

Written Submission

United Nations Committee on the Rights of Persons with Disabilities – draft General Comment on the right of persons with disabilities to live independently and be included in the community (Article 19)

19 June 2017





Introduction

The Law Society of Scotland is the professional body for over 11,000 Scottish solicitors. With our overarching objective of leading legal excellence, we strive to excel and to be a world-class professional body, understanding and serving the needs of our members and the public. We set and uphold standards to ensure the provision of excellent legal services and ensure the public can have confidence in Scotland's solicitor profession.

We have a statutory duty to work in the public interest, a duty which we are strongly committed to achieving through our work to promote a strong, varied and effective solicitor profession working in the interests of the public and protecting and promoting the rule of law. We seek to influence the creation of a fairer and more just society through our active engagement with the Scottish and United Kingdom Governments, Parliaments, wider stakeholders and our membership.

The Society's Mental Health and Disability Sub-committee welcomes the opportunity to consider and respond to the United Nations Committee on the Rights of Persons with Disabilities draft General Comment on Article 19. The Sub-committee has a very significant amount of direct experience and expertise available among its membership of personal engagement with supporting people with intellectual disabilities in relation to exercise of their legal capacity. Among its members and observers it also has a unique amount of experience of membership, in a capacity of offering legal expertise, of the principal national organisations of and for people with various intellectual disabilities.

The Sub-committee is currently taking a leading role, in conjunction with Scottish Government, in reviewing current legislation in Scotland in order to introduce reforms necessary to achieve compliance with the Convention on the Rights of Persons with Disabilities.

The Sub-committee has the following comments to put forward for consideration.

General – identification of paragraphs in the Draft General Comment

In this submission "paragraph" refers by number to a paragraph of the draft General Comment. Please note, however, that in general this submission refers to themes which should be strengthened, added or adjusted throughout the report: references to paragraphs identify the principal paragraphs generating our comments, but not all of those where adjustment might be appropriate if the principle of our comments is accepted. "Article" refers by number to an Article of the Convention on the Rights of Persons with Disabilities.



Specific Comments

Paragraphs 4 and 12

To an increasing extent, people with disabilities in Scotland are being denied their right to choice of residence under Article 19. In the personal experience of members of the committee, support and related funding is reduced below levels reasonably necessary to support them in their own homes, in order to pressurise them to move into nursing home or group accommodation. Alternatively, they are pressurised to allow someone else with a similar disability to live in their own homes on a board and lodging basis, so that necessary support can be provided more cheaply: typically these are not a friend or companion chosen by the person with disability, but someone chosen by social work authorities on the basis that they have similar care needs. In relation to all violations of their rights, people with disabilities should have the same access to legal services and legal representation as people without disabilities whose rights might be threatened. People with disabilities in Scotland (and probably elsewhere) are generally more in need of Legal Aid services. However, funding policies adopted by the Scottish Government and implemented by the Scottish Legal Aid Board routinely prevent even experienced lawyers from spending sufficient time to interact with people with disabilities in order to ascertain the will and preferences of each in relevant matters, and to ensure that human rights and legal entitlements are understood by persons with disabilities (which often requires duplication of explanation, for example both in face-to-face meetings and thereafter in writing, either to the person with disabilities or to a trusted supporter). In paragraph 4 and elsewhere, the provision of the services of a lawyer to address violations, or threatened violations, of Article 19 should be explicitly mentioned as a form of support. In paragraph 12 and elsewhere, there should be mention both of the need for availability of such legal services, and the need for them to be fully and adequately funded for persons with disabilities not otherwise able to afford them.

In making the above comments we acknowledge the assertions in paragraph 67, but the link needs to be made between that paragraph and other references to provision of support, and adequate funding of that provision.

Paragraphs 15(b) and 16

These paragraphs should be adjusted to emphasise that they apply fully to people with intellectual disabilities and that needs for choice and personal control should include situations where these can only be met by measures for support of the exercise of legal capacity compliant with Article 12.4.



Paragraph 23

This paragraph oversimplifies, and risks unhelpful misinterpretation, by referring simply to a "shift from the medical model to the human rights model of disability". There is a risk that this will be interpreted in many quarters as meaning that where a medical model has been abandoned, what remains will automatically be fully compliant with international human rights standards. That is not the case. A shift from a medical model to a social care model may not, and in our experience often does not, amount to a satisfactory shift to a human rights model. A human rights model is only achieved if persons with disabilities are treated primarily as holders of rights, rather than objects of care – meaning any category of care. The experience, and concerns, expressed above about violations of Article 19 with a view to delivering necessary support more cheaply are an example of violations arising from a social care model, not a medical model.

Paragraph 34

As drafted, this paragraph presents the danger that support and other services will be geared to the generality of disabilities in a particular community, to the disadvantage of a person with unique disabilities. It should be stressed that this form of planning should never be allowed to justify inadequate or inappropriate provision for anyone with rarer or unique disabilities.

Paragraph 38 and elsewhere

There should be acknowledgement that for some people with particular disabilities it can be harmful, and sometimes acutely distressing, to enforce policies of non-segregation. This can apply at least at times to people with agoraphobia and some forms of autism, for example.

Paragraph 42

The requirement for adequate planning by states parties should not limit or discourage inventive private initiatives. These should be encouraged, provided that they are seen as additional to, rather than in place of, the basic obligations of states parties.

Paragraph 47

It is important to stress that Article 19 rights include the right to choose to remain in the same home, and that Article 19 rights are violated if a person is presented with choices all predicated upon removal from the existing home, and which do not include adequate support to remain there.



Paragraph 48

The last sentence is predicated upon models of guardianship and mental health laws which are designed to force people into institutions, which are now outdated in many countries where – on the contrary – guardianship laws in particular support community living and transition out of institutionalised care.

Paragraph 52

There should be explicit prohibition here of policies by Legal Aid authorities which have the effect of depriving people with disabilities who cannot afford legal services of the right to legal representation to prevent or remedy violations of their Article 19 rights.

Paragraph 53

In the last sentence of this paragraph, in order to avoid "de facto guardianship" there should be explicit obligations to provide – for those who need them – measures relating to the exercise of legal capacity that are fully compliant with Article 12.4.

Paragraphs 56, 65 and elsewhere

We acknowledge that upon careful reading the draft does not limit "institutionalization" and "deinstitutionalization" to references to old-fashioned concepts of care in large institutions. However, this is not sufficiently strongly emphasised and there is a significant risk of assumptions that compliance in this respect has been achieved simply if people have been removed from old-style institutions, and/or are no longer admitted to them. If the terms "institutionalization" and "de-institutionalization" are to continue in use at all, we would recommend a specific project (or subproject, which could of course be part of this drafting exercise) to create suitably clear and comprehensive definitions. Necessary elements of a definition of "institutionalization" should make it clear that any one of a list of criteria could amount to institutionalisation regardless of living arrangements, and thus including any form of living alone, living alone with family, shared or group accommodation, and so forth. The criteria would all relate not to living arrangements, but to lived experience. They would include elements such as "one size fits all" provision; services determined by diagnosis of a particular disability rather than the total wishes and needs of the individual (including but not limited to those resulting from the disability); failure to provide and properly operate measures of support for exercise of legal capacity, where needed, which comply with Article 12.4 safeguards; and so forth. Concentrating on lived experience would also recognise that some persons with disabilities may choose to live in communities which may – superficially – resemble institutional facilities. It is just as wrong to break up such a community – if it reflects genuine choice (where relevant, 'constructed' on the individual's behalf in such a way as to comply with Article 12.4) – as it is to require an individual to live in such a community. In other words, the right to independent living must encapsulate the right to live in the



way the individual chooses, rather than an (understandable) drive to de-institutionalise, which has shades of forcing individuals to be free.

Paragraph 74

The converse of the first sentence is also true. What should be emphasised is that an appropriately wide range of choices should be available, and there should be full support for the right to make choices and then, subsequently, to alter them.

Paragraph 76

This should be expanded to cover barriers faced by people with intellectual disabilities, and not just barriers of a more physical nature. Typical and frequent barriers are those wrongfully placed by banks and financial institutions in the way of exercise of relevant measures, even measures (such as powers of attorney) put in place by people themselves.

Paragraph 78

Under reference to our comments on paragraph 34 above, the assertion that "they have to be a part of the community" should be deleted. Where people have a strong and consistent will and preference for solitude, or to engage only with well-known others, that should be respected, whether a consequence of a disability or not, and whether of a temporary or permanent nature.

Conclusion and further comment

This submission is designed to assist improvement of what we believe to be the underlying intentions of the draft General Comment. We support those intentions. We particularly support the recommendation in paragraph 94(b) as regards promotion of the principle of universal design in law. We would suggest that the Committee consider suitably supporting projects to develop the principle of "reversed jurisprudence", involving a shift from expressing laws as they would apply to adults with no significant disabilities or susceptibilities, then trying to accommodate the latter by way of special provisions, moving instead towards expression of all laws in fully inclusive form, containing protective and supportive provisions which will not be required by everyone, but will be required by some in society (regardless of disabilities, but including some people with some disabilities).



For further information, please contact:

Marina Sinclair-Chin Policy Team Law Society of Scotland

DD: +44 (0)131 476 8136

marinasinclair-chin@lawscot.org.uk