

Submission from the Royal College of Speech and Language Therapists to the Department of Health, Social Services and Public Safety and the Department of Justice's Consultation on proposals for the Draft Mental Capacity Bill

Please find enclosed the Royal College of Speech and Language Therapists (RCSLT) response to the draft Mental Capacity Bill

General comments

- 1. The Royal College of Speech and Language Therapists (RCSLT) is the professional body for speech and language therapists (SLTs), SLT students and support workers working in the UK. We have around 15,000 members (around 400 in Northern Ireland) including 87% of the SLTs practising in the UK. We promote excellence in practice and influence health, education, employment, social care and justice policies.
- 2. SLTs have a major role in working directly with adults and young people, as well as supporting and training other professionals in working with speech, language and communication needs (SLCN).

The context of speech, language and communication needs

- 3. Speech, Language and Communication (SLC) difficulties are core impairments for many individuals with learning, physical or sensory disability.¹ Children and adults with communication difficulties may also present with marked emotional and behavioural difficulties often leading to clinical depression.
- Speech, language and communication skills are essential for maintaining relationships, understanding social contexts, expressing individuality and exercising choice and control over personal decisions.

¹ Northern Ireland Speech and Language Therapy Task Force: Report on Speech and Language Therapy Services for Children and Young People, July 2008

- 5. Individuals with advanced Dementia, Brain Injury, Aphasia due to a Stroke, Motor Neurone Disease, Multiple Sclerosis, 'Locked -In Syndrome,' Learning Disability, Autism and other long term conditions may rely on alternative or augmentative communication (AAC) in order to express themselves or understand verbal communication. Some individuals may use assistive technologies such as eye gaze electronic communication aids in order to communicate. Others may be so physically compromised that they are unable even to use the most sophisticated communication technologies as in 'Locked -In Syndrome'.
- 6. Whilst carers and extended family members may be able to interpret some non verbal communication attempts, they may need additional support in interpreting the complex communication needs of a partner or child who uses AAC. At times carers may overly interpret non verbal behaviours as indicating that their partner or child understands speech whereas in fact they may be relying on external cues.
- 7. As the paragraph below illustrates, there are also instances when an individual may present as having good communication skills when in fact there may be significant underlying receptive language difficulties that impact upon their ability to understand speech.

In brain injury the language deficit is not always obvious. For example, the person may talk fluently but the information they give can be confused in content.

This reflects an inability to retain and weigh up the implications of complex information and may impair their ability to make an informed decision. The information/decision they give cannot therefore be taken at face value and may change from day to day.

Cases like this can be more challenging to identify than someone with a very obvious expressive aphasia.

8. SLTs provide specialist advice/strategies to family members and multidisciplinary staff to minimise communication difficulties between the person with the communication disability and others. SLTs also provide specialist, individualised treatment/advice/strategies for the person to maximise communication.

The implications of Communication Disability for this Bill

- 9. Principle 3 states that 'the person is not to be treated as unable to make a decision for himself or herself in relation to the matter unless all practicable help and support to enable the person to make a decision in relation to the matter have been given without success'
- 10. Supporting someone with communication disability requires an in depth knowledge of their receptive and expressive language ability and their alternative and or augmentative communication systems. If individuals are to be given control over how their desires and needs should be met, it is vital that communication assistance arrangements are put in place to support those who have difficulty communicating their needs and wishes.

A 17 year old girl is referred to the autism assessment clinic with concern regarding her social communication, social interaction and social behavior. She has no obvious language difficulties. The referral has come from mental health services where there has been a previous diagnosis of anxiety disorder and obsessive compulsive disorder. Treatment for these conditions has not been successful and *Jenny* is now refusing to attend school or leave home.

Jenny is able to engage in conversation, and presents with excellent expressive language. Academically she performs very well in many subjects. However, as part of the autism assessment, the speech and language therapist discovers she has no social reasoning skills. She does not understand social rules of conversation, does not realize there is a social hierarchy, is unaware of the social rules of specific situations, and presumes certain rules and regulations do not relate to her, like having to attend school. She has significant difficulty in reading others non-verbal communication skills (i.e. eye contact, facial expression, tone of voice, body posture, gesture).

She is unaware of her own role in affecting other people's emotions and her responses are often complex and usually socially immature or inappropriate. This complex social communication difficulty can often be missed or misdiagnosed due to a misapprehension that because she can speak in complex sentence structures and academically perform to a high standard that she must have insight into social reasoning.

Cases like Jenny's require specialist speech and language assessment to determine the nature of the social communication deficit, advise on the level of the difficulty and propose strategies best suited to use with her during therapy, and future assessment/interviews.

- 11. The Bill states that 'A person lacks capacity in relation to a matter if at the material time the person is unable to make a decision for himself or herself in relation to the matter because of an impairment of or a disturbance in the functioning of the mind or brain'. The RCSLT is concerned that health and social care professionals may assume someone lacks capacity to consent or to make decisions due to their communication disability when in fact, with the correct support, the individual could fully participate in decisions about their lives.
- 12. If an untrained health or social care provider makes these determinations on the individual's behalf, variable outcomes may result, dependent on the healthcare professional and the level of information that they possess.
- 13. It should be recognised that people with complex communication needs in receipt of the correct communication support may be perfectly capable of exercising choice and making decisions. Appropriate support from speech and language therapists 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.
- 14. An independent assessment is necessary because there may also be instances where a nominated person or carer may not want the individual to be able to fully communicate their wishes if it makes the home/care/financial situation more challenging for their caring role.

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, the care home and Mrs Jones were given some training in how to use visual strategies, communication aids and appropriate language to enable Mr Jones to understand conversations and questions. Mr Jones was subsequently able to be discharged home. Supports were put in place to ensure that his communication needs were met and Mrs Jones felt able to deal with his behaviour in a more effective way.

- 15. 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 carers to make judgements about what support should be requested.
- 16. Speech and language therapists frequently see situations where others may attribute the individual with good verbal understanding/comprehension when in fact situational cues have led to compliance with an instruction. This means that the individual has not understood the verbal instruction but has responded to other cues.

For example, Mr Jones is asked if he wants to go out. He stands up and goes to get his coat—his carers take this as a sign that he understood the question when in fact he has seen the care staff holding car keys and he assumes that he is being taken out.

- 17. Speech and language therapists can facilitate a conversation so that information is conveyed in a manner which enables someone with a significant communication disability;
 - To understand the information relevant to the decision
 - Be able to retain the information for the time required to be able to make the decision
 - Be able to appreciate the relevance of the information and to use and weigh that information as part of the process of making the decision
 - Be able to communicate his or her decision whether by talking using sign language or any other means
- 18. For engagement to be truly meaningful individuals must be able to access information in easily understandable formats, for example by using reduced sentence complexity and length, verbal and written easy read materials, symbols, sign, and aids such as Talking Mats². By receiving appropriate support and preparation for the participation process, they will be enabled to express their views.

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² Talking Mats is an interactive resource that uses three sets of picture communication symbols – topics, options and a visual scale – and a space on which to display them. This can either be a physical, textured mat, or a digital space, for example a tablet, smart board or computer screen. It can be used for consulting children and young people, used as a stroke communication resource, or used to overcome communication difficulties for people with learning disability or dementia. http://www.talkingmats.com/about-talking-mats/

- 19. In determining capacity, communicative competence is the key factor. For someone with good communication skills it will be fairly straightforward but for someone with very limited communication skills it may be time consuming and involve a multi disciplinary approach.
- 20. The RCSLT consider that there needs to be a clear statement in the legislation that a full independent assessment of receptive language ability should be made for individuals with a complex communication disability prior to the determination of capacity.
- 21. During the formal assessment of capacity, the legislation needs to be explicit regarding;
 - What factors should trigger an assessment of additional support needs (for example a severe expressive or receptive communication disability)
 - Who is considered an appropriate person to make the assessment of need for additional support
 - What additional supports should be provided to enable the individual to understand the issues surrounding a decision
- 22. The RCSLT consider that all professionals involved in the capacity assessment including advocates, should receive mandatory training from a speech and language therapist to ensure that they are able to understand and use the most appropriate mode and level of communication with the individual.
- 23. For individuals with a significant communication disability, the formal capacity assessment should ensure that the assessment is carried out by **a suitably qualified person.** The RCSLT consider that this should be someone who has knowledge of how to communicate most effectively with the person and is independent of any caring or advocacy roles.
- 24. This person should be able to clearly define by report that despite the appropriate **help and support**, **the person is still unable to** make a decision in relation to the matter.
- 25. The Department of Justice has recognised the importance of an independent assessment of communication skills in delivering best evidence. Criminal Justice legislation in NI now requires that individuals with communication difficulties are identified as requiring special measures and have access to a communication assessment by a registered intermediary.

26. The RCSLT would like to see that the Mental Capacity Bill also takes account of the fundamental importance of establishing a communication competence level before advising what types of additional supports are required for supported decision making.

Jo Smith has ASD and has an expressive communication disorder. If changes happen to his routine without appropriate explanation he can become aggressive and disruptive. He assaulted a member of staff at work when he was made to put on his coat in readiness for going home. He was told that he was going home early because of a heating issue in his work placement but he didn't understand this. The police were called as he was becoming increasingly violent and was unable to be restrained.

He was taken to the police station. Under special measures legislation, an intermediary was appointed to make an assessment of his communication needs and was then able to provide supports for his communication. It was then possible to ask him why he had hit someone and explain to him why he had been told to go home.

It was also possible to reason with him and reduce his aggressive behaviour. This was enabled because he had an independent communication assessment. The evidence of the impact of his communication difficulty was later used in court and a more lenient disposal was given.

The implications for speech and language therapy services

- 27. In England SLTs have been involved in providing support to persons falling under the mental capacity legislation in the following ways.
 - Completing communication assessments with a view to support the assessments of decision-making capacity.
 - Developing a practical pack for health professionals working with adults with communication impairment in capacity assessment.
 - Managing additional referrals for capacity communication assessments. (There was an influx of referrals to SLT shortly after the publication of the MCA Code of Practice in England. There are servicelevel implications as SLTs find themselves supporting communication for patients who may not necessarily have been referred to SLT otherwise).

- Providing 'in-house' or 'ad-hoc' training/information-sharing for junior members of staff regarding the SLT role in capacity assessment in the acute hospital setting.
- Presenting to SLT clinical excellence networks (CENs)
- 28. There are undoubtedly personal and professional impacts upon the SLT in assisting a person to demonstrate capacity. Jodi Allen is an RCSLT member with experience of working in this area. She writes...

'Helping to 'reveal' capacity in a patient with substantial communication impairment so that they can make a decision for themselves is hugely rewarding for everybody involved.

Families/carers have sometimes communicated a sense of 'relief' because they haven't needed to take the decision on behalf of their relative (and are thus spared the 'worry' of making the *wrong* decision on behalf of the patient).

Even at times when patients haven't been able to demonstrate full decision-making capacity, there are instances when they have demonstrated their wishes sufficiently enough for family and health-care teams to take them into account in the decision-making process (for example a patient may indicate a strong desire to be discharged home but may not necessarily be able to demonstrate full understanding of the risks/consequences/benefits around this)'.

- 29. There is of course also an implication for individual SLTs in terms of developing & maintaining their own skills in supporting communication in capacity assessments.
- 30. All roles are will need to be clearly defined prior to the capacity assessment so that the SLT is clear about their involvement in the determination and reporting of capacity. There needs to be clarity between the role of the SLT (as the person supporting communication) and the person who makes the decision as to whether the individual has capacity or not.
- 31. The RCSLT believes a Code of Practice would be enhanced by including illustrative examples of how providing appropriate communication support can assist in determining capacity and the benefits of involving communication professionals such as speech and language therapists for assessment advice and communication support. RCSLT will be happy to supply additional case scenarios to be considered for inclusion.

- 32. The RCSLT would like to contribute to any advisory group on drawing up guidelines for the Code of Practice to ensure the successful implementation of the Act.
- 33. The RCSLT could assist by contributing to the necessary information and guidance for practitioners, which may include speech and language therapists, to help them discharge their functions.

This response was submitted by the Royal College of Speech and Language Therapists on 28th August 2014.

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