



## **Challenging Behaviour – National Strategy Group (CB-NSG)**

**Thursday 24<sup>th</sup> November 2022 via Zoom**

### **Workshop 5:**

### **Advocacy**

**Workshop Facilitator: Kate Mercer & Julie Thorpe**

**Time: 11.00am-12.45pm**

#### **The aim of the workshop is:**

- To identify what high-quality advocacy for people with learning disabilities looks like and what it should deliver
- To identify the barriers to receiving high-quality advocacy, and the barriers advocates (both formal – e.g. IMHAs – and family advocates) face when advocating for people with learning disabilities – and how these can be overcome
- To identify actions to ensure advocacy is effective

#### **The objectives are:**

- To discuss & understand the experiences with advocacy of people with learning disabilities, and of family members who provide advocacy for their relatives.
  - What evidence and data is available about advocacy delivering good outcomes?
  - What works well? How can that be replicated?
  - What can be improved, and how?
  - What prevents the delivery of high-quality advocacy, and what can be done?
- To identify best practice around advocacy for people with learning disabilities whose behaviour challenges – and how this can be made available to all who need it
- To identify actions to include in a co-produced Transforming Care action plan for people with learning disabilities

## **Background**

Advocacy is a key way of ensuring that people with learning disabilities have their needs met, their rights upheld, and their views heard. It is crucial that people with learning disabilities whose behaviour challenges can access high quality specialist advocacy that is person-centred and independent.

People in England who have been detained under the Mental Health Act<sup>1</sup>, who are subject to guardianship, who are on a community treatment order (CTO) or who have been conditionally discharged are entitled to an Independent Mental Health Advocate (IMHA). IMHAs roles include helping their clients to exercise their rights under the Mental Health Act, express their views and make complaints, as well as supporting them at Mental Health Tribunals and representing them in meetings and hearings. In Wales, as well as these 'qualifying compulsory patients', people who are in a hospital voluntarily are also entitled to IMHAs. In Scotland, all people with learning disabilities are entitled to independent advocacy. In Northern Ireland, under-16s who are admitted to hospital are entitled to an independent advocate.

Additionally, under the Mental Capacity Act 2005, people who lack capacity are entitled to Independent Mental Capacity Advocates (IMCAs), although unlike IMHAs, IMCAs are generally only appointed if there are no suitable family members or friends to represent the person.

In addition to this formal advocacy provided by IMHAs and IMCAs, family members are also frequently advocates for relatives with learning disabilities, helping to enforce their rights and make their wishes known.

The Building the Right Support Action Plan discusses both formal and informal advocacy, and describes it as a key part of ensuring people with learning disabilities have the support that they need.

## **Barriers**

In this workshop we would like to discuss:

- Barriers faced by people with learning disabilities whose behaviour challenges in communicating with advocates and getting their wishes/needs heard/advocated for by their advocates
- Barriers faced by family members who act as advocates for their relatives
- Barriers faced by formal advocates when trying to advocate for their clients

People with learning disabilities whose behaviour challenges, in particular people who communicate in non-verbal ways (e.g. use sign language, Makaton, Picture Exchange Communication Systems, etc), can face difficulties in communicating with advocates who may not be trained in/familiar with these communication methods.

People with learning disabilities whose behaviour challenges in inpatient units can also face difficulties in getting access to an advocate (see appendix).

---

<sup>1</sup> except where they have been detained in an emergency under [section 4](#), under [section 5 holding powers](#), or where they have been taken to a place of safety under [section 135 and 136](#) of the Mental Health Act

When advocating on behalf of their relatives, family carers can be sidelined; it is important that advocacy by family carers to support their relatives is given the same respect as formal advocacy (e.g. that is provided by IMHAs and IMCAs).

Formal advocates such as IMHAs have to navigate complex systems to represent their clients and can find it difficult to ensure their clients rights are respected, complaints are heard and needs are met.

Advocacy is mentioned in the 'Building the Right Support Action Plan', but this is limited and the issues here are not adequately addressed (see appendix A).

### **Opportunities**

By bringing together people from a range of backgrounds with different experiences, this workshop is an opportunity to hear from different partners and communicate openly, which will help lead to effective actions and the develop of a plan that will deliver good outcomes.

While the commitments in the published 'Building the Right Support Action Plan' do not adequately address the concerns above, the stated commitments/messages around advocacy give us a starting point to develop and recommend more effective actions.

### **Workshop agenda (Timings TBC)**

- 1. Welcome and introductions**
- 2. Presentation to give the background and context for this work**
- 3. Group discussion**
- 4. Actions**

**Actions: (To be completed during workshop)**

<b>Action: What is needed</b>	<b>How it will be done</b>	<b>Who will do it</b>	<b>When it will be done</b>
1.			
2.			
3.			
4.			
5.			

## Appendix A – Advocacy in the BTRS Action Plan

- ❖ BTRS Action Plan Commitments linked to advocacy
- ❖ Our concerns
- ❖ Comments and recommendations from the Campaign Families group of family carers (in green)

### Action Plan Commitments

Commitment	Content	Measure of Success	Key Concerns	What Else is Needed?
1a - Committing £4.5 million to a joint DHSC and NHSE review of inpatient advocacy	<p>DHSC/NHSE to complete review and develop recommendations for next steps by Summer 2022 (i.e., already due to have occurred)</p> <p>Findings of review to be used to develop best practice</p>	“Progress on this review will be reported to the Delivery Board as appropriate”	<p>Not a SMART target</p> <p>Review due to have been completed by Summer 2022 but has not been published(?)</p>	<p>Review and recommendations need to be published</p> <p>Should address quality, availability, co-ordination, independence<sup>1</sup>, funding, non-instructed advocacy, delivery of positive outcomes</p> <p>Should look at long-term/proactive advocacy vs issue-based/crisis advocacy</p> <p>Should have consideration of Voiceability’s recommendation for nationally commissioned advocacy for inpatients</p> <p>Findings of the review should be used to inform pre-legislative scrutiny of the draft Mental Health Bill</p>

3j - Developing commissioning guidance to build the capability and knowledge of the commissioning workforce, designed to complement qualifications and training	Publish guidance and information for commissioners Hold webinars with sector partners to promote the use of this guidance	Guidance for <a href="#">autistic people</a> and <a href="#">people with learning disabilities</a> has been published  See appendix B for more details	Guidance is non-statutory and there is no governing professional body	
---	--	--	---	--

### Action Plan Statements

Statement	Key Concerns	What Else is Needed?
Chapter 2 of Action Plan – “involving families and advocates where appropriate” in discharge planning	Does not include any specific commitments related to including families and advocates in discharge planning, despite stating it in introduction to chapter	Publish commitments and/or guidance setting out how they will better include families and advocates in discharge planning
Chapter 2 of Action Plan (‘I’ Statements) – “I am able to build a trusting relationship with an advocate who knows me and my family”	Does not set out how they intend to ensure that the person and family are able to build relationship with advocate  <i>IMHAs do not always see talking to families as part of the job</i>  <i>Although people may have an advocate, it can be difficult for them to see them – one example of a person who could only see their advocate on one day per week and had to specifically ask to see them, but would not be given support to ask</i>	Guidance for IMHAs should be published which includes the requirement to talk to families and friends of the person to understand their wishes/concerns  Publish guidance to ensure that people in inpatient services are easily able to contact and build a relationship with their advocate

<p>Chapter 1 of Action Plan - “We are proposing expansion of IMHAs’ roles and responsibilities so that they are better positioned to support patients to make decisions around their care and treatment”</p>	<p>What are these proposed roles and responsibilities?</p>	
<p>Chapter 1 of Action Plan – “We will continue to explore the best way to improve the quality of IMHA services with stakeholders, and work with stakeholders to ensure that culturally appropriate advocacy better meets the needs of patients from ethnic minority backgrounds.”</p>	<p>Included in Action Plan but does not include any specific commitments related to this</p> <p>Not a SMART target</p> <p>Details of how they will do this may be included in the review of inpatient advocacy, but as this has not been published it is difficult to tell</p>	<p>Publish commitments/guidance setting out what will be done to work with stakeholders to ensure culturally appropriate advocacy</p> <p>Publish review of inpatient advocacy and recommendations</p> <p>Provide SMART target and deadline for review of how to improve quality of IMHA services</p>
<p>Chapter 1 of Action Plan – “We recognise that families, loved ones and unpaid carers often make the best advocates”</p>	<p>There is “recognition” but there is no/limited support, and families can be sidelined when trying to advocate for their relatives</p>	<p>Ensure that families/loved ones are respected as advocates and provide support/training to families to enable them to act as advocates to support their relatives</p>
<p>Action Plan Table of Commitments – Other Areas of Work:</p> <p>Draft Mental Health Bill reform – DHSC proposing to “extend the right to an Independent Mental Health Advocate (IMHA) to all people who are mental health inpatients, including voluntary patients who are not detained under the Mental Health Act”</p>	<p>Extending the <i>right</i> is not enough; you also need to ensure it is possible to access an IMHA</p> <p>No timeline for doing this – the Mental Health Act reform has a timetable up until 2030</p>	

## **Appendix B – Commissioning Guidance for People with Learning Disabilities**

### Guidance asks commissioners:

- What advocacy services do you have locally? How are they funded? How secure are they? What do they offer? (i.e. Citizen advocacy, access to legal advice)
- What self-advocacy support and services are available for people with a learning disability, unpaid carers and families?

### Commissioners should:

- Develop low-level preventative services addressing practical life skills, social engagement, therapeutic support, employment and advocacy
- Ensure good quality advocacy services are there for people who need them, making sure that people receive proactive and effective signposting to advocacy services