Legal Memo

Re: **Segregation and segregated facilities as a prima *facie form* of discrimination.**

The Impermissibility of using the ESIF to invest monies in long term care residential institutions for persons with disabilities.

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Date: **17 March, 2018.**

Purpose of This Memo.

1. The UN CRPD - a prohibition against institutionalisation and a positive philosophy of community living.

i. General Obligations- to refrain from any act inconsistent with the convention and to eliminate discrimination.

ii. Segregation, Separate Treatment & Institutionalization as a *prima facie* form of discrimination (Article 5 UN CRPD).

iii. Article 19 of the UN CRPD - A Positive Philosophy of Human Flourishing.

iv. 'Progressive Realization' of Article 19 does not mean smaller long term care residential institutions.

v. Reconciling Investments to Improve Conditions within Long term care residential institutions with Investing to Close down Long term care residential institutions.

2. The Bridge/s between the UN CRPD (non-Discrimination and Community Living) and EU Law.

i. EU Negotiation & Ratification of the UN CRPD - the centrality of Equality & Non-Discrimination.

ii. The 2010/2017 EU Declaration/s of EU Competence - Pegging the UN CRPD Directly to the ESIF.

iii. The Centrality of Non-Discrimination in the EU Charter of Fundamental Rights (Article 21).

iv. The Centrality of Non-Discrimination in the ESIF common Provisions Regulation (Article 7).

v. The Status of the UN CRPD in EU Law - where/how the CRPD and the ESIF meet.

3. Conclusions.

Purpose of this Memo.

The purpose of this memo is to address the legality of Member States spending of any ESIF monies to invest in long term care residential institutions for persons with disabilities. We treat this a sub-set of the larger question of the permissibility of segregated facilities (including residential institutions) more generally for all.

It is our considered opinion that such expenditures are not permitted either under international law to which the EU is party or under EU law (or a combination of the two). As will be seen, there is one minor exception to the bar on investment in institutions which has to be interpreted extremely narrowly.

The relevant *ex ante* conditionality (and criterion of fulfillment) in the ESIF Regulations purports to positively channel resources toward community-based living options for persons with disabilities (and others). It does not - at least not on its face - explicitly prohibit the expenditure of ESIF monies on long term care residential institutions. Some say - on a theory that if something is not explicitly prohibited it is permitted - that this means that the investment of ESIF monies in long term care residential institutions housing persons with disabilities (thus perpetuating their existence) is allowable. We do not agree.

We do not agree because some sense of articulate consistency and coherence (between the *ex ante* and other parts of the ESIF) would naturally militate against such a conclusion. Otherwise, the purpose of the *ex antes* would be easily defeated. And we do not agree because segregated facilities and treatment (especially one like long term care residential institutions that constricts living conditions and therefore life-chances) are a *prima facie* form of discrimination. This falls foul of the relevant non-discrimination provision in the UN convention on the rights of persons with disabilities, in the common provisions Regulation, and in the EU Charter of Fundamental Rights.

This memo is divided into three Parts:

1. **An Analysis of the Normative Content of Article 19 (community living) combined with Article 5 (non-discrimination) of the UN CRPD.** An examination of whether any such expenditures violates the right to live independently and to be included in the community under Article 19 of the UN Convention on the Rights of Persons with Disabilities (and relevant jurisprudence thereunder) combined with the prohibition against discrimination (Article 5). ***We believe it does.***

   The one (narrow) exception allowed by the UN Committee on the rights of persons with disabilities is set out - as well as some important limiting principles that logically apply to it. ***We believe this exception - properly understood - does not give a license to spend ESIF monies on long term care residential institutions for persons with disabilities.***

2. **An Analysis of the Status of the UN CRPD in EU Law and the ESIF**

Regulations.

An examination of the legal status of the UN CRPD in EU law and especially as it relates to the ESIF Regulations and the practical implications thereof.

We believe that not only is the UN CRPD relevant, it powerfully informs Article 7 of the common provisions regulation (non-discrimination in the implementation of all ESIF Funds) as well as the ex ante.

Even if Article 7 were not there it would be implied through Article 21 of the EU Charter of Fundamental Rights (non-discrimination).

Conclusions

3. An analysis of whether, and to what extent, expenditures on long term care residential institutions amount to a violation of EU law. ***We believe they do.***

The logic of this memo applies equally to many different groups - whether children, the elderly or persons with disabilities. By focusing on persons with disabilities this constitutes a first step in elaborating a broader legal argument.

The inter-sectional dimension to this memo will be elaborated below in Part 1. It should be borne in mind that older persons are referenced in the preamble of the CRPD and there is an explicit article in the CRPD on the rights of the child (Article 7).

To a large extent this memo focuses on UN and EU law. The relevant standards of the Council of Europe instruments are not directly included in this analsysis. Instead this memo focuses on UN law and standards as they have been ported over to EU law as a result of EU accession to the UN convention on the rights of persons with disabilities. However, the signatories to this memo express confidence that an analysis of the Council of Europe standards would reinforce their conclusions and that this extra layer of analysis may be done as part of a follow-on or separate exercise.[1]

This memo represents the considered opinions of the signatories attached.

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1 A useful comparative guide to both Council of Europe and EU discrimination law (as it applies across a broad range of grounds including children, gender, age and disability) is, **Handbook on Non-Discrimination Law**, a joint publication of the EU Fundamental Rights Agency (EU FRA) and the Registry of the European Court of Human Rights (2010) with an updated version due Spring 2018).

1. The UN CRPD - a prohibition against institutionalization and a positive philosophy of community living.

The main purpose of this Part is to examine the interaction of Articles 5 and 19 of the UN CRPD before going on to analyze how they inform the relevant provisions in EU law.

Article 5 places all unequal treatment or segregated treatment (which includes placement in long term residential institution) on the defense as a *prima facie* form of discrimination. Article 19 focuses on the positive steps that need to be taken to ensure a right to live independently and be included in the community.

i. General Obligations- to refrain from any act inconsistent with the convention and to eliminate discrimination.

The UN CRPD is a legally binding treaty that has been adhered to (ratified) by the EU and all of its Member States save one (Ireland, which has announced that it will ratify shortly).

As far as international law is concerned, the Vienna Convention on the Law of Treaties between States and International Organizations and between International Organizations (1986) applies with respect to EU adherence to the UN CRPD. Similarly, the Vienna Convention on the Law of Treaties (1969) applies with respect to ratification by the Member States. Both treaties - especially with respect to treaty interpretation - are essentially the same.

The principle '*pacta sunt servanda*' applies to the effect that the States Parties are assumed to take their obligation seriously (Article 26 of the Vienna Convention) and must be '*performed* by them in good faith' (italics added). The EU is considered to be a 'State Party' to the UN CRPD (Article 44(2) UN CRPD).

Effectively, this means that the relevant obligations are not to be considered as frivolous nor kept at arms' length. Instead, they are intended to be taken seriously and especially where the States Parties exercise power - whether through financial instruments or otherwise.

As far as EU law is concerned, the EU and its Institutions, and the Member States are bound, in accordance with Article 216(2) of the TFEU, by the terms of a treaty the EU has concluded (ratified). Hence the CRPD is binding on the EU and its institutions (including when they act to legislate), as well as on the Member States. Further, and importantly, EU law must be interpreted in the light of treaties which have been signed and ratified by the EU.

State Parties submit initial and periodic reports to the UN CPRD Committee which then issues Concluding Observations with recommendations directed to the same. Additionally, and from time to time, General Comments are adopted

which represent the considered views of the CRPD Committee on the interpretation of the Convention. These will be referred to where relevant below.

The general obligations of States Parties to the CRPD are set out in Article 4. They require States Parties, *inter alia*,

- to repeal inconsistent laws and policies (4.1.b),

- to enact new laws and policies where needed to give effect to the convention (4.1.a)

- to refrain from any action inconsistent with the convention (4.1.d),

- to take all measures to eliminate discrimination by both public and private actors (4.1.e)

- and to mainstream disability (4.1.c).

All of these are important. They point to a dynamic of change that requires ongoing reflection about how to give the Convention life in practical laws and policies and not just a passive genuflection to its abstract principles.

The general obligations in 4.1.a to *refrain from any action inconsistent with the Convention* and in Article 4.1.d. *to eliminate discrimination* are particularly important in the context of this memo. It is maintained below that expenditures of the type indicated clearly violate these obligations.

Importantly, the UN CRPD blends together civil and political rights (with attendant obligations of 'immediate result') and economic, social and cultural rights (with obligations of 'progressive achievement') - Article 4. 3. Article 19 is no exception. The CRPD Committee has opined that Paragraph 1 of Article 19 is of immediate effect - ensuring voice, choice and control - and the remainder are to be 'progressively achieved' (see General Comment 5 of the UN CRPD Committee below). That, most assuredly, does not rob these obligations of meaning.

The leitmotiv of the Convention is equal treatment and non-discrimination (Article 5). The intention of the drafters was not to create any new rights but to ensure that the relevant general rights and obligations enjoyed by all under existing UN human rights treaties were tailored to ensure they could be *equally* and effectively enjoyed by persons with disabilities. This normative concept of equal treatment and non-discrimination is central to both the UN CRPD and the broad thrust of EU law on disability (and indeed was relied on heavily to enable the EU to ratify). [2]

[2] See, de Búrca, G., '*The EU in the Negotiation of the UN Disability Convention*,' 35 European Law Review, No 2, 2010 (stressing the importance of the non-discrimination idea as the core of EU efforts and concerns).

It goes without saying that the CRPD applies across the life-course - to children with disabilities and to older people with disabilities.

And, because the CRPD does not invent any new rights but just takes existing rights and tries to make them *equally effective* for persons with disabilities, it also follows that the general right to live and flourish in the community applies also to older persons and children. It gives expression to what is implicit in those pre-existing treaties and indeed it is being more explicit in newer treaties such as the Inter-American Convention for the Protection of the Rights of Older Persons.[3]

ii. Segregation, Separate Treatment and Institutionalization as a *Prima Facie* Form of Discrimination.

The relevant provision - Article 5 UN CRD - reads as follows:

> 1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.
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> 2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
>
> 3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.
>
> 4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

The Chair of the UN CRPD Committee, Professor Theresia Degener (Germany), has characterized the concept of equality in the Convention as 'inclusive equality.[4]' In a similar vein, Professor Oddny Arnardottir (substitute judge on the European Court of Human Rights) has characterized the concept of equality in the convention as 'multi-dimensional' - something that is keenly attuned to accumulated disadvantage.[5]

What they both had in mind was the practices of segregation and exclusion that persons with disabilities experienced as a result of laws, policies and practices in the past. A classic example - though by no means the only one - is segregation into separate residential institutions. Undoing the legacy of this exclusion (unequal treatment) was one of the central goals of the new CRPD. Of course,

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3 The recently adopted Inter-American Convention on Protecting the Rights of Older People (2015) includes a right to independence and autonomy including a right to choose where to live and with whom that is drawn heavily on Article 19 of the UN CRPD. Available at: http://www.oas.org/en/sla/dil/docs/inter_american_treaties_A-70_human_rights_older_persons.pdf

4 See Degener, T., '*Disability in a Human Rights Context*,' 5(3) Laws, (2016), 35.

5 Arnardottir, M.O, *'A Future of Multidimensional Disadvantage Equality*,' ch. 3. in Arnardottir, M.O. & Quinn, G. (Eds), The UN Convention on the Rights of Persons with Disabilities: European & Scandinavian Perspectives, (Nijhof, 2009).

something similar could be said of most excluded groups including children nd the elderly.

The import of these observations is that the norms of the CRPD convention (and especially the core norm of non-discrimination) are not intended to simply assume the validity of existing practices - especially segregationist practices - but to directly challenge them. In other words, the norm of equality/non-discrimination was not intended to leave intact accumulated practices (like the practice of placing persons with disabilities into institutions) but to deeply interrogate them and change them where needed.

It is true that traditional equality analysis usually pivots on notions of equal treatment *relative* to others. This leaves opens an examination of whether the compared groups are actually similarly situated and unequally treated. That is to say, if there is a *material difference* between the two groups being compared then this may warrant some degree of unequal or special treatment.[6]

Along these lines, it can certainly be argued that certain categories of persons with disabilities with high intensive care needs are in fact *materially different* relative to others. If one were to view this exclusively from the perspective of orthodox discrimination law and theory (which one cannot because Article 5 has to be read in light of other provisions in the CRPD) then it is possible to argue that having segregated facilities (particularly long term care residential institutions) is simply a way of acknowledging this *material* difference and responding to it. Indeed, the argument could be pushed even further to the effect that the State Party has an *obligation* to respond to the difference and provide for separate treatment or institutionalization. It is suggested that, though plausible, this is wrong-headed.

We say so for three reasons.

First of all it ignores Article 12 of the convention that places decision-making power in the individuals in question. That is to say, ignoring or overriding their choice to live in the community is simply not an option. Furthermore, if the 'architecture of choice' is such that there are no realistic alternatives then it can hardly be said that they have a choice and that systems are simply responding to that choice. This concept (autonomy, legal capacity with support where needed) places orthodox equality analysis into a different frame - one that just defer the actual wishes of the individual. This is new and an inescapable implication of the mix of Article 12 with Article 5 in the UN CRPD.

Secondly, even if special or segregated treatment might be warranted to respond to the peculiarities of either individual or group circumstances, this must always be achieved within a system that is underpinned by an overarching philosophy of inclusion. That is to say, special treatment is only contemplated when set against the backdrop of a positive and measureable dynamic toward inclusion. It

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6 See generally Colker, R., **When is Separate Unequal - a Disability Perspective**, (Cambridge, Disability Law & Policy Series, 2008).

follows that if this dynamic is absent then the special treatment in question is just a 'gilded cage' - a temporary expedient that effectively entombs people forever.

Thirdly, even where temporarily warranted, such separate or segregated treatment must be functionally responsive to a particular need. Total and totalizing institutions in the form of long term care institutions could not possibly qualify. Being spatially placed in the community would not be enough. For one thing, the likelihood of genuine community inclusion is remote when ordinary people in the community only 'see' the disability that unites the residents and not human beings - which they tend to do in the context of all congregated settings. Article 8 of the convention is important in this respect. It enjoins States Parties to 'nurture receptiveness to the rights of persons with disabilities.' This is simply impossible in the context of segregated and congregated settings. All the more so, being placed remotely from the community (which is often the case) just exacerbates this tendency. Put another way, separate treatment in the form of totalizing institutions is a disproportionate response to any material difference.

This framing of the discrimination/equality idea in the Convention fits perfectly with extremely authoritative interpretations by courts from other jurisdictions of the concept of discrimination in the particular context of disability and institutionalization – interpretations which were very influential when the CRPD was being drafted. That is to say, many influential courts have used the non-discrimination idea to reveal unequal treatment in the context of institutionalization - and to apply remedies to reverse it.

For example, the US Supreme Court effectively held in a famous 1999 decision (*Olmstead v LMC*) that the institutionalization of persons with disabilities is a form of discrimination prohibited by the Americans with Disabilities Act (ADA).[7]

At a conceptual level, the 1999 decision is significant and instructive as it draws an *express link* between the concept of discrimination and the very existence of long term care residential institutions. The Supreme Court held:

> Unjustified isolation, we hold, is properly regarded as discrimination based on disability.
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> [p. 12 of Decision.]

It went on:

> Recognition that unjustified institutional isolation of persons with disabilities is a form of discrimination reflects two evident judgments.

[7] *Olmstead v L.C.* 527 U.S. 581 (1999). A ten year retrospective symposium on *Olmstead* was held in Georgia State Law School in 2009 and the proceedings published in 2009-2010 Georgia State Law Journal: *The Long Road Home - Perspectives on Olmstead Ten Years Later*, Vol 26, issue 3 (2009-2010).

> First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of partici- pating in community life.....
>
> Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.....
>
> Dissimilar treatment correspondingly exists in this key respect: In order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice.
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> [Pp. 15-16. of Decision.]

This interpretation of the general norm of discrimination in the concrete context of institutionalization and disability is negative in the sense that it demonstrates what the non-discrimination idea is against (institutionalization). In a sense it is powerfully ingrained in Article 5 of the UN CRPD. The framing is not exactly on all fours with the UN CRPD. Nevertheless, it is the linkage of discrimination with extreme forms of segregation as in ling term care residential institutions that matters. The more positive side - how to give positive expression to the idea of living independently and being included in the community is what Article 19 is all about.

One result of *Olmstead* has been a policy adopted by the US Justice Department to require some offending States to enter into agreements to end institutionalization in favour of a placement in the 'most integrative setting possible' (usually independent living in the community). Institutionally, and to give concrete expression to this turn - the US created a newly dedicated Federal Agency (Administration for Community Living)[8] to harness a diverse array of Federal monies to assist States transition to community living options. It aims to re-direct those funding streams to assist States in their transition to community living. There is an obvious parallel here to both Article 19 of the UN CRPD and the 2013 Regulations of the ESIF.

The US Supreme Court decision did allow for some exceptions that are not pertinent here and arise more through the peculiarity of US legislation in the field. What is important, though, for present purposes is that the Court *expressly drew a link between institutionalization and discrimination.*

What follows from this is that even if Article 19 did not exist in the UN CRPD its intent would in any event be inferred from the overall prohibition of discrimination in Article 5 of the convention.

Put another way, institutionalization - and the expenditure of monies on long term care residential institutions - can fairly and clearly be characterised as a *prima facie* form of discrimination under Article 5 of the UN CRPD.

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8 The US Federal Administration for Community Living is at: https://www.acl.gov

Discrimination is defined in the CRPD as:

> ...any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation... (Article 2 - Definitions).

The 2017 General Comment 5 of the UN CRPD Committee (on the right to live independently and to be included in the community) reiterates in several places the strong organic bond between Article 5 on non-discrimination (tilting against institutionalization) and Article 19 (community living). For example, it says:

> Article 19 reaffirms non-discrimination and recognition of the equal right of persons with disabilities to live independently in the community. In order for the right to live independently, with choices equal to others, and be included in the community to be realized, States parties must take effective and appropriate measures to facilitate the full enjoyment of the right and the full inclusion and participation of persons with disabilities in the community. (Para 18 of General Comment 5.)

The first sentence in the above paragraph effectively invokes the norm of non-discrimination (Article 5) as favouring living in the community (without institutions). The second sentence effectively refers to the more positive focus of Article 19 - how to build up community living.

This has been made even more explicit by draft General Comment 6 on Non-Discrimination which has been put out by the CRPD Committee on 8 March 2018 for consultation and for adoption later in 2018.[9] It should be emphasized that these General Comments are meant to draw together and crystallize the various strands in its established jurisprudence and not to invent new law or understandings. It states (para 58):

> *Institutionalization is discriminatory* as it demonstrates a failure to create support and services in the community for persons with disabilities who are forced to relinquish their participation in community life to receive treatment. The institutionalization of persons with disabilities as a condition to receive public sector mental health services constitutes differential treatment on the basis of disability and, as such, is discriminatory.
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> [Italics added.]

Interestingly, and in keeping with a core thesis of this memo, the draft General Comment also characterizes other forms of segregation (e.g., in employment and education) as a *prima facie* form of discrimination. It is particularly strong on the right of children to be kept out of institutions and to be placed instead in family-like surroundings (para 38).

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9 The draft General Comment no 6 is available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en

In sum, the US Supreme Court interprets US civil rights law to mean that institutionalization is a *prima facie* form of discrimination. The UN CRPD equally 'see's institutionalization as a form of discrimination. While it might be possible to construct an argument to the effect that some form of special treatment or segregated treatment is not only possible but required to accommodate *material difference* then, at a minimum, it would have to be shown that the voice of the person/s affected has been genuinely sought and respected, that the treatment is genuinely part of a broader inclusion strategy and that totalizing institutions that effectively deny any meaningful connections with the broader community are, in any event, not permissible.

iii. Article 19 of the UN CRPD - A Positive Philosophy of Human Flourishing in the community.

Article 5 of the UN CRPD - the overarching norm of non-discrimination - already places all forms of institutionalization on the defensive. Then why was Article 19 needed?

As will be seen, Article 19 is the positive flip side to the non-discrimination idea - setting out the ingredients of what it would mean to live outside institutional arrangements, according to one's own genuine preferences and organically connected to the community.

Much of the content of the Convention follows a traditional approach. The equal opportunities/non-discrimination tool applies to many domains of life to break down barriers to ensure an equal and effective right to participate (education, employment). And much of the Convention seeks to re-engineer social support to ensure that such support does not entrap people but enables them to use their new opportunities. For children with disabilities - indeed all children - this means a right to grow up in a family. And for families it means adequate support to be able to support their children with disabilities and indeed all children.

Added to this traditional mix was an emphasis on the personhood of persons with disabilities. This took two forms: one was the insistence of the equal right of persons with disabilities to self-determination and autonomy in all decision making (Article 12). And Article 19 on the right to live independently and be included in the community also fits here. It makes explicit what is generally assumed for everybody - namely that persons with disabilities have a right, like everybody else, to live on their own terms and be connected with community life.

Article 19 of the CRPD therefore sets out a very positive philosophy of living independently and being included in the community - the positive side of the prohibition against long term care residential institutions that it assumed and grounded in Article 5 of the CRPD (non-discrimination).

The opening chapeau to Article 19 stresses that its main objective is to achieve a right to live in the community for persons with disabilities with '*choices equal to*

others.' On the face of Article 19, these choices refer to choices as to how to live one's own life *in the community* and not otherwise.

Put another way, the long term vision of Article 19 is a web of community-based supports to enable people with disabilities to live in the community. That assumes that at some end point there will no longer be a choice to live in an institution since they will not exist. In the meantime, what we said above with respect to Article 5 (non-discrimination) applies. That is to say, special or segregated treatment must be framed within an inclusive policy and failure to progress it means that the special treatment is not allowable. Further, the genuinely expressed wishes of the person is controlling. And any total form of separate treatment (such as provided by many long term care residential institutions) is not permissible.

Paragraph 1 of Article 19 affords persons with disabilities a right to choose their residence, with whom to live and on what basis and 'are not obliged to live in a particular living arrangement.' This speaks to the centrality of individual autonomy and choice (Article 12) as applied to Article 19 - something conspicuous by its absence in most institutional arrangements in the world today. States cannot keep their funding lines open for long term care residential institutions on a theory that they are just anticipating (and planning for) a possible decision on the part of a person or persons with disabilities to live in an institution. That does not accord with the vision of Article 19 and especially when combined with Article 5 of the CRPD.

All the more so, States cannot invest in long term care residential institutions without an individualized assessment of the genuine will and preference of the persons residing therein. This cannot be *pro forma* - Article 12 is to the effect that persons with disabilities may need to be independently supported to enable them make their choices. If the 'architecture of choice' is already constrained (as it nearly always is with respect to institutions) then there is no real choice.

Paragraph 2 of Article 19 addresses the vital need for individualized and personalized arrangements to ensure that the supports needed to implement Article 19 are tailored to individual circumstances. Implicit in this is the need to make sure that solutions are individualized and not just crafted for lumpen groups. Yet, the very essence of an institution is to congregate people because of common traits (like disability) and not to individualize services. The thrust of Paragraph 2 of Article 19 fits perfectly with the need to re-imagine the European social model to make it more inclusive

And paragraph 3 of Article 19 requires that services already available in the community are made accessible to persons with disabilities thus measurably facilitating their right to live independently and be included in the community. This is a facet of universal design.

Neither of the words 'long term care residential institutions' nor 'de-institutionalization' appear on the face of Article 19. That was because it was assumed - following the non-discrimination norm - that long term care

residential institutions are a *prima facie* form of discrimination (addressed, as it were, by Article 5 of the convention). Instead the framers deliberately intended Article 19 to project a very positive philosophy of independence and flourishing in the community and to lay out what the legal obligations and policy ingredients were to progress the right in that context. By definition, institutionalization is at odds with this philosophy.

The framers did not use the term 'independent living' and choose instead 'living independently.' This was because they were conscious of the disastrous effects of simply decanting residents of long term care residential institutions onto the streets in the early 1980s. That was to be avoided at all costs.

It is to be noted that Article 19 does not distinguish between levels of disability (high or low intensity needs). Nor does it distinguish between different kinds of disability (physical, sensory, psycho-social). Nor does it erect any distinction (direct or indirect) between those who live in long term care residential institutions but who can and should live in the community and those who live in long term care residential institutions and presumptively cannot live in the community. Nor does it make any distinction as to age - both children and older people are included. All are presumptively able to benefit from the right to live independently and to be included in the community.

Put another way, the *material difference* that flows from, e.g., high intensity needs, does not operate in the eyes of Article 19 to detract from the right to live independently and be included in the community.

This insistence on ending long term care residential institutions is all the more obvious when Article 19 is interpreted alongside Article 8 of the UN CRPD which demands that the States Parties nurture receptiveness to the rights of persons with disabilities. Again, we stress that this is inherently impossible when the average person on the street will only see what unites a group in a congregated setting (like their disability) rather than the individual behind the disability.

iv. 'Progressive Realization' of Article 19 does not mean smaller long term care residential institutions.

Since some of the obligations associated with Article 19 (paragraphs 2 & 3) partake of the form of social and economic rights they are, to that extent, subject to the obligation of 'progressive achievement' (governed by Article 4.2 of the CRPD). This obligation is not, however meaningless and does not give an open-ended license to the States Parties to do as they please.

The question naturally arises: what if State X invests in order to progressively downsize long term care residential institutions with a gradual reduction in size from 200 to 100 to 50 persons over, say, a ten year period. Does this qualify as 'progressive achievement?'

One thing is abundantly clear: the creation of (and the expenditure of funding on) ***new*** long term care residential institutions (large, or small, or smaller) is not

permissible. Investing in any institution is presumptively discriminatory. As the UN Committee puts it - while the programme to deinstitutionalize is subject to 'progressive achievement' the actual end goal of deinstitutionalization ('replacement' in the words of the Committee) is non-negotiable. Besides, which it is a palpable waste of taxpayer's money and certainly not in the European public interest.

For another, transitioning away from long term care residential institutions requires foresight and planning. The planning must assume closure - and not way stations toward closure. This does not mean planning for a half-way stage or multiple stages in between. Investment in temporary solutions have a habit of becoming long term. And the cost of undoing these half-way stages is often prohibitive and an effective bar to change in the future - a false economy that entraps people and is a waste of taxpayers' money.

Further, the planning process to eliminate an institution must genuinely include persons with disabilities and their representative organizations (such active consultation is required by Article 4.3). And the implementation of the plan should be closely monitored by independent bodies such as those prescribed for under Article 33 of the CRPD.[10] In sum, the issue is not progressive downsizing: the issue is progress toward replacement (elimination) of long term care residential institutions.

One twist commonly occurs - which is that downsized long term care residential institutions can sometimes be situated in remote areas. That clearly does not amount to community living - no matter how nice the housing is.

Equally, situating a unit spatially in the community is not enough unless thought is given as to how to genuinely include the residents within their community.

v. Reconciling Investments to Improve Conditions within Long term care residential institutions with Investing to Close down Long term care residential institutions:

What then of the need to improve conditions within existing long term care residential institutions?

Inhuman and degrading treatment cannot be tolerated anywhere. Do the States Parties not have an obligation to ameliorate conditions within existing long term care residential institutions to the point that they can no longer be characterized as inhuman or degrading? Can Article 19 (the closure of long term care residential institutions) be postponed until after conditions have been 'humanized' within existing long term care residential institutions? More bluntly,

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10 See Part III. 3, *'Progressive Achievement and the Necessity for a Dynamic of Change & Planned Transition*, in UN OCHR Report, **Getting a Life - Living Independently and Being Included in the Community: Legal analysis of the Current Use and Future Potential of the EU Structural Funds to contribute to the achievement of Article 19 of the UN convention on the rights of persons with disabilities**,' UN OHCHR Regional Office for Europe (Brussels, 2012).

can ESIF Funds be used first to ameliorate conditions in the long term care residential institutions and secondly to move resources to the community and gradually close down the residential institutions?

The answer is clearly not - with one important but tightly controlled exception.

First of all, allowing for an open-ended liberty to invest in long term care residential institutions creates a real temporal complication when it comes to the prime directive of Article 19 (combined with Article 5) which is to close long term care residential institutions. A temporary (and often expensive) fix is highly unlikely to lead to 'progressive achievement' toward closure. In fact, it tends to work the other way round. Temporary fixes consume discrete amounts of monies that are unlikely to be replicated soon (if at all) and if there are subsequent calls for closure that brings into the question the wisdom of spending those monies in the first place.

Secondly, the normative admixture of one set of norms aiming at closure and another set aiming at amelioration seems conceptually confused. Setting one exigency (ending inhuman and degrading conditions) against another (advancing the right to live independently and be connected to the community) is misplaced. They are not two component parts of a natural balancing matrix whereby one naturally yields to the other in the context of resource scarcity. One (ending inhuman and degrading treatment) should not be advanced to the detriment of the other (extending the lifetime of an institution). Or, one exigency should not be excused (not ending long term care residential institutions) on the basis that advancing the other (ameliorating conditions) is more morally urgent.

However, there is one exception. As General Comment 5 (on Article 19 of the UN CRPD) itself states:

> No new long term care residential institutions may be built by States parties, nor may old long term care residential institutions be renovated beyond the *most urgent measures necessary to safeguard residents' physical safety.*
>
> Para. 49.

The UN CRPD Committee concedes above that exceptional investments might be made on the basis of *urgent measures* to advance the *physical safety* of the person. This is already an exception to an important general rule (deinstitutionalization) that has, itself to be read narrowly.

Even the language used points to a balance between Articles 5, 19 and 17 (integrity of the person). It does not point to a balance between Articles 5, 19 and 16 (protection against violence, exploitation and abuse). This is important. The way to deal with, and to end vulnerability to violence, exploitation and abuse, is to close long term care residential institutions - and not more and more regulation which only ends up in 'over-regulated' people.

It is to be noted that various anti-torture treaty monitoring bodies in the UN and the Council of Europe have come closer and closer to characterizing long term care residential institutions as a *per se* form of inhuman and degrading treatment.

Article 17 of the UN CRPD directly refers to the right to 'physical integrity...on an equal basis with others.'

Having said that and given that the UN Committee allows for some interventions/investments where urgently needed to preclude dangers to 'physical safety' then what is permissible? What limiting principles apply?

Even at a strictly textual level, it should be obvious that not everything will count as a threat to 'physical safety.' Logically there ought to be a tight nexus between the relevant investment and physical safety. Physical safety does not mean physical comfort. And indeed, following the language of the Committee, only the *'most urgent'* investments are allowable.

It would also follow logically that the investment would also have to be visibly seen as part of (and not undermining) a larger strategy to close the institution down ('replace' to use the words of the UN Committee). Again, the exception can only be tolerated if part of a genuine long-term pan of inclusion and investment in the community.

And, to forestall abuse of this exception, it is equally obvious that a transparent process must be in place to objectively determine the need for the measure, its urgency, its acceptability to the residents and a genuine exploration of alternatives. There may well be alternatives to such investments which ought to be first explored. Needless to say, the risk assessment of need should be individualized and not simply assumed on the basis of a common characteristic like disability or common residence.

Thirdly, and of particular importance in the EU context, is the question of who (or what) has been the original agent creating the threat to physical safety and allowing it to fester? As a matter of fact, this is hardly ever the EU as such.

If (as is almost always the case) a State has allowed conditions to deteriorate in an institution then it is almost always the State that must simultaneously correct for those poor conditions as well as phase out the relevant long term care residential institutions. However, the European Union, as such, usually bears none of the moral or legal liability for having allowed the conditions that pose a threat to 'physical security' to deteriorate.

Presumptively therefore, EU monies should be spent on the latter (assisting Member States to end long term care residential institutions and transition to the community) and not the former (ameliorating conditions).

Indeed, such a conclusion is copper fastened by the general principle of 'additionality' that is said to characterize the Funds. This assumes that EU monies come *on top of* what a State is already expected to do. It stands to reason

that a State is expected to use its own funds to right its own wrongs, and to draw down on EU monies (if at all) to move in a completely different direction.

The Funds are meant to spark innovation - not to make good for deficiencies for which the EU is not the originator.

2. The Bridge/s between the UN CRPD (non-Discrimination and Community living) and EU Law.

The main purpose of this Part is to trace the organic links betwen the relevant UN CRPD norms and EU law.

This entails an examination of EU ratification of the UN CRPD and its practical implications under EU treaty law, an examination of the two Declarations of Competence made by the EU to the UN (2010 & 2017) which directly cites to the ESIF Regulations (and thus attaches the UN CRPD to the ESIF) and an examination of the portals in EU law through which the CRPD norms become relevant including Article 21 of the EU Charter of Fundamental Rights and Article 7 of the common provisions Regulation.

i. EU Negotiation & Ratification of the UN CRPD - the Centrality of Equality & Non-Discrimination.

The EU participated actively in drafting the UN CRPD. The drafting process started only 5 years after the monumental changes in the Treaty of Amsterdam (1997) that allowed the EU to see disability (and other grounds) through the lens of non-discrimination.

And the drafting of the CRPD started only two years after the adoption of the EU Framework Directive on Equality (prohibiting, *inter alia*, discrimination on the ground of disability in the field of employment).

Indeed, even before the negotiations on the Treaty of Amsterdam had concluded, the European Commission brought senior civil servants on disability issues from all EU Member States to Washington in 1997 to learn about the non-discrimination approach to disability from US Federal officials.[11]

There were three broad options presented to the framers of the UN CRPD. First it might become a social development instrument (as originally proposed by Mexico). This was rejected (even by Mexico). Second, it might become a very fulsome instrument like the UN Convention on the Rights of the Child. This too was rejected as being too cumbersome. Third, it was suggested it might become a simple one page instrument with two or three operative paragraphs that

11 Led by the first named author of this memo. On the shared meanings as between US and EU anti-discrimination law as applied to disability see generally Quinn, G., and Flynn., E., *Transatlantic Borrowings: the Past and Future of EU Non-Discrimination Law & Policy on the ground of disability*, Vol 60, No 1, American Jounal of Comparative Law, (2012) 23-48.

simply outlawed discrimination on the ground of disability (proposed in a non-paper by Finland). This too was rejected since it did not get to the heart of the various rights where tangible obstacles were faced and which had to be more overtly tackled. Fourth, it might become a thematic convention on a specific ground using an overall framework of equality but which applied that philosophy to each right. In doing so, it would identify the ground-specific obstacles to the enjoyment of that right and then frame targeted obligations for their removal.

The last option was the one adopted. It involved a thematic equality-based and non-discrimination based approach - but co-mingled with the various rights. The task was to secure these rights *equally* to person with disabilities which meant tackling discriminatory barriers and creating a more inclusive approach.

The EU took the position - along with most other States - that the non-discrimination norm had to be made real and tied to each of the substantive rights.[12] The non-discrimination provision is both stand-alone (Article 5) but weaves into the body of each other substantive provision. That is why the opening narrative to nearly all the rights is to the effect that they have to be secured on an '*equal basis with others.*' The effect is that each right is to be secured in a non-discriminatory basis.

One simply cannot avoid the overlap of non-discrimination with respect, e.g., to Article 19 which itself uses the formula *'on an equal basis with others*.' The logic of the US Supreme Court (a decision that happened only 3 years before the drafting of the convention) would presumptively apply: dissimilar treatment that leads to social isolation can be characterized as a *prima facie* form of discrimination.

ii. EU Declaration/s of Competence - Pegging the UN CRPD Directly to the ESIF.

Article 44 of the UN CRPD envisaged that a 'regional integration organization' might ratify (adhere) to the same. Such an organization is one to which some sovereignty is conferred from its Member States. Article 44 was tailor-made for the EU. This was subject to a *proviso* that a Declaration of Competences would be laid alongside the instrument of adherence setting out where the regional integration organization has competence (relative to its Member States) with respect to the CRPD.

The original Declaration of Competence was transmitted to the UN by the EU in 2010.

The Appendix to Annex II in the 2010 Declaration sets out a number of legislative and other measures that indicate where the EU has asserted competence to "the extent to which they establish common rules that are affected by the provisions of the convention." Among these legislative measures indicated are Council

12 See de Búrca, supra note 2.

Regulation 1083/2006 (common provisions then governing the ESF and the ERDF). There can be no doubt therefore that from the moment of ratification (adherence) the EU saw a direct link between the UN CRPD and the ESIF.

In its Concluding Observations on the Initial EU Report (2015) the UN CRPD Committee called for an updating of the 2010 Declaration. This was done in 2017. The updated Declaration now specifically refers to Regulation (EU) No 1303/2013 (common provisions Regulation) and Regulation (EU) 1301/2013 ERDF) and Regulation (EU) 1304/2013 (ESF).

Thus, there can be no doubt that the UN CRPD applies to the broad field of the ESIF.

The accompanying narrative in the 2017 Declaration with respect to the ERDF states:

> [T]ransition from institutional to community based care is an investment priority."

And the accompanying narrative to the 2017 Declaration relating to the ESF states:

> [I]t sets down principles, rules and standards for the implementation of the ESF in 2014-2020, including in the areas of *social inclusion, non-discrimination* inter alia of disabled persons and promotion of accessibility."
>
> [Italics added].

That is to say, it refers to the centrality of the non-discrimination norm in the ESIF.

Annex XI to the common provisions Regulation (1301/2013) contains the relevant *ex ante* conditionalities. With respect to the Thematic Objectives of Promoting Social Inclusion, combatting poverty and discrimination as well as Poverty Elimination certain investment priorities were set that include, for the ESF, "active inclusion, and promoting equal opportunities" and, with respect to the ERDF, "investing in social infrastructure...promoting social inclusion...and the transition from institutional to community based services." This framing is important. It is plain that any investment in social infrastructure must promote social inclusion - something that, *prima facie*, cannot be done in a segregated institution.

The relevant *ex ante* conditionality that applies is the existence and implementation of a national strategic policy framework for poverty reduction. And the relevant 'criterion of fulfillment' that attaches is "depending on the identified needs, includes measures for the shift from institutional to community based care."

The relevant *ex ante* points in one positive direction and purports to channel funds accordingly. By implication it inveighs against long term care residential institutions.

Just as important, Article 7 of the common provisions Regulation applies the principle of non-discrimination across all the Funds - implementation as well as design. That being so, Article 7 complements the positive *ex ante* in the Regulations

with a more negative prohibition against long term care residential institutions - drawing as it inevitably does on Article 5 of the UN CRPD.

Put another way, because of EU adherence (ratification) of the UN CRPD there is a symmetry between the UN CRPD's understanding of discrimination and how Article 7 of the common provisions Regulation is to be interpreted.

iii. The Centrality of Non-Discrimination in the EU Charter of Fundamental Rights (Article 21.1).

This article prohibits discrimination on a range of grounds including age, disability, membership of a national minority, etc. It unquestionably applies to, informs and controls, the operation and implementation of the ESIF.

In 2016 the European Commission adopted guidance on ensuring compliance with the Charter when implementing the ESIF. It states:

> ...the UN CRPD forms an 'integral part of the European Union legal order' ([2]). Furthermore, international agreements concluded by the European Union have primacy over instruments of secondary law. Thus, the latter ***must*** be interpreted in a manner that is consistent with the UN CRPD
>
> [emphasis added].

The question arises which concept of discrimination emanates from Article 21 and would it contemplate viewing long term residential institutionalization as a *prima facie* form of discrimination - in much the same way that the US Supreme Court has?

We contend that, in a suitable case, the CJEU would be likely to follow the logic of the US Supreme Court and hold that long term care residential institutions would, on their face, amount to a *prima facie* form of discrimination.

Additionally, Article 26 of the Charter refers to the specific rights of persons with disabilities and reinforces our view of Article 21. It is to the effect that:

> **Integration of Persons with Disabilities.**
> The Union recognises and respects the rights of persons with disabilities to benefit from measures designed to ensure their *independence,* social and occupational integration and *participation in the life of the community*.
>
> [Italics added].

Even the very first word in the title intimates its key orientation. And the words highlighted above also reinforce that view. As some authoritative commenttors on the Charter have stated:

> Article 19 on 'living independently and being included in the community' offers some insight into what might be meant by Article 26 CFR reference to 'independence... and participation in the life of the community....'
>
> This could be read as a list of narrow requirements precluding forced institutionalisation, requiring some degree of social service provision, where deemed 'necessary' and

> prohibiting discriminatory service provision. But it could also create stronger positive duties - the choice of where to live could also include rights to range of suitably adapted social housing....[13]

iv. The Centrality of Non-Discrimination in the ESIF common Provisions Regulation (Article 7).

The prohibition of discrimination is not only central to the EU Charter of Fundamental Rights, it also sits as one of the horizontal common provisions of the ESIF (Regulation 1303/2013- general or common provisions Regulation):

> ...The Member States and the Commission shall take appropriate steps to prevent any discrimination based on....disability, age...in the preparation and *implementation* of programmes...
>
> [emphasis added].

The Regulation goes on to emphasize the necessity of accessibility in the preparation and implementation of programmes.

This provision should also be understood in light of Article 10 TFEU which provides that:

> In defining and implementing its policies and activities, the Union shall aim to combat discrimination based on … disability … .

It is to be observed that one of the criticisms of the insertion of a general prohibition of discrimination included in the previous round of ESIF Regulations was that it generated next to no change in practice at least with respect to persons with disabilities.[14]

Therefore, it should not be assumed that the reinforcement of the prohibition of discrimination in the 2013 Regulations (above) is similarly intended to be mere window dressing or surplusage.

v. The Status of the UN CRPD in EU Law - where/how the CRPD and the ESIF meet.

What difference does the UN CRPD make? Can - should - Article 7 of the common provisions Regulation be interpreted in light of Article 5 of the UN CRPD (the non-discrimination provisions)? That turns on the legal status of the CRPD in EU law.

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13 See Peers, Hervey, Kenner & Ward (Eds.), The EU Charter of Fundamental Rights - a Commentary, (Hart, 2014), at paras 26.35 and 26.36.

14 *Study on the Translation of Article 16 of Regulation EC 1083/2006 for Cohesion policy programmes 2007-2013 co-financed by the ERDF and the Cohesion Fund* (Public Policy and Management Institute (PPMI, Lithuania) in partnership with Net Effect (Finland) and Racine.

Effectively, the UN CRPD lies somewhere between primary EU law (the EU treaties) and secondary EU law (Regulations, Directives etc).

The CRPD is a 'mixed convention' which essentially means that competence is spread or shared as between the EU and its Member States. Article 612(2) of the TFEU is to the effect that:

> [A]greements concluded by the Union are binding upon the long term care residential institutions of the Union and on its Member States.

With respect to such agreements there is a convention that a heightened level of cooperation between the EIU and its Member States will take place to ensure a harmonious approach to implementation. This only serves to underscore a point made earlier - that Member States should take primary responsibility for the amelioration of conditions that they themselves were responsible for creating in the first place.

As indicated above, the provisions of the CRPD are, in accordance with Article 216 TFEU, binding on the EU and its long term care residential institutions. This means that the ESIF Regulations should be drafted and adopted - and implemented - in conformity with the requirements set out in the Convention.

Further, and following the consistent and clear case law of the CJEU, EU secondary legislation (such as the ESIF regulations) should be interpreted in the light of, and so as to give effect to, the relevant obligations contained in international treaties ratified by the EU. This obligation of interpretation of relevant EU secondary law in conformity with international law and international treaties has been laid down as a general matter,[15] and also in the specific context of the CRPD.[16] The Convention is clearly a highly relevant and authoritative interpretive source which should inform the substantive content of the ESIF Regulations.

Further, even without reading in any such obligations, the EU is already clearly failing in its CRPD Article 4.1.a obligation to refrain from any actions inconsistent with the terms of the Convention by not demanding that no investments (no use of the ESIF Funds) in institutions are permitted. Obviously the Member States are themselves separately accountable to the UN CRPD Committee for the use of funds for such a purpose. But the point remains which is that the use of such funds is also questionable purely as a matter of EU law.

To sum up, the relevant non-discrimination provision of the ESIF should be read alongside and in the light of Article 5 of the UN CRPD (the drafting of which in itself was informed by the instructive precedent of the US Supreme Court) to the effect that the mere existence of long term care residential institutions is a form of discrimination. And the relevant *ex ante* conditionality in the ESIF should be read in light of Article 19 - channelling scarce EU resources to assist Member

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15 C-286/90 Poulsen.

16 C-335/11 and 337/11, Ring & Skouboe Werbe, paragraphs 30-32.

States in a positive endeavour to put in place the means for effective community living.

3. Conclusions.

What conclusions are warranted by the above analysis?

First of all, the combination of Articles 5 and 19 of the UN CRPD clearly establish that long term care residential institutions are a *prima facie* form of discrimination that must be ended and Article 19 points to a positive process of transition and replacement.

Second, the question whether high intensity needs amounts to a *material difference* from within equality analysis sufficient to justify or even oblige the creation of long term care residential institutions cannot simply be assumed. The actual wishes of the person counts and must be ascertained in circumstances that allow for realistic alternatives. The separate treatment, if it is allowed, must always be pegged to a larger dynamic of inclusion which foresees measureable investments in alternatives. And in any event, a totalizing option (like a long term care residential institution) that effectively constricts a person's life-chances could hardly be warranted.

Third, 'progressive achievement' does not mean a stepped change from 100, to 50, to 10 bed long term care residential institutions. Progressive achievement refers to the way long term care residential institutions are to be eliminated - and not graduated or with stepped changes in between - which can only delay the inevitable and is a waste of taxpayers' money.

Fourth, investments by Member States in existing long term care residential institutions is permissible but only in the extremely narrow circumstance of advancing 'physical safety.' This has to be interpreted very narrowly as indicated in Part 1.v above. And it has to be part of a larger strategy to ensure inclusion which effectively means investing in the community.

Fifthly, EU law, including the ESIF, should be interpreted in the light of the clear obligations contained in the UN CRPD. The relevant *ex ante* conditionality points to a positive process of change. It implicitly assumes that all forms of institutionalisation must be brought to an end. Article 7 of the common provisions Regulation provides for a strong and capacious concept of discrimination that applies at all stages of implementation of the Funds and should be read in light of Article 5 of the UN CRPD whereby all forms of institutionalisation are to be deemed a *prima facie* form of discrimination.

Finally, the purpose of the ESIF is to spur innovation. Investing monies to fix problems generated by the Member States themselves hardly achieves this. States might themselves invest in institutions under the exception outlined by the UN Committee (urgent repairs to protect physical safety) - but not without

active and prior listening to the voices of the persons involved, not without it being visibly a part of a larger strategy to progress away from institutions and toward inclusion, and not without a process to determine its objective need. Allowing ESIF monies to be spent for this purpose works against the principle of additionality and might even delay the adoption of larger inclusion strategies.

In sum, and on the basis of the above analysis, it is our considered view that spending monies using the ESIF to invest directly or indirectly in long term care residential institutions for persons with disabilities is not permitted under both the UN CRPD and EU law.