



Learning Disabilities: Challenges and Choices in Care & Accommodations

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Human Rights,
Dogma, Domestic Law and Village /
Intentional Communities

International Human Rights

International Human Rights

Plethora of provisions:

European Convention on Human Rights

- Article 5 ~ Liberty
- Article 8 ~ respect for Family Life

UN Convention on the Rights of Persons with Disabilities signed 2007

Article 19 ~ Living independently with full and equal access to the community

+ General Commentaries

United Nations

CRPD/C/18/1



Convention on the Rights of Persons with Disabilities

Distr.: Restricted
29 August 2017

Original: English
English, Russian and Spanish only

Committee on the Rights of Persons with Disabilities

Eighteenth session

14-31 August 2017

Item 8 of the provisional agenda

General comments

General comment on article 19: Living independently and being included in the community

I. Introduction

1. Persons with disabilities have historically been denied their personal and individual choice and control across all areas of their lives. Many have been presumed to be unable to live independently in their self-chosen communities. Support is unavailable or tied to particular living arrangements and community infrastructure is not universally designed. Resources are invested in institutions instead of in developing possibilities for persons with disabilities to live independently in the community. This has led to abandonment, dependence on family, institutionalization, isolation and segregation.

2. Article 19 of the Convention on the Rights of Persons with Disabilities recognises the equal right of all persons with disabilities to live independently and be included in the community, with the freedom to choose and control their lives. The foundation is the core human rights principle that all human beings are born equal in dignity and rights and all life is of equal worth.

3. Article 19 emphasizes that persons with disabilities are subjects of rights and rights-holders. The general principles of the Convention (art. 3), particularly respect for the individual's inherent dignity, autonomy and independence (art. 3 (a)), and the full and effective participation and inclusion in society (art. 3 (c)), are the foundation of the right to live independently and be included in the community. Other principles enshrined in the Convention are also essential to interpret and apply article 19.

4. Independent living and inclusive life in the community are ideas that historically stemmed from persons with disabilities asserting control over the way they want to live by creating empowering forms of support such as personal assistance and requesting that community facilities are in line with universal design prerogatives.

5. In the Preamble to the Convention, States parties recognized that many persons with disabilities live in poverty and stressed the need to address the impact of poverty. The cost of social exclusion is high as it perpetuates dependency and thus interference with individual freedoms. Social exclusion also engenders stigma, segregation and discrimination, which can lead to violence, exploitation, abuse in addition to negative stereotypes that feed into a cycle of marginalization against persons with disabilities. Policies and concrete plans of action for social inclusion of persons with disabilities, including through the promotion of their right to independent living (article 19), represent a cost-effective mechanism to ensure the enjoyment of rights, sustainable development and a reduction in poverty.

International Human Rights

Article 19 - Living independently and being included in the community

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

International Human Rights

GC No.5 (2017) article 19

Independent living/living independently means that individuals with disabilities are provided with all necessary means enabling them to exercise choice and control over their lives and make all decisions concerning their lives. ... Independent living is an essential part of the individual's **autonomy** and freedom, and does not necessarily mean living alone.

International Human Rights

Although, institutionalized settings can differ in size, name and setup, there are certain defining elements, such as:

- obligatory sharing of assistants with others and no or limited influence over by whom one has to accept assistance,
- isolation and segregation from independent life within the community,
- lack of control over day-to-day decisions,
- lack of choice over whom to live with,
- rigidity of routine irrespective of personal will and preferences,
- identical activities in the same place for a group of persons under a certain authority,
- a paternalistic approach in service provision, supervision of living arrangements and usually also a disproportion in the number of persons with disabilities living in the same environment. (para 16)

Dogma and distraction

Dogma and distraction

The Centre for Social Justice (CSJ)

‘It is important that care commissioning decisions are based on evidence-led research and assessment of need **not on ideological considerations.** When making commissioning decisions we should place the individual’s needs and preferences at the heart of process; not the form of care in which these needs are met.’

The Need for Community: A study of housing for adults with learning disabilities
CSJ 2016 cited in *There is no evidence that village or intentional communities cannot meet the principles of Right Support Right Care Right Culture Our Life Our Choice* 30 October 2023

Dogma and distraction

Dogma gets official traction when it offers significant cost savings and transfers risk from the state to the disabled person / their families:

- Strength's based practice
- Mandatory personal budgets
- Closure of all support that might be capable of being characterised as institutional
- Homes bad / community care good
- Normal communities good / non-normal communities bad

Dogma and distraction

CQC Registering the Right Support (2017)

Advocated small services and adopted the view that this meant “usually accommodating small size services”.
Went onto state (at p.7) that it was not intended to be dogmatic – not to be

“overly prescriptive, and it is not our intention to take a ‘one size fits all’ approach but that is exactly what we have done”

Centurion Health Care Ltd v CQC [2018] EWHC 1201



Dogma and distraction

The importance of adding ambiguity into this mix

- Choice
- Autonomy
- Dignity
-

Ambiguities

Choice

undoubtedly for many it has proved to be positive BUT

- Classic transfer of risk / responsiblisation mechanism
- clear information (and personal experience) a precondition for effectively exercising choice;
- increased choice tends to bring with it greater uncertainty and dissatisfaction;
- choice is only of value if positive options are available (ie not a choice between the unsuitable and the inappropriate);
- choice can be detrimental to the common good.

Ambiguities

Autonomy

- Critiques of the Committee's incomplete conceptualisation of 'autonomy' – retaining as it does, strong indications that this means universal / individual autonomy – where 'any interventions by the State in the individual's choices are seen as an interference with their autonomy'.
- Growing body of research of autonomy as 'relational'

See for example Amanda Keeling, (2022) *The Problem of Influence: Autonomy, Legal Capacity and the Risk of Theoretical Incoherence*. In: Donnelly et al (eds.) *Supporting Legal Capacity in Socio-Legal Context*. Bloomsbury

The Care Act 2014

Section 1

The general duty of a local authority [under the Act] is to promote an individual's well-being.

Well-being

“Well-being” relates to:

- (a) personal dignity
- (b) physical / mental health / emotional well-being;
- (c) protection from abuse and neglect;
- (d) control over day-to-day life inc nature of care provided;
- (e) participation in work, education, training or recreation;
- (f) social and economic well-being;
- (g) domestic, family and personal relationships;
- (h) suitability of living accommodation;
- (i) the adult’s contribution to society.

Well-being

“Well-being”

LA must have regard to—

- (a) assumption that the ‘**individual**’ is best placed to judge well-being;
- (b) **individual’s** views, wishes and feelings;
- (c) take into account all the **individual’s** circumstances (and non-discriminatory in terms of stereotyping etc);
- (d) **individual** participating (with support if needs be) as fully as possible in decisions about them;
- (e) a balance between the **individual’s** well-being and that of any friends or relatives involved in their care;
- (f) the need to protect people from abuse and neglect;
- (g) any restrictions kept to the minimum necessary.

Meeting needs

Section 8 (1) The following are examples of what may be provided to meet needs ...

- (a) accommodation in a care home or in premises of some other type;
- (b) care and support at home or in the community;
- (c) counselling and other types of social work; ...

the list is illustrative ... other methods include an individual service fund / the authority funds a provider that holds a budget over which the individual has control etc etc

Statutory Guidance para 10:14

Independent living

- The wellbeing principle is intended to cover the key components of independent living, as expressed in the UN Convention on the Rights of People with Disabilities (in particular, Article 19 of the Convention). Supporting people to live as independently as possible, for as long as possible, is a guiding principle of the Care Act

Guidance (para 1.19)

Assessing needs

AH v. Hertfordshire Partnership NHS Foundation Trust & Ealing PCT (2011)

Facts (taken from the judgment)

- AH lived in purpose built high quality 'bespoke' service for 33 residents in a rural location that was both safe and tranquil.
- AH 48 years with autism and severe learning disabilities non-verbal highly distressed / unsettled by moves and a long list of difficult behaviours including a particularly troubling form of pica all of which exacerbated by changes in his routine or environment, but all of which had steadily reducing since he has been at SRS (10 years previously).

AH v. Hertfordshire Partnership NHS Foundation Trust & Ealing PCT (2011)

It was proposed that AH move to a secure flat in Ealing with a 150 foot garden. There would be sensors so that staff would be aware of their moving around. He would be able to personalise his space and his routine.

It was accepted by Ealing that AH's needs were being well met where he was and that there would be an immediate detrimental impact of any move 'that would be felt by AH as a 'bereavement'.

AH v. Hertfordshire Partnership NHS Foundation Trust & Ealing PCT (2011)

The only identifiable impetus for the move was the philosophy of Valuing People and its message that too often adults do not get choices.

Ealing accepted that it had never conducted a baseline exercise about whether it was in AH's interests to move or not. Its assessments had either been conducted on the assumption that he would one day have to move, or took the form of arguments justifying a decision already taken.

*AH v. Hertfordshire Partnership NHS Foundation
Trust & Ealing PCT [2011] EWCOP 276*

Judgment Mr Justice Jackson

10. While care in the community may not be without its problems, it is clear that many, perhaps most, of those settled after lifetimes in long-stay hospitals have benefited. However, it is not an absolute policy, still less is there anything unlawful about 'campus living'. [citing a Government 2000 statement that] emphasised the importance of ensuring that 'any decisions are based on the overall best interest of the individual', and continued:

AH v. Hertfordshire Partnership NHS Foundation Trust & Ealing PCT (2011)

- ‘The Government are strongly committed to ensuring that people with a learning disability have the right to choose the kinds of services and accommodation they prefer ... We also acknowledge that small-scale domestic accommodation can often provide a high quality of care. Such accommodation can offer more potential for social inclusion and enhanced rights. However, as in any society, some people choose - for a variety of reasons - to live in alternative communities ... People with a learning disability should also have that right and choice wherever possible’

AH v. Hertfordshire Partnership NHS Foundation Trust & Ealing PCT (2011)

Judgment para 77

- Although [Ealing's] ambition to maximise AH's opportunities is laudable, it has not been possible to identify a single dependable benefit arising from the proposed move. The thesis is that it would provide him with a greater experience of ordinary life in a local community, and that this would improve his quality of life. Each element of this proposition is incongruous with the realities of AH's life. His experience is so far from being ordinary that it is not useful to use ordinariness as a yardstick. Ealing is not local for AH and there is no community there which would be meaningful for him.

AH v. Hertfordshire Partnership NHS Foundation Trust & Ealing PCT (2011)

Judgment para 77

- I also accept the evidence ... that the prospect of him living a more expansive and fulfilled life following a move is a chimera. It is more likely that it would lead to a deterioration from which he might – or might not – recover. It is not enough to say that ‘the benefits of community living may matter to AH’ if one cannot show that they will. Facing up to these realities does not in any way diminish or demean AH, but values and respects him for who he is.

AH v. Hertfordshire Partnership NHS Foundation Trust & Ealing PCT (2011)

Para 80

guideline policies cannot be treated as universal solutions, nor should initiatives designed to personalise care and promote choice be applied to the opposite effect.

... .

These residents are not an anomaly simply because they are among the few remaining recipients of this style of social care. They might better be seen as a good example of the kind of personal planning that lies at the heart of the philosophy of care in the community.