Integrated Care Systems: CB-NSG Feedback

THE CHALLENGING BEHAVIOUR FOUNDATION

The Challenging Behaviour Foundation

making a difference to the lives of people with severe learning disabilities

Introduction:

The following feedback on Integrated Care Systems (ICS) and Provider Collaboratives (PC) was delivered at the Challenging Behaviour National Strategy Group (CB-NSG) Autumn meeting on the 22nd of November 2021.

The CB-NSG is made up of a range of different experienced stakeholders working together, motivated to drive change to make a real difference to the lives of children and adults with learning disabilities whose behaviour challenges. During the Autumn (2021) CBNSG meeting, a presentation on ICS and PC was given and attendees then split up into breakout rooms to answer a series of questions on ICS/PC and discuss the new healthcare structures.

Key Themes:

CB-NSG attendees were allocated to one of three breakout rooms to discuss ICS and PC and answer questions on key topics. These questions are listed in the appendix.

The feedback we received centred around some key themes:

- Accountability and oversight
- Representing the needs of children, young people and adults with learning disabilities.
- The structure of the new Health and Care systems
- Meeting government targets/keeping to existing commitments
- Workforce and training

Accountability and Oversight:

Both the ICS and PC discussions concluded that the new systems must have effective accountability and oversight procedures, and expressed concerns that this may not be present in the current Health and Care Bill. Here are some of the key concerns and recommendations that our attendees identified:

- New systems must ensure that they capture the unmet need amongst people with learning disabilities and their families. We must be able to hold ICS to account on this.
- How can we ensure (at ICS and 'place' (formerly 'district') level) that ICS are taking into account recent report findings and recommendations? Or the areas of good or poor practice within the ICS? A method of reporting on ICS service delivery, and plans for how it can be improved, should be developed and used to hold ICS to account.
- The was a lack of clarity on who will be in charge of each ICS, the body that will hold them accountable and how ICS as a whole will be regulated. The Health and Care Bill must include clear legislation on these points.
- A participant with learning disabilities commented that if she could not understand how ICS were to be held to account, then it was unlikely that they would be effectively held to account. It was agreed that the simpler and clearer the system of accountability for ICS, the more successful it was likely to be. In addition, the new systems must be explained in an accessible fashion so that everyone can understand them.
- There were additional concerns raised around the standardization and consistency of these new systems, and how this can be monitored.
- Participants felt that there was a lack of clarity on how much time and work Integrated Care Boards would spend overseeing PC within their ICS.

- Another group wondered about representative roles within the ICS, and whether there should be a ‘senior leader’ in learning disabilities and autism within each ICS. One of the participants brought up that NICE guidance recommends that each local authority have a Learning Disability commissioner, and that the ICS should be made to sign up to NICE guidelines.

Accountability and oversight of these new systems is crucial, if we are to ensure that people with learning disabilities are not adversely affected by changes in structure, and can access care and treatment more easily, in the community, and to a high standard. The concerns raised at CB-NSG must be addressed by clearer guidance on ICS and PC.

Representing the needs of children, young people, and adults with learning disabilities:

This was a key focus of the discussions around ICS and PC. It is important that the needs of people with learning disabilities do not become lost within the new structures. Some key recommendations and concerns about the current ICS/PC proposals included:

- There should be consultation with people who have learning disabilities as well as family carers when designing and implementing the new systems, to ensure that their voices are heard and impact the roll-out of ICS.
- The Health and Care Bill does not consider the needs of children and young people with learning disabilities, and they should have bespoke statutory guidance for ICS.
- Every ICS should consider creating a sub-committee or board that represents the voices of people with learning disabilities, and this should include people with learning disabilities, family carers and experts in the learning disability field. Concerns were raised that without such a body, the voices of people with learning disabilities, their families and carers may get lost within the new structures.
- ICS should consider implementing a ‘senior leader’ in learning disabilities and autism within each ICS.
- Early intervention and investing in families were key points that our participants raised throughout the day. It was not yet clear how the new healthcare structures would support this.
- Ensure organisations which represent the views of people with learning disabilities are being invited to the conversation and are listened to during decision making.

Structure of the new systems:

It was expressed by our attendees that there were clear areas of concern regarding how the new systems would be structured and the impact this could have on the quality of care for people with learning disabilities.

Some concerns/recommendations that were discussed are:

- The new systems are too healthcare focused and there is not equal consideration, or authority, given to social care. This raised concerns that social care would not receive adequate funding. The new Health and Care bill should consider these comments and we recommend that social care and healthcare are seen as equal partners, when implementing the new systems.
- Additionally, there were concerns about PC being involved in community support. If these new structures are health led, are they the right body to be organising community support provisions? Some of our participants discussed the lack of social care inclusion in PC and further that under the new system social care is only considered at ‘place’ level (formerly ‘district’). Given government targets to provide better community support for people with learning disabilities, this is particularly concerning and could lead to inconsistent and inadequate community support, led by a medical-model of care.

Meeting Government Targets and Keeping to Existing Commitments on Learning Disability Issues:

Participants agreed on the importance of pursuing the commitments and targets previously set by the government in Transforming Care and Building the Right Support (BTRS), and continuing with any progress that has already been made to try and meet these targets. Further comments included:

- ICS could reanimate efforts to meet the targets and promises in BTRS, as they bring together different parts of the system caring for people with learning disabilities. However, how do we ensure effective collaboration between health and social care, within ICS, and is there anything in current ICS guidelines that ensures this?
- There are concerns that the current Transforming Care Partnership (TCP) boards will be subsumed by ICS, and that their work and aims will be discontinued. Will there be aspects of the Transforming Care framework included in ICS? How will ICS progress commitments made by Transforming Care and BTRS, in light of continuing structural pressures on the NHS (I.e., increasing waiting lists)?
- ICS must co-produce all plans and strategies for people with learning disabilities, as it they were within TCPs.

Workforce and Training:

The recent CQC State of care report (2021) and concerns around the current health and social care workforce during the pandemic were a prominent area of discussion. Further areas of concern were:

- ICSs must tackle re-building services, post-austerity. Given the **national care workforce crisis**, and that the system seems “so broken post-austerity”, how will ICS function effectively within this depleted workforce environment?
- Family carers are a key part of the workforce, and we must invest in them. The new systems should consider how families are being invested in, with special consideration being given to training for families (in psychological therapies such as Positive Behavioural Support).
- The social care workforce needs to have the correct training to care for people with learning disabilities, and generic training (such as the Oliver McGowan training) is not sufficient.
- Family carers and support workers should be involved in conversations around workforce issues, if we are to understand the specific needs of this group. The new systems should also have specific guidance for the health and social care workforce relating to children, young people and adults with learning disabilities.

Actions table arising from discussion:

Action	How will it be done?	Who will do it?	When will it be done?
Sustaining Best Practice in ICS	Contact DHSC/Dave Nuttall with briefing paper on best practice and the importance of implementing what we have learned Engage in systematic data gathering and gather case study examples FOI – ask NHS/DHSC for data that supports best practice examples Contact CBNSG workshop presenters / members for stories/lived experience. Locate an ICS contact as a point of influence	Mencap, CBF? Include in letter to ICS CEOs CBF/Freddy Jackson Brown	Included in letters to ICS Chairs
ICS must integrate best practice learning from previous systems and roll it out nationally, so that this learning is not lost – (I.e., examples of services which have successful low OOA placements so ICS can change their investment decisions) This could include sharing stories of good practice to influence ICS, instead of only reports and data			

Influence standards / guidelines drawn up for ICS	Influence govt to commit to NICE guidelines for ICS	Alison Carpenter Multiple CBNSG to influence ICS to adopt NICE guidelines?	
Inpatient facilities within ICS	Discuss with CQC how they will work with ICS Discuss with DHSC (Dave Nuttall) and write to Minister for Care	Theresa Joyce/CBF/Mencap to influence LD senior leaders in ICS Possible ESG action Highlight this in letter to ICS Chair/CEO	Draft email to Steve Holmes/Alison Carpenter
ICS should be involved in closing facilities like St Andrews, I.e., services with an inadequate rating should be barred from joining provider collaboratives			
Recognising the current situation	Write to DHSC - state that the legacy of austerity, of unmet need, for people with LD, must be appraised at the onset of each ICS BTRS action plan feedback section on investing in families	CBF/Margaret Flynn (Ask Margaret?) Leader of children workforce Discussion with Skills for Care	Included in letters to ICS Chairs
As a starting point, ICS must capture unmet need across the UK Including how families are being invested in, as they are part of the workforce but remain unpaid and unsupported			

	sent to ICS CEOs/contacts	(Charlotte or Marie Lovell)	
ICS must address the workforce crisis in social care	Contact DHSC, ask how the ICS are planning on addressing this	Contact Skills for Care Include in letter to ICS Chair/CEO – how each ICS is planning on tackling this	Included in letters to ICS Chairs
Influencing ICS structure	CBF/LDE/ Mencap/ Speakup to undertake a project to create this system This could involve influencing ICS to sign up to NICE guidelines (if they do not meet them, they must justify why)	CBF/LDE/ Mencap Speakup (Discussion on feasibility and next steps) Alison Carpenter Multiple CBNSG members in favour of ICS adopting NICE guidelines (e.g Richard Hastings)	Included in letters to ICS Chairs
Develop a system of accountability to understand where, and how far, ICS are responding to reports (people with LD must be involved).			
Representatives of people with lived experience of LD, on ICS boards/committees, should not be	Have multiple groups (mild LD, moderate LD, severe LD, profound and complex LD, autism) within the	Include in letters to ICS Chair/CEOs Contact Sam Clark/Pat Charlesworth / LDE	Included in letters to ICS Chairs

tokenistic/small in number	lived experience group, as well as family carers. Need to understand what sort of representation is available in ICS Find out about positive impacts being made by people with LD and autism representing themselves on the ICS board (Valuing People Alliance etc)	(Contact Charlotte Newman re. Skills for Care action)	
Rebalance ICS so that Health, Social care and housing are a ‘partnership of equals’	Flag this issue with Minister for care/DHSC	CBF Update on H&SC bill (Indigo?)	To discuss at Campaigns Subgroup
Progressing previous commitments	Influence LD senior leads in ICS	Ashok Roy CBF LDE Mencap NHS (CB-NSG member)	Included in BTRS feedback
Ensure TC commitments are worked towards at each level of the ICS This will be achieved if ICPs/ICBs must be kept aware of recent	Working document of report summaries and recommendations to	CBF to discuss	

reports/strategies and must act on recommendations (e.g BTRS action plan)	be shared with ICS chairs	Include this in letter to ICS Chairs/CEOs (quote NHS Long Term plan)	Reference document in ICS letter
ICS must ensure that the needs of the wider LD population are being met (needs highlighted in previous reports)	Ask DHSC to get ICS to report on how they are ensuring the broad needs of this population are being met (have they got a space on the board for someone with an LD, a FC, provider) Pass on request for information to people who can take responsibility for whole pathway of care	CBF/VC Discuss how this could be reported and monitored Include in letters to ICS Chars/CEOs	Included in letters to ICS Chairs

Appendix: Breakout Room Questions

The above discussions and topics raised were in response to a number of questions suggested by the CBF. These questions discussed our key areas of concern regarding ICSs and PC.

ICS breakout room questions:

1. How do we ensure that ICS are (or can be) held accountable for care/treatment/funding decisions they make? Who will oversee this? (What are the risks of Integrated Care Provider Contracts?)

2. Who should oversee the promotion of Transforming Care (TC)/Building the Right Support (BTRS) commitments within ICS? What should this look like in terms of leadership?

3. How will ICS reduce the number of inpatient admissions, and how will it commit to the necessary components to meet the promises of TC/BTRS (e.g available housing, available community care and support, early intervention)?

4. Where will funding previously ringfenced for TC/BTRS commitments be directed within ICS? How can we ensure that this funding goes towards the discharge and community care of individuals whose behaviour is described as challenging? (How will pathway panels affect this?)

5. How do we ensure Integrated Care Partnerships (ICP) represent the interests and wishes of the learning disability community? (For example, through the role of a learning disability Champion within the ICP or a sub-committee on community care which tackles learning disability issues)

6. How will primary care networks be affected by the new ICS's and how will this impact the care available to people with learning disabilities?

7. Should ICS be responsible for the training and retention of the NHS and Social Care workforce? How do we ensure that the workforce has received the training necessary to care for and support individuals with learning disabilities and autism (e.g Positive Behaviour Support)?

8. Following HSCC committee discussions, the government promised to better address children and young people's care and interests in the next draft of the Health and Care Bill. How do we ensure that the changes they make are sufficient to represent the interests of children and young people?

9. Are there any other issues or concerns surrounding ICS that you would like to discuss today?