*Webinar*

Disability Rights International (DRI), US International Council on Disability (USICD), VALIDITY, European Network on Independent Living (ENIL) with the University of Leeds – Centre for Disability Studies

Group Homes for children with disabilities?

A disability rights perspective

Symposium

Reflections, practices and a call to action

**Tuesday 7 September 2021**

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# Remarks by Gerard Quinn

# UN Special Rapporteur on the Rights of Persons with Disabilities

Thank you for organizing this extremely important event today.

Angharad, as always, has expertly unpicked the issues as they apply to children and families.

I want to stand back and give some perspective on the disability convention – and especially the image of the person and his/her connection to the community that applies inter-sectionally and not just in the ‘ground’ of disability.

If you asked me at the end of the drafting of the UN disability treaty whether we would still be debating group homes today I would be surprised and shocked.

Part of the reason this debate lingers must surely have to do with the reception – or really the half reception - of the core message of the convention even a decade on.

New directions are often dragged back by the undertow of old ideas which we thought we had banished.

Let me remind you that we started drafting the treaty as if the equality idea exhausted the ground. Due entirely to the presence of far-seeing civil society groups the drafters quickly made something else the foundation stone of the convention - personhood.

Once you grasp the significance of this then there really should be no room for a debate on group homes.

Why personhood as the key lens?

First of all, equality on its own is not enough. Traditionally, equality theory looks to how one group is treated relative to another. There is always ample room to argue that the groups (persons with disabilities or children) are not similarly situated – that there are real material differences (e.g., cognitive ability) that justify – even require differential treatment. There is a lot of room within this narrow theory of equality to treat persons with disabilities – or children or older persons – differently.

This is why some have argued that the classic approach to equality is ‘morally empty’ – it looks for justice in the relativities of treatment and not substantively.

Now, we managed to cut down the space to argue about material difference in the convention.We moved toward an ideal of equality that also looks backward at how you got here – what accumulated disadvantages are borne on your shoulders. The CRPD Committee itself adopted a theory of ‘inclusive equality.’

To me the most interesting thing about this concept of ‘inclusive equality’ is that it is most definitely not ‘morally empty.’ Indeed, in the eyes of the UN CRPD Committee it is anchored on recognition of personhood.

**So I keep coming back to this idea of personhood as a core anchorage point in the convention – as a lens through which to understand Article 19. Why and how?**

At the behest of civil society, the drafters showed great wisdom. What’s’ the point of rolling back unequal laws, policies, practices and programmes if you do not tackle the underlying reasons for these laws in the first place.

One driver of these bad laws and policies was the sheer invisibility of persons with disabilities – as persons. Put it another way around, their humanity and personhood was discounted. You all know the horrible phrase in field of ethics on ’persons of lessor moral worth.’ Guess what, if that view is embedded in the rarefied field of ethics then it can come as no surprise that it is widely shared and is woven deep into our political and popular culture across the board.

Hence an insistence in the convention on personhood as an anchor. This is best exemplified in Articles 12 and 19 – but I would argue trace elements of it are to be found throughout.

Leaving legal formalities to one side (at least for the moment) what are the key ideas at play?

Well, we can’t go too far wrong with the notion of the person as an end in him or her self. This commitment to human autonomy allows – enables – all of us to choose for ourselves our own path in life – our own ‘conception of the good.’ This choice has a deep wellspring of sources – some unique to you- some biographical, some emotional, some rational. We may question the wisdom of each others’ choices – but we don’t generally question each other’s right to make those choices. And so it should be with disability.

Notice that the image of the person in the disability convention is both highly atomistic (with the focus on me) as well as social. I think this is as it should be not just in the disability field but across the board.

At a deep level my personhood is shared in curious ways with my wife – I don’t make decisions without factoring in and anticipating her views. In this and other ways she supports me. Of course, this requires social capital – the presence of others in our lives – something that persons with disabilities have not enjoyed as much for a wide variety of reasons. This dimension of shared personhood is even more obvious with children – who, through it, deserve to be protected, nurtured and gradually empowered.

Notice also the crucial importance of ‘home’ to the self – and indeed to the social self.

Humans are curious. Most animals see ‘home’ simply as shelter from the elements. Humans are different. Home to us is a crucial part of personhood. It’s a place of repose. It’s a place where identity is fixed – and changed – and fixed again.

It is both the scaffolding of who we are and an extension of who we are. It is a scaffolding in that we see our ‘selves’ reflected back in our choice of furniture, wallpaper, pictures and our coffee pot. In this way it ‘holds’ our identity and helps us form our own unique biography through time. If our home is burgled, we do not just see it as a violation of property but as a violation of our sense of self.

And home is an extension of our selves. It projects who we are to the world and potentially connects to the world. Our gardens – if we are lucky enough to have one – is a standing invitation to connect. As is our front door. Our immediate thoughts when passing by a nice front door is ‘Hmmm I wonder who lives there – I’d like to know them.’

So home is both public and private. It creates an intimate human circle we can call our own. It allows for our sense of self to grow – mostly with intimate others. Its boundaries are the boundaries of the self.

And it connects us to the world. It is situated in the lifeworld and is not apart from it. It is a bridge to the community – to the social capital we all need to be, and to feel, that we belong.

Stripped bare of legal niceties, this is what Article 19 is really about.

**The accent is always positive.** It contains a very positive philosophy of human flourishing at ‘home’ and in the community.

To me, the negative side (if you want to call it that) is contained in Article 5 – segregation in an institution is *per se* form of unequal treatment or discrimination. Don’t take my word for it. This is the essence of the famous *Olmstead* decision of the US Supreme Court as far back as 1999.

I have no problem arguing – and the UN CRPD Committee has no problem reaching the same conclusion – that Article 5 on its own is enough to delegitimate any form of institutionalization.

Of course, Article 19 mirrors these negative assumptions – but then goes beyond them. How so?

Let me just point to two or three things about Article 19 that accentuate its grounding on personhood and especially the importance of the social self.

First of all, its opening language speaks of a ‘right to live in the community.’ It doesn’t say a right to choose *whether* to live in the community. For a child, that means the family.

I have always taken the view that there is no individual right to choose to live in an institution – especially one funded out of public monies. Put another way, there is no observable public interest in allowing for a right to choose to live in an institutional setting especially one paid for out of public monies.

This is the backdrop to the first operative paragraph on an individual right to choose. It is not open-ended – it has a context. The second operative paragraph points to the revolution that is still needed in how we conceive and deliver services to enable this to happen. And the third operative paragraph speaks to the broader agenda of opening up general community amenities to make them accessible to persons with disabilities who live in the community.

Secondly, this fits with the core idea of ‘home’ – a place for the formation and evolution of identity and a sense of self – and a place spatially connected to the community. I often point to the golden triangle between Articles 5, 19 and 8 in the convention.

Why 8? The drafters knew that the underlying cultural shift in the convention would need a proactive push to accelerate it. This is why there is an added obligation to nurture public opinion to be sensitive to the rights of persons with disabilities.

Thirdly, is there really any difference between a 100 bed institution and a group home?

Bluntly, no.

To me, one must take seriously the underlying conception of personhood and home that suffuses the convention and is especially to the fore in Article 19.

Can you honestly tell me that congregating people on the basis of a trait like disability allows for the growth of their sense of self? Would we allow this on the ground of race? Can you honestly tell me that group homes nurture receptiveness to the rights of persons with disabilities in the community? No – it’s more likely that passers-by will just see the trait that unites the inhabitants (disability) rather than as persons.

Lastly, are group homes a sort of intermediate step - a form of ‘progressive realization.’ This is a clever argument as it seems to side step the question of principle and seemingly places the question on a more pragmatic foundation. Who’s not for pragmatics!

I personally give little credence to the argument. Such ‘pragmatic steps’ end up having long-term generational impacts. Even if group homes only last 20 years, two generations will be affected. The human impact is far too severe – and almost irreparable. Group homes are not a ‘stepping stone’ toward community living – a form of ‘progressive realization.’ They are a needless, costly and damaging diversion. Why is it tolerated for persons with disabilities including children?

Could it be that States do not have the knowledge or resources to move beyond such ‘pragmatic’ solutions to something different.

I believe that both knowledge and resources are available – it is just a matter of having the will to use them – and having a fresh policy imagination.

The august EU Fundamental Rights Agency did a full report on how to shift budgets to make community living a reality.

There is a now a discernable worldwide trend toward devolving budgets to give more voice and power to the person with support.

There is even a trend toward e-platforms removing the large (and often inefficient) service providers and shaking up the terms of entry and participation in that segment of the market. It has always struck me as odd that competition law and policy seemingly do not apply to that market?

And there is a discernable shift toward community engagement and empowerment – not least in the much debated potential UN Decade of Community Living.

And, to invoke another instrument, investing in group homes could hardly be characterized as sustainable social development!

In sum, this image of the person and the core role of ‘home’ militates against institutions including group homes.

I believe we need to start thinking seriously intersectionality about the issues – covering disability, children and older persons if not more.

An artificial and polarizing debate has indecently concealed the real issues – inadequate family support and the feminization of poverty by over-reliance on informal carers, including mostly women. In another setting I have called the family the indispensable eco-system of persons with disabilities – child or otherwise. It is time we focused on that eco-system to avoid all forms of institutions including group homes. This is what should unite us.

To conclude, it is time a for a fresh policy imagination -inter-sectionally - across the board.

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