentally changes in a congregated setting.** As I said, when you see the nice flower patch your mind turns to the kind of person who tended it – no matter how modest it is. Let me put that more bluntly – *you instinctively think of the person behind the façade*. If, on the other hand you pass an institution, a group home or nursing home do you think of the person? Let’s be honest - not really. You are more likely to think (and perhaps even recoil) of the trait that unites the persons inside like disability or old age.

Even the architecture of an institution broadcasts that this is not a 'home' in the traditional sense with all its allure of intimacy, autonomy, personality and the implicit invitation to social connectedness - but a home in terms of confinement and care.

The human soul wasn't meant to be confined. Who loses? You lose. But the community loses too. In a word, what you lose is the essence of your very **personhood**.

## **2. The Pandemic: Build Back Better.**

What of the pandemic?

Let me not belabour the point. The pandemic has shown that institutionalization is not only a human rights issue but also a pressing public health issue. That is obvious.

And the pandemic has also shown that service paradigms in the community were far too weak. The World Bank pressed home this point last Summer in the context of the need to create a much more stable and robust service paradigm in the community in order to be able to withstand the next crises.

Bodies like the EU FRA have done much to paint this picture of a new service paradigm.

For my part, let me express the hope that the EU Recovery funds that have been set aside by the EU are not used to fund an old model but can help fund only new models into the future. Otherwise the farthest left behind will be left even further behind.

## **3: Intersectional Perspectives.**

And what of intersectionality? I am greatly heartened that, overall, the Council of Europe seems to be re-framing 'long-term care' of older people in terms of DI strategies and associated community living strategies.

I particularly admire the work of the European Committee of Social Rights in this regard. Let me suggest that we move forward on DI and community living across identity groups. An inter-sectional approach has to be part of the future.

In short, we look to the Council of Europe to play its part in building our common European home for persons with disabilities and indeed for older persons too. What you do in Strasbourg helps motivate others too like the African Union and the Organisation of American States.

I am greatly heartened by the de Bruijn-Wezeman report and see it as a step in the right direction.

Thank You/....

Gerard Quinn

ENDS/