



IASLT Position Statement on The Role of The Speech and Language Therapist in Assessing Capacity and Facilitating Understanding to Support Decision Making for Adults with Communication Disabilities

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Executive Summary

This paper has been written by the Irish Association of Speech and Language Therapists (IASLT) to educate Speech and Language Therapists, other stakeholders and the public regarding IASLT's position with respect to the role of the Speech and Language Therapist (SLT) in assessing capacity and facilitating understanding to support decision making in adults (people over 18 years) with communication disorders.

The IASLT hold the position that:

- SLTs have a role in capacity assessment of adults with known or suspected communication disorders.
- SLTs have the necessary skills to be able to participate in capacity assessor training.
- SLTs play a key role in supporting people with communication disabilities in maximising their decision-making ability, building their capacity and supporting capacity assessments when required.
- As experts in communication, it is the role of the SLT to assist their healthcare colleagues, and individuals with communication impairment in capacity assessments
- All professionals involved in capacity assessments including advocates, should receive mandatory training from a speech and language therapist to ensure that they are aware of how best to support communication access in their interactions.



1.0 Background

The IASLT is the recognised professional body for Speech and Language Therapists in the Republic of Ireland. One of the key functions of the IASLT is to represent the views of its members and to inform position statements in relation to the provision of speech and language therapy services for the best interests of service users.

Working groups are routinely convened to develop position papers in response to events relevant to SLTs, both within and outside the SLT profession. This working group was established in January 2017.

2.0 Definitions

Speech and Language Therapist (SLT): For the purposes of this document a Speech and Language Therapist is a person who holds a professional qualification in SLT and who is registered with CORU and eligible for membership of the Irish Association of Speech and Language Therapists (IASLT).

3.0 Introduction

The Assisted Decision-Making (Capacity) Act (ADMA, 2015) was enacted to ensure the autonomy of adults in making personal decisions. A cornerstone of the Act is that adults are presumed to have the ability, or capacity to make decisions about their personal lives. In the Act, capacity for decision-making is defined as the ability to understand, at the time the decision is being made, the nature and consequences of the decision in the context of the available choices

at that time (ADMA, 2015, s 3 (1)). This means that a person has a right to make decisions (including unwise ones) on their own behalf and is assumed to have decision making capacity to do this unless proven otherwise.

The Act takes a functional approach to decision making capacity. This approach recognises that decisions are complex and cognitive deficits are only relevant if they actually impact on decision making. The legislation supports the premise that all people be assisted and supported to take part in decision making processes that affect them. The Act also outlines the supports which will be made available to people when the Office of Decision Support Service is established within the Mental Health Commission.

Decision making capacity is the ability of the person at the time the decision is to be made to:

- Understand information relative to the decision
- Retain the information long enough to make a voluntary choice
- Use or weigh the information
- Communicate the decision.

When an adult's capacity to make a decision is called into question, a capacity assessment may be necessary. Capacity is considered on a continuum: a person may have the capacity to make some decisions and not others. Also, a person may have capacity for decision-making at one point in time, and not another. Communication skills are key for quality of life and key for decision making.



4.0 Position

It is the position of IASLT that SLT's are uniquely qualified to assess and support a person with communication difficulties to understand and then communicate that understanding for the purposes of establishing their capacity for decision making. This is an essential component of the work of SLTs in order to ensure that individuals continue to exercise choice and control in their daily lives (RCSLT, 2014 cited in IASLT, 2016). It is the IASLT's position that SLTs have a role in capacity assessment of adults with known or suspected communication disorders.

SLTs have the necessary skills to;

- Participate in capacity assessor training.
- Promote awareness of communication needs and how best to make communication accessible.
- Support people with complex communication needs to make choices and decisions and maximise capacity.
- Assess capacity as part of the MDT.
- Support people to understand information.

SLT's have a unique role in identifying the specific nature of communication difficulties in adults. SLT's also have a unique role supporting and training other professionals in working with speech, language and communication needs. As experts in communication, it is the role of the SLT to assist their healthcare colleagues, and individuals with communication impairment in capacity assessments. IASLT consider that all professionals involved in the capacity assessment including advocates, should receive mandatory training from a speech and language therapist, developed by speech and language therapists to



ensure that they are able to understand and use the most appropriate mode and level of communication with the individual.

5.0 Background

A capacity assessment involves determination of whether the adult being assessed is able to understand the information relevant to the decision, to retain that information long enough to make a voluntary choice, to use or weigh that information as part of the process of making the decision, and to communicate that decision (ADMA, 2015).

Because communication is central to determination of capacity, individuals who have communication disorders are at a disadvantage during a capacity assessment.

According to the Act (ADMA, 2015), an adult has the right to “an explanation of [the decision] given to him or her in a way that is appropriate to his or her circumstances (whether using clear language, visual aids or any other means)” (ADMA, 2015 s. 3 (3)). The person being assessed also has the right to communicate their decision by talking, writing, using sign language, assistive technology, or any other means.

Individuals with communication impairment may have difficulties in expressing thoughts, asking questions, and demonstrating that they understand the information presented to them. These difficulties can be subtle, complex and sometimes undetermined – requiring specialist SLT assessment, and specialist skills to be in a position to support individuals.

While it is the responsibility of the assessor to provide appropriate communication assistance arrangements IASLT affirms that given their expertise



and therefore their ability to contribute most to valid person-led choice the fundamental role of the Speech and Language Therapist needs to be clearly included.

People with communication difficulties need additional support during capacity assessments but may not always receive this (Jayes, Palmer & Enderby, 2016). Research shows that staff recognize that they need training and resources to provide this additional support. As experts in communication, it is the role of the SLT to assist their healthcare colleagues, and individuals with communication impairment in capacity assessments. This is supported by HIQA. Expertise and training in communication is recommended as a fundamental requirement for those working with individuals with a communication impairment (HIQA 2012, 2016) – this expertise and training becomes even more important where individuals are making decisions about their lives and care.

Annually in Ireland (Tighe, 2017)

- **10,000 people affected by stroke**

Up to 43% of these individuals have communication impairment (National Aphasia Association, 2017; Engelter et al., 2006)

- **10,000 sustain a traumatic brain injury**

Up to 43% of these are living with a TBI-related disability, including communication impairment and cognitive linguistic difficulties (*Selassie et al., 2008; Zaloshnja et al., 2008; Thurman et al., 1999*)

- **4,000 people develop dementia**

(over 11 people every day). There are over 50,000 people living with dementia in Ireland today. Communication impairment is intrinsic to dementia diagnosis (American Psychiatric Association, 2013) – therefore



all of these individuals may present with some level of communication difficulty.

■ **1 in 4 affected by a mental health condition**

Research in the UK showed that 90% (n=95) of people with mental health disorders and dementia presented with language and communication impairments significant enough to impact on everyday functioning (Bryan & Maxim, 2006). In an Irish context, Walsh et al. (2007) examined a sample of adults (n=60) with mental health disorders attending a psychiatric service for the presence of impairments in language and communication. Results showed that over 80% of subjects showed impairment in one or more of the tests of language administered and over 60% showed impairment in communication skills.

■ **17,872 adults with intellectual disability (HRB, 2016)**

People with intellectual disabilities (ID) form the largest group of communication impaired individuals in the general population (RCSLT, 2007). *There are 17,872 adults with intellectual disability in Ireland registered (HRB, 2016).* Emerson et al (2001) estimate that up to 90% of people with learning disabilities have communication difficulties, about 80% of those with severe learning disabilities fail to acquire effective speech, while 60% of people with learning disabilities have some skills in symbolic communication, such as sign languages or picture symbols. There is a further 20% of people who communicate at intentional level, but do not have symbolic understanding and another 20% who are at the preintentional levels of communication (Emerson et al, 2001).

■ **22,813 people with physical and sensory disabilities (HRB, 2016)**

There are 22,813 people with physical and sensory disabilities registered. Approximately 63% of these are over the age of 18. Speech and

Language disability was one of the 3 most commonly cited disabilities (HRB, 2016)

6.0 Benefits of including Speech and Language Therapists in the implementation programme for the ADMA

1. Ensures a complete, person-centred capacity assessment, which takes specific account of an individual's communication ability and needs, in line with the Act.
2. It is not possible to implement a quality or fair process without addressing some core issues such as communication needs. Involving SLT ensures that individuals have the opportunity and means to understand and express themselves as fully as possible.
3. As experts in communication, SLTs are uniquely placed to advocate for individuals with complex communication needs undergoing capacity assessment. SLT assessment is independent of any other caring or advocacy roles.
4. The SLTs assessment and facilitation of targeted communication either verbal or non verbal is required when there is a communication impairment. Otherwise, the process cannot be said to be individualised, responsive or fair.
5. The provision of support and training to colleagues carrying out capacity assessments. Research confirms that capacity assessment is more difficult in cases where there is communication impairment, and healthcare professionals recognize that extra support and help is needed.



6. By facilitating (through direct involvement and/or training in communication) a more truthful capacity assessment, which adheres to directions relating to supporting specific communication needs, SLTs can reduce the risk to an organization, reduce incidence of inappropriate interventions, subsequent challenges to outcomes of capacity assessments.
7. SLTs have the ability and skill set to develop tools, supportive materials, and local expertise for carrying out capacity assessment – for developing a practical pack for health professionals working with adults with communication impairment in capacity assessment.
8. SLTs are experts in Augmentative and Alternative Communication (AAC), and prescribe and support a range of non-verbal communication systems.

7.0 The risks of not involving SLTs include:

1. Individuals with communication impairments being wrongfully judged to lack capacity, thereby denying their basic human rights to be involved in decision making about their personal life.
2. Assumptions in relation to an individual's communication skills may occur. There is also a risk that health and social care professionals may assume someone lacks capacity to make decisions due to their communication disability when in fact, with the correct communication support, the individual could fully participate in decisions about their lives. There is evidence that carers assume greater communication (receptive and expressive) skill that is present especially in the context of AWID. Staff can overestimate comprehension abilities, underestimate hearing difficulties and overuse verbal/instructional language even with the clients with the most profound disability.



3. Information not being presented to an individual in the most accessible format to meet their needs. This would impact the fairness of the capacity assessment, and breach the fundamental terms of the Act.
4. Other professions not having the appropriate support or training in communication to be able to carry out a fair capacity assessment with an individual with communication impairment.
5. Where inaccurate capacity assessments are carried out, due to communication impairment, there is a risk of litigation, clinical errors and inappropriate interventions being pursued. SLTs are in a position to complete an independent communication assessment for an individual undergoing capacity assessment. An independent assessment of communication and enablement of communication skills throughout the process ensures that the individual can fully communicate their wishes. This is crucial as there may be instances where a nominated person or carer may not want the individual to be fully able to communicate their wishes if it makes the home/care/financial situation more challenging for the caring role. Assessment of communication competence where appropriate is the first step towards enabling that which the act purports to achieve – fair and truly assisted decision making.

8.0 Recommendations

For individuals with a significant communication disability, the formal capacity assessment should require that the assessment is carried out by a suitably qualified person. The IASLT 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.

Involvement of SLTs in capacity assessment should include, but is not limited to:

- Screening communication of adults for whom capacity assessment is recommended.
- Evaluating the abilities of individuals undergoing capacity assessment: when a person presents with communication support needs the SLT should facilitate assessments relating to decision making capacity to ensure that the person's communication skills are optimised and therefore that their capacity is maximised throughout the journey.
- Implementing and/or recommending facilitative communication strategies to be used by the communication partners/capacity assessors during capacity assessments, based on documented communication abilities of the person being assessed.
- Developing and implementing high/low tech assistive technology where appropriate to meet the communicative needs of each individual
- Facilitating a capacity assessment by being present to provide communication support as required by the assessor and the individual being assessed.
- Making information accessible through the individualised assessment of the person's communication strengths and needs.
- Supporting the person to build capacity around choice making and decisions.



- Supporting staff/ co-decision makers while consulting with people with complex communication needs.
- Providing training and education to other health and social care workers, to allow them to better support understanding, and expression for decision making.
- Referring individuals to specialist services.
- Educating the public and other health and social care professionals regarding (a) the impact of communication disorders on capacity assessments and (b) the link between cognition, decision making, capacity and communication.

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