

DISABLED PEOPLE (COMMUNITY INCLUSION) BILL 2015 ('#LBBILL') Explanatory Notes for Draft 2

These notes explain the background and contents of the Disabled People (Community Inclusion) Bill 2015, which is now at its second draft. The Bill been put together by the Justice for LB campaign and has the shorthand 'LBBill' in memory of Connor Sparrowhawk, whose nickname was 'Laughing Boy'.

Connor was a fit and healthy young man, who loved buses, London, Eddie Stobart and speaking his mind. He also happened to have autism and epilepsy. On 19 March 2013, he was admitted to Slade House Assessment and Treatment Unit run by Southern Health NHS Foundation Trust. After 107 days in the unit, he drowned in the bath on 4 July 2013. An entirely preventable death.

The Justice for LB campaign was formed to harness the energy, support and outrage that emerged in response to LB's death and ensure that lasting changes and improvements are made. In addition to campaigning for accountability for Connor's death, the Justice for LB campaign has a set of wider objectives to seek to stop what happened to Connor happening to other young people. The full list of campaign objectives is here: <http://107daysofaction.wordpress.com/what-does-justiceforlb-look-like/>

The discussions about the wider change required led to the campaign proposing legislation in the form of a Private Members Bill, which on social media has been called '#LBBill'. The thinking around #LBBill to date, including the process and timeline, is at www.lbbill.wordpress.com

The second draft of the Bill contains a range of provisions which are intended to reinforce disabled people's right to live in the community in the place they choose. The basic idea behind #LBBill is that the law should make it harder for the state to force disabled people to go into institutions and to keep them there, where this isn't what the disabled person and / or their family want. Unless the measures in the bill are adopted by government, the campaign plans to lobby backbench MPs to adopt the bill in the 2015 Private Members Bill ballot.

This second draft of the Bill remains for discussion. Everything in the draft Bill is up for debate and a third draft will be produced if there is significant feedback suggesting further changes. Justice for LB would like the widest possible debate about the Bill – please contact us if you can arrange an event, distribute materials or otherwise spread the word.

You can get in touch with the Justice for LB campaign in the following ways:

- email justiceforLB@gmail.com
- Twitter [@justiceforLB](https://twitter.com/justiceforLB) – or use the hashtags **#justiceforLB** or **#LBBill**
- Facebook – there are groups both for '**Justice for LB**' and '**LBBill**'
- Via the Bill blog – www.lbbill.wordpress.com – where you will also find an Easy Read version of the Bill and these notes and a background paper explaining why we are trying to change the law and what we hope to achieve.

You can say anything you like about the Bill. We would particularly welcome responses to the following questions:

1. Do you think it is a good idea to campaign for a Private Members Bill to change the law in these ways? If not, why not?
2. Are there any 'big issues' in relation to the way in which disabled people are forced into residential care that this draft of the Bill doesn't cover?
3. Do you understand what each of the current draft clauses is trying to achieve?
4. Do you agree with the current draft clauses? Are there any that would make things worse rather than better?
5. Is there anything in the wording of the current draft clauses that you would like to see changed?
6. Which terms used in the draft Bill do you think need to be defined?

There are some specific questions about each of the draft clauses in the notes below.

Commentary on draft clauses

Clause 1. Implementation of Article 19 of the Convention on the Rights of Persons with Disabilities

This clause has been strengthened as a result of feedback on the first draft. Instead of requiring 'due regard' to community inclusion, clause 1 would now require local authorities and NHS bodies to achieve an outcome, being that 'ensure that all disabled people can live in their community, with choices equal to others and the support necessary to ensure their full inclusion and participation in the community.' There are further specific outcomes which local authorities and NHS bodies would be required to achieve, drawn from Article 19 of the UN Convention on the Rights of Persons with Disabilities.

Do you agree that it is right to change clause 1 from a general principle to a duty to achieve specific outcomes?

Should the Bill begin with any further or different principles?

Clause 2. Residential care not relevant to decisions in relation to community support for disabled people

Clause 2 is designed to address a growing problem, which is that public bodies are using the cost of residential care (or residential college places) as an effective cap on the cost of care they are willing to provide to a disabled person in their own home. The consequence of this is that a disabled person would either have to accept less care at home than they need or go into residential care. We do not accept that this approach is lawful at the moment – and the Care Act guidance agrees – but this isn't clear. Clause 2 would clearly state that the cost or availability of residential care is not relevant to any question to do with care in the community.

Do you agree that this is the right approach?

Are there situations where the cost or availability of residential care or residential college provision ought to be able to be considered?

Clause 3. Duty to secure sufficient supply of community support

The wording for draft clause 3 again draws on Article 19 of the UN Convention on the Rights of Persons with Disabilities. The clause is drafted as a ‘sufficiency duty’, which is now a common approach Parliament takes to social welfare law. What it would do is to require the state to ensure that there is a sufficient supply of community support in every local area and so reduce the need for residential care.

After feedback on draft 1, clause 3 now contains the following additional obligations:

1. A requirement that sufficient services must be available to assist disabled people and families in crisis
2. A requirement that disabled people must be employed in the teams responsible for the planning and commissioning of services
3. A requirement to report on the steps taken to meet the duty
4. An obligation to produce a ‘local offer’, which mirrors a key part of the reforms to disabled children’s services (see section 30 of the Children and Families Act 2014)

Do you agree with the principle in clause 3, as amended for the second draft? If so, does it go far enough?

Clause 4. Duty to secure most appropriate living arrangement

Clause 4 is designed to do two things. Firstly, it aims to keep disabled people in their own homes when this is the most appropriate place for them to live. Secondly, if it isn’t possible for the disabled person to live at home (or they don’t want to do so) then it requires high quality residential provision to be made which is suitable to the disabled person’s needs and respects their wishes, feelings and preferences.

A new consultation requirement has been added to clause 4 as a result of feedback on draft 1.

We have accepted that the resources available to the public body should be relevant to the question of which living arrangement is most appropriate. However as a result of feedback we have added to clause 4(4) a provision that the right for disabled people to choose where they live (clause 1) overrides resource constraints.

The review requirement has also been significantly strengthened – see clause 4(5) and (6).

Does clause 4, as amended, provide enough of a safeguard?

Are there any other needs to which the public body should have regard in determining which living arrangement is most appropriate?

Clause 5. Living arrangements to be subject to approval

Clause 5 has been amended to make clear that all living arrangements which are made for disabled people by the state, not just 'residential' arrangements, will need to be approved.

The people who can give approval are:

- For children under 16, the child if they have capacity, otherwise their parent or the Family Division of the High Court
- For children aged 16 or 17 and adults, either themselves (if they have capacity to decide) or the Court of Protection, the Court set up to deal with questions of mental capacity and best interests under the Mental Capacity Act 2005, or an Attorney or Deputy.

To make the right to give approval real, the public body would be required to provide a range of information – both to the person giving approval and to the disabled person and anyone else interested in the disabled person's welfare, unless the disabled person objects.

Do you agree with the people who we have suggested should give approval?

Is there more information which we should require to be provided?

Clause 6. Duty to report on living arrangements and community support

Like clause 5, clause 6 has been amended so as to require reporting on all living arrangements made by the state, not just 'residential' arrangements. Local bodies would report on a case by case basis and the Secretary of State would publish a summary of this information annually.

Do you agree with the idea of requiring this information to be published?

Is there other information which should be published?

Should we require information to be published elsewhere than on websites? If so where?

Clause 7. Amendments to Mental Capacity Act 2005

We think the Mental Capacity Act 2005 ('MCA') can be changed in some specific ways to better protect the rights of disabled people and families. We recognise that the Law Commission is currently conducting a major review of the MCA with a particular focus on deprivation of liberty. However we believe that these changes do not need to wait for a full review but could and should be made now – particularly as

the Law Commission will not report until 2017 and any new legislation will come some time after that.

The changes to the MCA proposed in clause 7 are:

- A requirement to consult with the disabled person and their friends and family members before their capacity to make a decision is decided – not just at the later point when their ‘best interests’ are determined if they lack capacity.
- A requirement to treat the disabled person’s wishes, feelings and preferences as a primary consideration in best interests decisions. This reflects the recent report from the Essex Autonomy Project which says that the current wording on disabled people’s wishes and feelings is not compliant with Article 12 of the UN Convention on the Rights of Persons with Disabilities.
- A requirement, taken from the current Irish Bill, to give proper regard to disabled people’s rights in best interests decision making.
- A stronger obligation to consult with families in best interests decision making.

Do you agree that these issues can be addressed now or should changes to the MCA wait until the Law Commission has reported?

Do you agree with these proposed changes to the MCA?

Are there other issues with the MCA that this draft Bill should address – bearing in mind that the purpose of the Bill is to help keep disabled people out of residential care.

Clause 8. Removal of people with learning disabilities and autistic spectrum conditions from scope of Mental Health Act 1983

Clause 8 is simple but we think it is likely to be controversial. Its effect is to remove people with learning disabilities and autism spectrum conditions from the scope of the civil parts of the Mental Health Act 1983 (‘MHA’). This means that these people could not be ‘sectioned’ or otherwise treated under the MHA unless they also had a diagnosis of a recognised mental illness (known as ‘comorbidity’). If a person with a learning disability or autism needed to be detained, then this would have to be done under the MCA (assuming they lacked capacity to decide whether the detention was necessary, which we think is a reasonable assumption).

We think this is the right approach because the culture of treatment under the MHA does not properly respect the rights and needs of disabled people who do not have mental illnesses. However we are aware that family members of disabled people who are detained under the MHA in fact have strong rights, particularly the nearest relative. So we want to hear people’s views about whether the issue is in fact about awareness of these rights, or if it is wrong in principle (which is our current view) that disabled people should be treated under mental health legislation where they don’t have a mental illness.

Originally clause 8 would have removed people with learning disabilities and autism spectrum conditions from the scope of the MHA entirely, but much feedback said that this would be seriously problematic in relation to the criminal parts, as the result

would be more disabled people sent to prison. We would welcome more discussion and debate on this difficult question.

Should people with autism and learning disabilities be eligible for treatment and detention under the MHA?

Is it right to preserve the criminal parts of the MHA to avoid more disabled people being sent to prison?

Clause 9. Duty to provide community mental health services to disabled people

Clause 9 has been added as a result of the debate on clause 8, the proposed removal of people with learning disabilities and autism spectrum conditions from the scope of the MHA.

It seems to us that while preventing disabled people from being inappropriately 'sectioned', it is also necessary to ensure that their mental health needs are properly met. Clause 9 would address this by requiring the provision of appropriate mental health services in every area. This is an exception to the general approach that the Bill is for everyone, regardless of diagnosis. It reflects the particular mental health difficulties and exclusion from services that people with learning disabilities or autism spectrum conditions are likely to experience.

Do you agree that the Bill should contain a specific provision relating to the mental health needs of people with learning disabilities and autism spectrum conditions?

Clause 10. Duty to involve disabled people and supporters in decisions made about their care

Clause 10 is intended to address a problem which was raised repeatedly in feedback on draft 1 – that decisions on health and care services for disabled people are taken in 'secret' panel meetings without proper involvement of disabled people, their families and other allies.

The Care Act guidance is critical of the use of panels – but we think the law should ban their use outright. Any meeting that considers the care or health needs of a disabled person should be open to that person and those around them to attend and contribute.

Is the principle in clause 10 the right one? Have we gone far enough to ensure a fair decision making process?

Clause 11. Guidance

Some of the ideas in the Bill are quite complex and we think to make it a reality there should be statutory guidance issued by the Secretary of State to local authorities and

NHS bodies. The bodies subject to the guidance would have to follow it in the absence of a considered decision that there was good reason not to do so.

Do you agree that guidance would be helpful?

Is there anything we should specify that the guidance must (or must not) include?

Please send us your views and comments on these questions or any other issues relating to #LBBill and the draft clauses:

- email justiceforLB@gmail.com
- Twitter [@justiceforLB](https://twitter.com/justiceforLB) – or use the hashtags [#justiceforLB](https://twitter.com/hashtag/justiceforLB) or [#LBBill](https://twitter.com/hashtag/LBBill)
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