



Submission from the Royal College of Speech and Language Therapists to the Ad Hoc Joint Committee on the Mental Capacity Bill.

The Royal College of Speech and Language Therapists (RCSLT) has prepared this submission after consultation with its members. We consider that it will strengthen the legislation by adding additional safeguards for people with communication difficulties and for those with responsibility for determining capacity.

1. The RCSLT consider that our suggested amendments will;
 1. Ensure that individuals with significant communication difficulties are not unintentionally placed at a greater risk of being determined *not to have capacity* as a result of this legislation.
 2. Ensure that fewer individuals fall under the legislation unnecessarily by closing the gaps in the gateway clauses, thereby reducing the financial impact of the legislation.
 3. Ensure that those persons who have responsibility for supporting a person to make a decision have greater clarity regarding the steps that they should take in giving all practicable help.
2. The RCSLT has identified the following specific clauses in the legislation which we consider could be strengthened by changes to the numbering or wording.
3. *Part 1. Establishing Whether a Person has capacity.*
4. Current wording of Clause 4, **Meaning of “unable to make a decision”**
4.—(1) For the purposes of this Part a person is “unable to make a decision” for himself or herself about a matter if the person—
 - (a) is not able to understand the information relevant to the decision; or
 - (b) is not able to retain that information for the time required to make the decision; or
 - (c) is not able to appreciate the relevance of that information and to use and weigh that information as part of the process of making the decision; or
 - (d) *is not able to communicate his or her decision (whether by talking, using sign language or any other means).*
5. As written, this clause suggests that a person who cannot communicate (but who may be fully cogent) may be considered incapable. The RCSLT recognises that if a person is completely unable to express a decision (by any method of communication) then the inability to communicate a decision is a factor in the determination of capacity.

6. The RCSLT considers that because of the importance of establishing whether a person with a communication disability may have capacity but not the means to communicate, more emphasis needs to be placed on clause 4(d) 'An individual will be unable to convey any decision unless they can firstly demonstrate their ability to communicate'. The RCSLT considers that clause 4(d) should therefore be ranked first as the primary criteria to be considered. Clauses 4 (b) and (c) are dependant upon being able to understand information and should therefore be ranked lower.
7. **Proposed amendment to Clause 4;** The RCSLT consider that this clause could be strengthened by amending the rank order of the clauses as follows;
 - 4(d) to 4(a).**
 - 4(a) to 4(b)**
 - 4(b) to 4(d)**
 - 4(c) to 4(c)**
8. Impact of amendment. This change in emphasis will ensure that at the outset there is a focus on establishing if someone has the ability to communicate by considering additional communication methods such as those referenced '(whether by talking, using sign language or any other means)'. The impact of this will be that people with communication difficulties will be less likely to fall under the legislation unnecessarily, thus protecting them from the injustice of not being able to make their own decisions. It may also result in financial savings for Health and Social Care by reducing the numbers of people who may otherwise fall under the act.
9. Current wording of Clause 5. ***Supporting person to make decision***

5.—(1) A person is not to be regarded for the purposes of section 1(4) as having been given all practicable help and support to enable him or her to make a decision unless, in particular, the steps required by this section have been taken so far as practicable.

(2) Those steps are—

 - (a) the provision to the person, in a way appropriate to his or her circumstances, of all the information relevant to the decision (or, where it is more likely to help the person to make a decision, of an explanation of that information);
 - (b) ensuring that the matter in question is raised with the person—
 - (i) at a time or times likely to help the person to make a decision; and
 - (ii) in an environment likely to help the person to make a decision;
 - (c) ensuring that persons whose involvement is likely to help the person to make a decision are involved in helping and supporting the person.

(3) The information referred to in subsection (2)(a) includes information about the reasonably foreseeable consequences of—

 - (a) deciding one way or another; or
 - (b) failing to make the decision.

(4) Nothing in this section is to be taken as in any way limiting the effect of section 1(4).

10. The RCSLT consider that provision of communication support should be specifically referenced as one of the steps listed above. Clause 4 references the ability to communicate as one of the criteria for *making a decision*. It therefore follows that one of the steps above, should be the provision of communication support. If the provision of communication support is not specifically referenced here, persons with a communication difficulty may be placed at risk of not receiving the additional communication support that they require in order to convey their decision.
11. For example;
(c) ensuring that persons whose involvement is likely to help the person to make a decision are involved in helping and supporting the person.
This clause 5 (c) may be interpreted as meaning that advocacy should be provided. An advocate is not qualified to formally assess a person's level of understanding and is unable to recommend or provide communication supports such as symbols, signs or communication devices which may enable a person to communicate a decision. Advocates have advised the RCSLT that in order to carry out their role, they often request a formal assessment of their client's receptive and expressive communication skills prior to commencing their involvement.
12. Defining communication support in Clause 5 is also important because the lack of clarity may have consequences for the person making the determination if it is later demonstrated that they become liable as they have not taken all practicable or reasonable steps.
13. **Proposed amendment to Clause 5**; The RCSLT consider that this clause could be strengthened by including an additional step as follows;
(2) Those steps are—
(a) the provision to the person, in a way appropriate to his or her circumstances, of communication support, where there is a concern that a person is not able to communicate and where it is more likely to help the person to make a decision)
(b) the provision to the person, in a way appropriate to his or her circumstances, of all the information relevant to the decision (or, where it is more likely to help the person to make a decision, of an explanation of that information);
(c) ensuring that the matter in question is raised with the person—
(i) at a time or times likely to help the person to make a decision; and
(ii) in an environment likely to help the person to make a decision;
(d) ensuring that persons whose involvement is likely to help the person to make a decision are involved in helping and supporting the person.
14. Impact of amendment. Individuals with significant communication difficulties such as those seen in people with advanced dementia, brain injury, aphasia due to a stroke, motor neurone disease, multiple sclerosis, 'Locked -In Syndrome,' learning disability, and autism spectrum disorder, will be enabled to communicate their decision by the provision of appropriate support . The RCSLT consider that this amendment will ensure clarity around the meaning of *all practicable help* and will prevent people falling under the legislation unnecessarily.

15. The amendment will also provide further safeguards for those making the determination by ensuring that they have '*taken reasonable steps*' as referenced in Clause 6(3).

6 (3) If—

(a) the person making the determination has taken reasonable steps to establish whether P lacks capacity in relation to the matter,

(c) the principles in section 1(3) to (5) and section 5 have been complied with, for the purposes of section 1(2) the person is to be taken to have sufficiently "established" that P lacks capacity in relation to the matter.

16. Part 2 ADDITIONAL SAFEGUARDS FOR SERIOUS INTERVENTIONS

17. Current wording of clause 13; Formal assessment of capacity

13.—(1) This section applies where—

(a) section 9(1)(a) and (b) apply; and

(b) the act mentioned there is, or is part of, a serious intervention (see section 60).

(2) Where this section applies—

(a) the condition in section 9(1)(c) is to be regarded as met only if, before the act is done, a formal capacity assessment is carried out; and

(b) a belief by D, at the time the act is done, that P lacks capacity in relation to the matter in question is not to be regarded as a reasonable belief if no statement of incapacity has been made.

(3) The formal capacity assessment must have been carried out, and the statement of incapacity made, recently enough before the act is done for it to be reasonable in all the circumstances to rely on them.

18. The RCLT consider that where the person objects and or resists a serious intervention and where the determination of lack of capacity has been in whole or in part due to a lack of ability to communicate, an additional clause should be inserted making a formal assessment of communication a statutory provision.

19. **Proposed amendment to Clause 13;**

13.—(1) This section applies where—

(a) section 9(1)(a) and (b) apply; and

(b) the act mentioned there is, or is part of, a serious intervention (see section 60).

(2) Where this section applies—

(a) the condition in section 9(1)(c) is to be regarded as met only if, before the act is done, a formal capacity assessment is carried out; and

(b) a belief by D, at the time the act is done, that P lacks capacity in relation to the matter in question is not to be regarded as a reasonable belief if no statement of incapacity has been made.

(3) Where the grounds for a finding of a lack of capacity are, in whole or in part, based on clause 4(d) (the person 'is not able to communicate his or her decision), the formal capacity assessment must include a formal assessment of communication.

(4) The formal capacity assessment must have been carried out, and the statement of incapacity made, recently enough before the act is done for it to be reasonable in all the circumstances to rely on them.

20. Impact of amendment. This addition will ensure that persons with communication difficulties are safeguarded before the most serious interventions are enacted.
21. It will also ensure that the persons determining capacity are not made liable in the most serious interventions. People with complex communication needs in receipt of the correct communication support may be perfectly capable of exercising choice and making decisions. Appropriate support can contribute to the determination of capacity by providing an independent assessment of an individual's receptive language and by making recommendations as to the additional support which may be required to enable the individual to make a decision and express their wishes.
22. Our members have advised us that under the current legislation they are already providing formal assessments of communication competence for the determination of capacity, where there are persons with significant communication difficulties. This is because in these instances it is not possible to determine capacity without understanding a person's communication competence.

Mr Jones (retired) had been diagnosed with dementia following a series of unexplained changes in his behaviour and communication. He was getting up in the middle of the night and getting dressed for work, wrongly assuming that it was early morning and that he was still in work. His wife could not dissuade him or reason with him and was becoming increasingly distressed by this and other behaviours as she was losing sleep. After some months he was admitted to a care home on a temporary basis to give his wife some respite and to determine his diagnosis and avoid her having a breakdown.

Mr Jones remained in the home for five months. He continuously asked to go home. At a subsequent case review it was determined that Mr Jones lacked capacity to make a decision about his permanent care situation. His wife reported that he no longer understood her when she was speaking to him and that she felt unable to receive him home again.

Following an assessment by the speech and language therapist, and the introduction of appropriate supports, including visual strategies and appropriate language, Mr Jones was able to communicate sufficiently well to demonstrate that he could understand when asked if he wished to return home and thus was able to evidence that he was able to make a decision about his future care.

In this case capacity legislation did not have to be enacted and considerable financial savings were made. More importantly, with communication supports he was better able to understand the implications of his request to go home and he subsequently decided that he wished to stay in residential care voluntarily.

23. The scenario given above demonstrates that it is important to ensure that individuals with a significant communication disability should have access to an independent assessment to determine their need for additional support rather than relying on others to make judgements about communication competence.
24. The RCSLT consider that all persons involved in the implementation of this legislation should receive mandatory training from a speech and language therapist to ensure that they are able to recognise the importance of determining communication competence and use the most appropriate mode and level of communication with an individual with communication support needs.

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