Inclusion Scotland and People Led Policy Panel webinar

National Care Service Bill changes

20 July 2023
Today we are going to talk about:

The changes Inclusion Scotland would like to see to the National Care Service Bill. These are called amendments.

We will speak about a human rights-based approach to the bill and its delivery.
Scottish Government will update us on their own plans for the bill.

We will talk about other amendments we want to see.
What is missing and what should be changed.

We want to hear from you:

What are your concerns about the Bill? Do you think our amendments are right? Would you want to see something added?
Questions and discussion
What (we think) is missing?

- Self-Directed Support
- Numerous rights including Independent Living (and UN CRPD)
- Our own Human Rights Based Approach
- Evidence based practice and monitoring
What (we think) is missing?

- National eligibility based on need
- Inclusion of people with lived experience (support people and unpaid carers) in decision making
- Care Boards should be made up of people with lived experience and co-design/ co-production should be used throughout planning and delivery.
Inclusion Scotland’s priorities

- Ensure human rights are at heart of bill
- Independent living is defined clearly
- **Right to Need Satisfaction** is in the Bill

The Right to Need Satisfaction is an idea by Jim Elder-Woodward.

It will give people more rights to have their needs met under a new National Care Service.
• A wider approach to human rights than just PANEL

• A strong Charter of Rights and accountability

 **Accountability** means that there is someone in charge that is held responsible if things go wrong.

• Strengthening of **governance** and representation

 **Governance** is how a country or organisation is managed at the highest level
• Expand NCS principles in co-design with people with lived experience (e.g. to include commitment to capacity building, independent living rights, etc)

• Definitions of Advocacy and commitments to when it applies

• Data collection (unmet need) and strategic planning (with supported people and carers)
Our Priorities (continued)

- Ownership and access to care records
- Complaints and redress
Human Rights Based Approaches

What is a Human Rights Based Approach?

Human rights are a very useful tool for people who want to campaign for better services and support.

This is because they say how people should be treated.

Anyone can look at what human rights say should happen and see if this matches what is happening in their own life.

For example, deaf and disabled people can look at the rights they have in the CRPD.

They can check whether public authorities, like the NHS and the council, are doing things to make these rights real.
PANEL principles

**Principles** are the basic rules that need to be followed.

To help people remember all of these principles, we use the word **PANEL**.

- Participation
- Accountability
- Non-discrimination (equality)
- Empowerment
- Law
Are the PANEL principles enough for the delivery of social care support?

Or do we need to develop our own Human Rights Based Approaches (HRBA)?
Consider the following

- Vulnerability
- Power Relations
- Citizenship
- Justice
- Approaches to conflict
- Further accountability
- Dignity
Disabled people developed our United Nations Convention on the Rights of Disabled people (UN CRPD) to ensure these rights applied to our lives.

If the Bill is to have a human rights-based approach, the rights in the UN CRPD should be in the principles of the bill.

It should state how these rights should be delivered and measured.

We need a set of things that can be measured to show that rights are being delivered. These are called ‘indicators’.
Article 19: Independent Living

Independent Living means

• Living the life you want (having control)
• Making your own choices in your life.
• Being treated with dignity and respect
• Having the support and help when you need it to be fully included in society.
Independent living does not mean living on your own and fending for yourself.

It means a right to the practical support to take part in your community and to live an ordinary life.
Independent Living Jigsaw – showing the inter-relationship of the various aspects of independent living as experienced by the individual; one of which is Personal Assistance (SDS)
• A fully-accessible transport system

• Full access to the environment

• Adequate provision of technical aids and equipment
• Availability of accessible and adapted housing

• Adequate provision of personal assistance

• Availability of inclusive education and training
• Equal opportunities for employment

• Availability of independent advocacy and self-advocacy

• Availability of peer counselling
Break

15 minutes
Workshop 1

• Is PANEL enough? Do we need wider Human Rights Based Approaches (HRBAs) for the National Care Service?

• What do these look like?

For supported people? For Social Workers? For unpaid carers? For social care support providers?

• What can wider HRBAs achieve?

• How can they be measured?

• Where does the right to independent living fit in this (Scottish Government says that SDS (SC) (Scotland) Act 2013 has this definition – choice and control - but is it enough?)

• How can we ensure all the areas in the Independent Living Jigsaw are linked?
A right to need-satisfaction

This is a summary of a paper written by Jim Elder Woodward.

This “Right” will become important when people get their needs assessed or reviewed by the Social Work Department or any other government body.

At these times people can feel vulnerable and scared.
They may not have the information on services, people, or equipment, which could help them meet their needs.

Or, they might not have the help to express their needs.

This “Right” would help people feel **empowered** to have their needs heard,

And for the **satisfaction** of those needs to become central to the whole process of assessing them.
It won’t guarantee that all people’s needs will be met; but it will put them in a **stronger** position.

And if they are not met, then it will be people’s right to have them recorded for their next review.

Bringing together everyone's ‘unmet need’ will help plan future services nationwide.
What happens now?

- Determined by cost not needs
- No ability to appeal
- People can feel vulnerable and unable to speak up
- Decisions are made without involving the person and their family/supporters.
- People get what is available not what they need
What would right to need satisfaction give people?

Before the assessment

- Easy to understand information and accessible information
- That is right for the individual
- Right to independent advice and advocacy
- Time to prepare
Rights during assessment

- Advice and advocacy during the assessment if you want to help argue your needs
- You must be present in any meeting about your needs
- Time out in the meeting to gather thoughts and to calm yourself if needed
Rights after assessment

- Time after the meeting to look over your notes by yourself or with your advocate

- If you are unhappy you can write your own assessment or an advocate can support you

- This assessment will be looked at in a meeting along with the original assessment

- A discussion is held about the 2 plans and a new plan agreed

- If no agreement can be made, you have the right to an independent appeal
Charter and Accountability

- A full definition of independent, peer and collective advocacy (see Scottish Independent Advocacy Alliance). Why this is important.

- Commit to including the provision of independent, peer and group advocacy services within strategic planning.

- All these types of advocacy must be funded in the long term and to ensure coverage across the country.
Data Collection

- Should feed into strategic planning

- Use the Right to Need Satisfaction to record individual, local and national record of unmet need to assist with planning to meet it.

- Ensure data collected is intersectional

- That it can be used to measure lived experience of the NCS and to plan for improvements (including from complaints data).
Strategic Planning

Subsection 3 says local Care Boards should “consult on draft plans with community; National (Special) Care boards should consult on these plans with “the public in Scotland”.

Efforts need to be made to include people with lived experience in planning and ensure they are accessibly engaged with on any plan.

Go further, with an obligation to co-produce strategic plans and ethical commissioning with supported people/unpaid carers.
The bill should be more specific about who to engage with on local and special care board plans. Change from ‘local community’ and ‘Public of Scotland’, respectively, to:

[Subsection 3](a) … ‘the board must seek views on a draft of the plan from—

b) i) In the case of a local care board, **supported people**, their families, supporters/ unpaid carers, with support and timely accessible information for their meaningful involvement and *may* seek views from the wider public.

ii) In the case of a special care board, **disabled/** supported people, including people with mental health conditions and their organisations; their families, supporters/ unpaid carers and their organisations, with support and timely accessible information for their meaningful involvement.
On strategic planning, the following questions need to be addressed in the bill

- What is the relationship between the strategic plans of the care boards and the Ministers?
- What is the value of care board strategies?
- Who monitors these strategies?
- What happens if there is a divergence between these strategies?
Governance and Representation

2(1) and 2(2) lays too much authority on Ministers, who are distant from the day-to-day operations of care board management of individual cases.

We’d like to see a national Care Service Ministerial Advisory group with lived experience on it, supported, paid and trained. As per CCPS call: “a national forum for co-design and collaborative leadership”.

Commitment to co-design and coproduction at all levels of governance. This should include training of people with lived experience and their collectives.

Multiple representatives of lived experience on care boards (local and national/ special), supported to be involved in decision making and voting rights.
Care Records – Access and Ownership

Care records need to be freely available at all times to the recipients of health and social care support. Recipients may allow their families and advocates to have such free and immediate access but only with their active consent.

With supported decision making available for this for those that need it.
Strengthen the requirement to set up a robust complaints system that delivers accountability and justice for supported people and unpaid carers. Must not may.

Advocacy support for making complaints
Questions and discussion
Workshop 2

Is there anything else missing from the Bill?

Do you think these are the right priorities for amendment?

What do you think of our suggested changes?
Feedback

End of Meeting