



Mental Capacity Bill

1.0 About Mencap

Mencap's vision is of a world where people with a learning disability are valued equally, listened to and included, and have opportunities to achieve the things they want out of life.

We provide services and support to people with a learning disability across England, Wales and Northern Ireland, support a network of local groups and campaign to improve the lives of people with a learning disability.

Mencap has undertaken a range of activities to encourage people with a learning disability and families to contribute to the debates and discussions around mental capacity. This includes a roundtable discussion in November 2012, a symposium co-hosted with Niamh in March 2014 and the organisation of 3 events in 2014 to inform Mencap's own response to the proposals on mental capacity.

The All Party Group on Learning Disability considered the government's proposals and heard from people with a learning disability and families at its meeting in June 2014.

Mencap is a member of Inclusion International, a global federation of organisations of people with intellectual disabilities¹ and families. Inclusion International initiated a global campaign, "The Right to Decide" to advance the rights outlined in Article 12, UNCRPD² to support families and others understand the implications of legal capacity and how to support people with an intellectual disability make their own decisions³.

2.0 About learning disability

A learning disability is a reduced intellectual ability and difficulty with everyday activities – such as household tasks, socialising or managing money – which affects someone for their whole life. Learning disability is not a mental illness.

¹ Intellectual disabilities is the term used more frequently across Europe and America to describe learning disability. See Equal Lives, Bamford Review of Mental Health and Learning Disability DHSSPS 2005

<http://www.dhsspsni.gov.uk/equallivesreporannexes.pdf>

² General Comment no 1 (2014) Article 12 Equal recognition before the law
<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>

³ Inclusion International launched a report in 2014 containing the perspectives of people with an intellectual disability and their families on the right to decide. <http://inclusion-international.org/wp-content/uploads/2014/06/Independent-But-Not-Along.pdf>

For information on the global campaign: <http://inclusion-international.org/global-campaign-the-right-to-decide/>

People with a learning disability may experience significant difficulties in understanding, learning new things and communication. The level of support a person needs will depend on a number of factors including the severity of their disability. The absence of opportunities to gain experiences, knowledge and skills also impacts on the ability of a person with a learning disability to make decisions.

People with a learning disability may need support to make “everyday” decisions as well as support to make more serious decisions about their life.

Most people with a learning disability are treated as “different”. They do not have the same control over their own lives as others and face challenges and prejudice every day, including assumptions made about their competence and ability to make decisions based solely on their condition.

3.0 Compliance with UNCRPD and Article 12: Equal recognition before the law

Mencap believes that there is a unique opportunity to shape the new Mental Capacity legislation so that it is compliant with the UNCRPD and, in particular, Article 12.

Article 12 confirms the legal capacity of people with disabilities in all aspects of their life. It also recognises that some people may need support to exercise their legal capacity. General Comment No1, which provides guidance on Article 12, emphasised the fundamental shift away from substitute decision making to supported decision making, where people are provided with support to make their own decisions.

4.0 Principles

4.1 Capacity: 1 (1), (2), (3), (4), (5), (6)

Mencap supports the principles in this section.

4.2 Best interests

2 (2) Mencap is concerned that “best interests” is associated with a more paternalistic approach.

7 (6) We recognise that the Bill contains important elements, such as the need to have special regard to a person’s past and present wishes and feelings, their beliefs and values and other factors that the person concerned would be likely to consider if able to do so.

We believe, however, that, to be compliant with UNCRPD, the legislation should ensure special regard for the rights, will and preferences of a person. Where this is not possible to establish, then the “best interpretation of will and preferences” should replace “best interests”.

4.3 Meaning of “unable to make a decision”

4 (1), (3), (4) Mencap believes that the legislation should make clear that the information should be provided in a way that meets the needs of an individual as well as their circumstances and is accessible to them.

4.4 Supporting a person to make a decision

5 (1) Mencap supports the requirement to support a person to make a decision before they can be deemed to lack capacity.

5 (2), (3) We believe that the legislation should ensure that information and support is provided in a way that is accessible to the person concerned and based on their individual needs as well as circumstances.

Mencap is concerned that the legislation may create a perverse incentive to avoid assessing a person's capacity to make a decision or to ignore a person's need for assistance when making a decision because of financial and resourcing constraints.

We believe that the legislation should include a positive duty to provide people with disabilities with access to support to make decisions about their life. This support is of particular importance for people who experience significant difficulties in being involved when decisions are being made about their life or in communicating their decisions.

5.0 Safeguards

5.1 Additional safeguards for serious interventions – suitably qualified person

14 (2) Mencap believes that the person carrying out an assessment of capacity with respect to a person with a learning disability must have knowledge, skills and experience relevant to learning disability.

5.2 Serious intervention Treatment with serious consequences High Court Powers

People with a learning disability, particularly those with profound and multiple learning disabilities often have multiple health needs. Mencap is concerned that discriminatory assumptions coupled with a lack of understanding about how to involve families or those who know the individuals best in decisions about care and treatment, can lead to flawed “best interest” decision making⁴.

19, 20, 60, 61, 113 Mencap believes that the legislation should include decisions taken **not** to treat or investigate health concerns and non-emergency Do Not Resuscitate Orders.

Mencap believes, too, that medical interventions, such as decisions around sterilisation or medical procedures which limit growth should be included in the definitions of serious interventions and treatment with serious consequences.

6.0 Nominated person

15 (3) Mencap believes that the legislation should strengthen the requirement on the decision maker to involve and listen to the views of those who are close to and know the individual well and to ensure that these views are in line with the will and preferences of the individual concerned.

71, 74 Mencap believes that the legislation should consider circumstances where family carers share caring arrangements, for example, in circumstances where parents are separated or divorced.

⁴ See Mencap's Death by Indifference report: <https://www.mencap.org.uk/death-by-indifference> and 74 deaths and counting report: <https://www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%2074%20Deaths%20and%20counting.pdf>

Family carers report that they can feel excluded and disempowered by decision making processes, often fearing that decisions are already made before meetings take place with professionals and without taking fully account of the assistance and support needed by their family member.

7.0 Independent advocates

Advocacy plays a key role in protecting the rights of individuals, ensuring that their wishes and preferences are heard.

Mencap recognises that a range of advocacy support models are needed to respond to different needs and circumstances.

84 (1) We believe that advocacy support should be available to people with a learning disability when a concern is identified about their capacity to make a decision to ensure that their rights are protected.

Mencap agrees that Trusts should be required to ensure that an advocate is in place to support an individual as required by the legislation. We are concerned, however, about the possible conflicts of interest which arise if the Trust employs the substitute decision maker and instructs the independent advocate.

85 Mencap believes that the legislation should ensure that advocates respect the rights of the person and ascertain their will and preferences. Where this is not possible to establish, then the “best interpretation of will and preferences” should replace “best interests”.

We believe, too, that greater clarity if needed regarding the roles and responsibilities of nominated person(s) and advocate

86 (1) Mencap believes that professionals other than healthcare professionals should be able to request the relevant Trust to instruct an independent advocate.

88 We believe, too, that the person should, where possible, be able to decide the model and provider of advocacy support as well as decide if they do not wish the support of an advocate.

93 (3) Mencap suggests deleting the term “physically” as there may be other reasons for a person being unable to make a “mark” instead of a signature and this may not be due to a physical reason.

8.0 Court’s powers to make decisions and appoint deputies, Public Guardian

Mencap’s experience of the Mental Capacity Act indicates that families do not find the processes involved easy to access or understand. We believe that it is important costs should remain as low as possible and that the legislation should ensure the involvement and participation of the individual concerned to the greatest extent possible.

125, 126, 128 Mencap believes that the legislation should reflect the range of accommodation provision, such as nursing and residential care homes and supported living.

9.0 Unfitness to be tried

202 Mencap believes that the legislation should define “unfitness to be tried” and outline the procedure involved in assessing if a person is “unfit to be tried”.

Mencap believes that any assessment of capacity of an individual with a learning disability should be carried out by a professional with a good knowledge and understanding of learning disability. We believe that any assessment of capacity should involve making reasonable adjustments and the provision of support at all stages of the justice process.

242 Mencap believes that a person who is assessed as being “unfit to be tried” should be provided with information about the appeal procedures. Where a person is assessed as lacking capacity to make a decision with respect to an appeal, then the nominated person or advocate should be able to do so on their behalf.

10.0 In-patients under 18

Amendments to the Mental Health Order

254 Mencap welcomes the requirement on hospitals to ensure that the person’s environment is suitable for their age. We believe that the legislation should state that this includes being able to access educational support and facilities when in hospital.

255 Schedule 8 Mencap welcomes the requirement of the legislation to involve young people in decisions, to take account of their past and present wishes and feelings, beliefs and values; and to take account of the views of those who know the child or young person well.

Mencap believes that the legislation should provide access to an advocate for all children and young people who come within the remit of the amended Mental Health Order. We welcome the requirement to secure an independent advocate for children and young people under 16 years who are admitted to hospital for assessment and treatment.

Mencap believes that the legislation should provide access by children and young people who come within the remit of the amended Mental Health Order to the Review Tribunal.