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Mental capacity legislation and communication disability: A cross-sectional survey exploring the impact of the COVID-19 pandemic on the provision of specialist decision-making support by UK SLTs

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Abstract

Background: Mental capacity legislation in the UK is designed to safeguard the rights of people who may need support, or may be unable, to make autonomous decisions. Very limited evidence has been published about the impact of the COVID-19 pandemic on the application of mental capacity legislation and, to our knowledge, none on the ability of speech and language therapists (SLTs) to support people with communication disabilities to engage in decision-making.

Aims: To describe how UK SLTs supported people with communication disabilities to make decisions and participate in mental capacity assessments, best interests decision-making and advance care planning during the COVID-19 pandemic.

Methods & Procedures: This descriptive, cross-sectional study used an online survey to collect quantitative and qualitative data about SLTs' practice experiences between August and November 2020. SLTs working with a range of adult clinical populations in different care settings were sampled purposively from all UK jurisdictions. Participants were recruited through professional networks and social media. Quantitative data were summarized using descriptive statistics. Qualitative data were analysed thematically.

Outcomes & Results: Data were collected from 107 SLTs working in a range of settings across all four UK nations. The sample included SLTs working with people with neurological conditions, learning disabilities, mental health conditions and acute confusion. The need for SLT support appeared to increase during the pandemic. Most respondents were still able to offer support; however, the amount and nature of support varied. Quality of support was impacted by adjustments associated with social distancing and infection control restrictions. Personal protective equipment (PPE) was identified as a barrier to communication. Indirect working methods (e.g., telehealth) were inaccessible to some

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people with communication disabilities. Most respondents felt confident that legal requirements were upheld, but suggested this group was less able to engage in decision-making and had reduced access to support to manage their own health conditions.

Conclusions & Implications: Some SLT services were limited in their ability to meet the decision-making support needs of people with communication disabilities during the COVID-19 pandemic due to structural and systemic barriers. This suggests that existing inequities in the provision of care for people with communication disabilities in the UK were amplified during the pandemic.

KEY WORDS

adults, COVID-19, decision-making, disability, mental capacity, speech and language therapists

What this paper adds

What is already known on the subject

People with communication disabilities may require support from healthcare professionals, including SLTs, to make decisions and communicate their wishes and preferences about their care, in line with mental capacity legislation. There is a lack of published evidence relating to how changes in staff deployment and resource during the COVID-19 pandemic may have impacted on the ability of SLTs to provide this support.

What this paper adds to existing knowledge

This study provides novel evidence about the ways in which UK SLTs supported people with communication disabilities to engage in mental capacity assessments, best interests decision-making and advance care planning during the COVID-19 pandemic. In some cases, the amount and quality of decision-making support available was affected negatively due to changes in healthcare delivery and resource management and SLT working practices.

What are the potential or actual clinical implications of this work?

This study suggests that some people with communication disabilities experienced greater barriers to receiving professional support to maximize their autonomy and manage their health conditions during the COVID-19 pandemic. Speech and language therapy services and healthcare commissioners should consider how best to ensure equitable service delivery to this population in resource-limited situations.

INTRODUCTION

Legal requirements to ensure equity of access to health and social care and universal service design in the UK still applied during the COVID-19 pandemic (Farrell & Hann, 2020; Ruck Keene, 2020; Stavert & McKay, 2020). Similarly, mental capacity legislation remained largely unchanged across the three UK jurisdictions. UK mental capacity legislation (OPSI, 2005; The Scottish Government, 2008; TSO,

2016) requires healthcare professionals (HCPs) to provide decision-making support to people who need it and to complete a mental capacity assessment if they have reason to believe an individual may have difficulty making an informed decision. A mental capacity assessment involves a functional test of decision-making and establishes decision and time-specific incapacity if an individual is unable to make and communicate a decision because of an identified impairment or disturbance in the functioning of

the mind or brain (OPSI, 2005). When a mental capacity assessment finds that a person lacks capacity, HCPs must collaborate with the person and their significant others to make a decision in the individual's best interests. UK mental capacity legislation also enables individuals to engage in advance care planning, for example, by making advance decisions to refuse certain types of treatment, advance statements of wishes and preferences relating to care, and by donating power of attorney to others to enable surrogate decision-making at a future time when they no longer have mental capacity.

Very limited evidence has been published about the impact of the pandemic on the application of mental capacity legislation and, to our knowledge, none on how people with communication disabilities were supported to make decisions. This population is of interest because they require individualized communication support, usually from speech and language therapists (SLTs), to understand information and express themselves when making decisions; without such support, decision-making capacity may be masked (Ferguson et al., 2010). This study aimed to address this evidence gap by exploring how UK SLTs supported people with communication disabilities to engage in decision-making and whether legal principles pertaining to autonomy and the rights of people with communication disabilities were upheld during the pandemic.

People may have communication disabilities caused by lifelong or acquired health conditions including learning disability, stroke, brain injury and dementia. Many HCPs without specialist training in communication disorders do not know how to identify and support communication needs reliably (Carragher et al., 2020). The SLT role in supporting people with communication disabilities to engage in decision-making, including advance care planning, is recognized and promoted (National Institute for Health and Care Excellence [NICE], 2018). However, some HCPs do not refer to SLTs when support is indicated and may make inaccurate judgements about the mental capacity of people with communication disabilities, or conflate impaired communication with impaired decision-making capacity (Borrett & Gould, 2020; Jayes et al., 2021; McCormick et al., 2017). The provision of specialist support by SLTs can ensure that mental capacity assessments are inclusive of the needs of people with communication disabilities. SLTs can support HCPs to understand people's wishes and preferences in relation to specific decisions. Without this support, people with communication disabilities may not be enabled to make informed decisions; furthermore, HCPs may not foreground individual wishes and preferences when making best interests decisions for people who have been deemed to lack capacity.

Changes in resource availability during the pandemic, in terms of staff deployment and time, may have impacted

further on the ability of HCPs, including SLTs, to provide communication support (Parsons & Johal, 2020). Moreover, social distancing measures and the use of personal protective equipment (PPE) might have had complex effects on verbal and non-verbal communications during capacity assessments for people with communication disabilities (Marler & Ditton, 2021). In order to explore these issues, this study aimed to describe how UK SLTs supported people with communication disabilities to make decisions and participate in mental capacity assessments, best interests decision-making and advance care planning during the COVID-19 pandemic. We wished to identify and describe any changes or adaptations to SLTs' practice in relation to the application of mental capacity legislation during the COVID-19 pandemic.

METHODS

This descriptive study used a cross-sectional design. An online survey was used to collect quantitative and qualitative data from participants from all four UK nations. A purposive sample of SLTs working with a range of adult clinical populations in a variety of service delivery settings was recruited through the Royal College of Speech and Language Therapists' (RCSLT) professional networks and social media. SLTs were included if they were involved in supported decision-making and mental capacity assessment for patients over the age of 16 years. All participants provided informed consent. The study received ethical approval from the Manchester Metropolitan University Faculty of Health, Psychology and Social Care Ethics Committee.

The survey (see the additional supporting information) was designed using Jisc online survey software (<https://www.onlinesurveys.ac.uk/>) to collect data anonymously. It included questions about: participants' demographic information and employment; involvement in mental capacity assessments, advance care planning and best interests decision-making during the pandemic; adaptations to working practices; and perceptions about the impact of the pandemic on the quality of practice and the human rights of people with communication disabilities. There were 40 questions in open, closed and multiple-choice formats. The survey took between 20 and 30 minutes to complete. Participants were asked to report on practice that occurred between March 2020 and the day they completed the survey. The survey was piloted and modified based on feedback from five SLTs. The final survey was live for a 3-month data-collection period between August and November 2020.

All authors contributed to analysis. Each was responsible for analysing a specific part of the data set, but adopted

the same analytical methods. No data sets were removed prior to analysis. Descriptive statistics (frequency counts and percentages) were used to summarize the number of respondents who provided a particular response to each question. The total possible number of responses varied across questions because not all participants responded to each question. Qualitative data were analysed using a six-stage thematic analysis method (Braun & Clarke, 2006). Initial analysis involved each author reading the qualitative responses for their part of the data set to become familiar with the data and to identify initial codes. The authors generated codes deductively from the research aims and inductively from the data. They identified further codes by re-examining the data against the developing coding framework. Each author then identified initial themes and subthemes by organizing codes into meaningful groups. Next, all authors reviewed the coding frameworks and initial themes together; they revised and refined themes and subthemes, and organized them all together within a thematic map. They then reviewed this map in order to define, name and further refine themes. The authors agreed upon the final set of themes through consensus. Finally, the first author produced a written report summarizing the outcome of analysis.

RESULTS

Participant sample

Responses were received from 107 SLTs working across the four UK nations. All participants completed the entire survey. We were unable to calculate the exact number of SLTs who received our invitation to participate, as we advertised the study using professional networks and social media. There were 17239 SLTs registered with the Health and Care Professions Council (HCPC) in November 2020 (HCPC, 2020). The most recent Centre for Workforce Intelligence (CFWI) data suggest that 39% of UK SLTs provided services to adults in 2014 (CFWI, 2014). If this percentage has remained largely unchanged, this would indicate that an estimated 6723 SLTs were potentially eligible to participate. This would equate to a response rate of 1.6%. However, it is important to consider that not all SLTs working with adults might be involved in practice relating to mental capacity legislation.

Participant characteristics are shown in Table 1. Respondents worked in a range of care settings. The majority of respondents worked with people with communication disabilities associated with neurological conditions, but the sample also included SLTs working with people with learning disabilities, mental health conditions and acute confusion. Most participants had been working for at least

5 years as SLTs and the majority were employed in specialist or highly specialist clinical roles (NHS Agenda for Change bands 6–7).

Findings

SLT involvement in mental capacity assessment, best interests decisions and advance care planning during the pandemic

The majority of respondents ($n = 96$; 89.7%) reported they had been involved in supporting or leading mental capacity assessments during the COVID-19 pandemic. These mental capacity assessments related to a range of patient decisions, including how to eat and drink safely in the presence of dysphagia (swallowing difficulties), treatment options, care arrangements, discharge destination and deprivation of liberty. Most respondents had been involved in making best interests decisions for people found to lack capacity ($n = 80$; 74.8%) and in supporting people to engage in advance care planning ($n = 99$; 92.5%). As shown in Table 2, although most respondents reported that they were involved in these activities as frequently as they had been before the pandemic, 8.1–17.7% indicated they were involved more frequently, whilst 14.1–20.8% indicated they were involved less frequently.

Potential reasons for changes in SLT involvement

Greater involvement

Respondents indicated that they were more involved in capacity assessments relating to discharge or care arrangements because fewer social workers (who would normally lead this type of assessment) had visited hospitals during the pandemic: 'I've been asked to support this process with the patient on the ward, and the social worker via video'. They also identified new types of patient decision that they needed to support: 'More decisions around testing, isolating and shielding, directly related to COVID-19'. Respondents suggested there was a greater focus generally on advance care planning in some hospital settings due to 'a surge of admissions for people who are acutely unwell with complex health conditions'. There was also increased emphasis on patients or service users' best interests due to 'a conflict between, for example, their mental and physical health needs due to the restrictions of COVID'.

Less involvement

Respondents working in hospital and community settings reported a reduction in referrals to SLTs for communication support generally during the pandemic. SLTs working

TABLE 1 Participant characteristics

Participant characteristic	Number of respondents	% of respondents
<i>Work setting</i>		
Acute healthcare	51	47.7%
Primary or community care	67	62.6%
Charity/third sector/private sector/other	19	17.8%
<i>Patient/client group</i>		
Young adults	10	9.3%
Older adults	58	54.2%
People with neurological conditions	84	78.5%
People with learning disabilities	30	28.0%
People with mental health conditions	27	25.2%
People with acute confusion	29	27.1%
Other (adults with head and neck cancer; children)	3	2.8%
<i>Geographical location</i>		
South West England	15	14.0%
South East England	10	9.3%
London	12	11.2%
East of England	14	13.0%
West Midlands	6	5.6%
East Midlands	11	10.3%
Yorkshire and the Humber	18	16.8%
North West England	4	3.7%
North East England	3	2.8%
Northern Ireland	4	3.7%
Wales	4	3.7%
Scotland	6	5.6%
<i>Years of experience</i>		
Newly qualified SLT	1	0.9%
1–2	13	12.1%
3–4	9	8.4%
5–10	37	34.6%
11+	47	43.9%
<i>NHS professional banding</i>		
Newly qualified band 5	1	0.9%
Band 5 with experience	8	7.5%
Band 6	37	34.6%
Band 7	43	40.2%
Band 8	11	10.3%
Not applicable (non-NHS staff)	7	6.5%

TABLE 2 Frequency of speech and language therapist (SLT) involvement in activities related to mental capacity legislation

SLT involvement	Mental capacity assessment	Best interests decision-making	Advance care planning
No change in involvement	59 (61.5%)	59 (73.75%)	77 (77.8%)
Involved less frequently	20 (20.8%)	12 (15%)	14 (14.1%)
Involved more frequently	17 (17.7%)	9 (11.25%)	8 (8.1%)

in hospitals suggested that fewer people with communication needs were admitted: 'our stroke unit was down to one patient at one point during lockdown'. They also suggested that due to the nature of COVID-19 symptoms, fewer inpatients with communication needs were well enough to receive communication support: 'The COVID ICU [patients] requiring trache[ostomy] were always sedated and were unable to participate'. In some acute hospital settings, inpatient rehabilitation (e.g., for neurological conditions) was unavailable or shortened; patients were discharged to their own homes or to care homes to reduce the risk of infection and manage clinical resources: 'some patients were transferred to nursing homes for interim stays when rehabilitation would have been the best option'.

Respondents also suggested that decision-making in hospitals was more rapid during the pandemic, which meant that patients were less frequently included in decision-making or patients' mental capacity was not always considered: 'Probably less capacity assessments [were] done re discharge destinations during [the] peak'; 'I believe much of the acute work was done quickly and didn't always ask the question of capacity'. Others indicated that some decision-making processes (e.g., around care arrangements post-discharge) did not actually take place in the hospital setting but were postponed until the patient had already been transferred (e.g., to a nursing home): 'People spending shorter time in hospital ... so more decisions being made in the community'; 'people were discharged from hospital to any other available setting potentially despite their wishes'. Participants also suggested that in some situations, discussions about best interests decisions did not take place, took place more rapidly, or without the inclusion or representation of patients or family members:

[a] directive from [the healthcare] Trust indicated that beds should be cleared. No opportunity to represent the views or interests of the patients.

Most of the time, decisions have been made in the [patient's] best interests however due to pressure of getting [patients] out of hospital, [patients] were made to go to rehabilitation units that weren't close by rather than wait until a bed was available in a nearby unit

Furthermore, changes in SLT staff resource allocation meant that some services needed to devote more resources to people with dysphagia during the pandemic; this reduced the resource available for people with communication needs: 'Staff shortages and skill mix meaning more time spent on dysphagia management and less

on communication'. In addition, infection control policies meant SLTs could not always work face to face with patients or service users. One SLT explained that their access to care home residents was significantly restricted and they only worked with residents who had relatives who were able to seek support on their behalf:

A considerable proportion of my clients are in residential care homes and I did not have any access or contact with the staff during the pandemic, which I normally do. Therefore it was only the clients whose families specifically asked me to help with communication support.

A high number of respondents ($n = 91$; 91.9%) reported they had not been asked to support people with communication difficulties to make decisions about Do not attempt cardiopulmonary resuscitation (DNACPR) orders during the pandemic. Respondents indicated that some of these people could have participated in DNACPR decisions if they had received communication support: 'I sometimes read in the notes that somebody couldn't take part in a conversation and all the information was gleaned from the partner, when I know the person is capable of participating effectively'. Many SLTs suggested their lack of involvement in DNACPR decisions pre-dated the pandemic:

'DNACPR discussions continue to be led by the medical team. Whilst they do seek SLT support for decision-making in other areas, they rarely request SLT input to facilitate DNACPR discussions'.

Adjustments to SLT working methods and impacts on patients/service users

The majority of respondents ($n = 69$; 93.2%) reported having to adjust the way they supported people with communication disabilities to make decisions, due to specific challenges presented by the pandemic.

Adaptation to working patterns

Although most SLTs ($n = 74$; 74.7%) were able to continue working directly with patients/service users, they had less time to support them, which had a negative impact: 'Shorter and quicker conversations, which does not sit well as people require time to make certain decisions of significance'. SLTs needed to adapt communication resources and materials creatively and rapidly, in line with social distancing and infection control restrictions: 'Use of larger physical/paper-based resources which can be

seen at social distance to reduce amount of touch/shared resources'. Respondents also reported that infection control measures made it more difficult to involve family members in mental capacity assessments and best interests decision-making processes. They felt that this had impacted negatively on patients/service users:

in one instance when trying to facilitate a question about whether the client would choose to live at home with her daughter or prefer to live in a care home, I did feel we could have maximized her capacity more if her daughter could have been present and put it in more context, but due to COVID restrictions her daughter had been unable to visit since [her] stroke and [could] only see [her] remotely.

Impact of PPE

Most respondents ($n = 62$; 89.9%) reported that use of PPE had impacted on the way they had supported decision-making. They described PPE, particularly face masks, as 'a barrier to effective rapport development' and a type of communication barrier:

'People with aphasia, cognitive communication difficulties and hearing impairment find it more difficult when I am wearing a mask as they cannot read my facial expression or lips, and the masks can make it harder to hear'.

Respondents reported increasing their use of supported communication strategies such as supplementing speech with images or written words, to compensate for this communication barrier. One SLT reported asking a therapist assistant colleague to communicate with a patient via video call whilst they worked directly with the patient; the assistant was able to explain what was happening and provide reassurance to the patient. Despite this, respondents stated that PPE impacted negatively on engaging people in decision-making conversations, adding that some people were more anxious or confused when staff wore masks.

Indirect working

Some respondents ($n = 25$; 25.3%) reported that they had not always been able to work directly with people. Instead, they used a range of remote methods: telehealth (video), telephone or email, which worked well for some patients/service users, particularly those with 'less severe communication and memory difficulties'. Some patients/service users found these methods convenient. Other respondents thought indirect work was not as easy or effective as direct work. For example, these methods

made it more difficult to work with the patient on their own, which raised issues relating to privacy and confidentiality: 'In safeguarding cases the vulnerable person often is unable to speak freely'.

Indirect working also impacted negatively on the ability of staff to gain rapport and on the nature and potential effectiveness of communication support available: 'I am conscious that face-to-face assessments can provide more detailed and accurate information'; 'Support is likely to have not been to the same high standard as prior to Covid-19'. Some respondents indicated that remote working had created barriers to having difficult conversations with people relating to advance care planning: 'these are not decisions you want to have over the phone'. Furthermore, use of technology was challenging for some people with communication disabilities because it affected functional communication or was difficult to operate: 'Variable WiFi speeds mean that it is difficult to be understood or to understand someone on a video call'; 'Many are unable to access video platforms, or are reluctant to do so, so there's been less clinical contact'. Other respondents suggested that digital poverty affected some patients'/service users' ability to engage with telehealth.

Respondents also worked through other professionals: 'Giving instructions on how to assess rather than being the person completing the assessment'. Some respondents found this more time consuming, challenging, and potentially less effective:

Only the social worker was in the room with the patient, whilst SLT supported over video call. It was difficult to explain to the social worker exactly how to minimize their language and maximize their communication in order to support the patient

I feel when you 'hand over' control in some way, for example, giving another professional resources that you produce to support the assessment, rather than doing it, there's a worry of them being used differently to how you would use them.

Perceived impact on practice quality and the rights of people with communication disabilities

Respondents reported that they did their best to support patients and service users during the pandemic. However, they expressed concern that these adapted ways of working did not provide the same level of support, and that certain patients/service users did not receive any support. Some respondents reported feeling less confident about the

outcomes of capacity assessments for people with communication disabilities ($n = 21$; 23.9%) and were not confident that decisions had been made in the best interests of these people ($n = 20$; 25%). However, most respondents ($n = 84$; 78.5%) stated they felt confident that legal requirements relating to mental capacity had been met where they worked during the pandemic.

More broadly, the majority of respondents ($n = 76$; 71%) reported that they believed the rights of people with communication difficulties had been adversely affected during the pandemic. They suggested that the voices of people with communication disabilities were less likely to be included in decision-making, either directly or through professional or family advocacy. They also suggested that this group had reduced access to professional, voluntary and family support, which meant their healthcare was impacted and they were put at risk of increased isolation:

‘An already marginalized and silenced group of people have had their services cut, health professionals redeployed and specialist teams change their way of working. Health professionals have had to submit safeguardings ... when essential visits have been declined by care staff’.

Furthermore, respondents observed that, unlike other populations, people with communication disabilities often need communication support to be able to access services, understand health information and seek help. As this type of support was less available and remote communication methods may be more challenging to access for this group, these people were at risk of not accessing appropriate support to manage their health:

‘There has been a lack of timely, accessible information about the pandemic and changes to guidance, provided to people with communication disabilities. For example, the lack of a sign language interpreter in government television updates’.

DISCUSSION

This study has provided evidence relating to the ways that SLTs supported people with communication disabilities in the UK to engage in mental capacity assessments, best interests decision-making and advance care planning during the COVID-19 pandemic. Encouragingly, most respondents indicated that they were still able to support different types of decision-making activity and felt confident about the robustness of mental capacity outcomes and best inter-

ests decisions for this population. Our findings suggest SLTs responded creatively to the challenges presented by the pandemic and were able to develop their practice innovatively in response to new infection control measures. Some suggested that the frequency of their involvement increased or that they found the use of novel, remote consultation methods beneficial for certain patients/service users. Less positively, our results suggest that referrals to SLTs for communication support decreased in some settings; this finding is consistent with a trend reported in other SLT service delivery data collected during the COVID-19 pandemic (Chadd et al., 2021). When referrals were received, the decision-making support available to people with communication disabilities was impacted negatively, despite SLTs’ best efforts to deliver individualized communication support.

Overall, this study suggests that the barriers that communication disability can present to informed, active participation in healthcare, increased this group’s vulnerability at a time when these people experienced reduced access to family, community and professional support. In some cases, structural and systemic factors and inequities already embedded in the healthcare system were magnified during the pandemic. This affected the amount, frequency and quality of support available for people with communication disabilities. An existing trend to prioritize allocation of SLT resources to the management of dysphagia over communication appeared to be exacerbated during the pandemic (Foster et al., 2016; Jayes et al., 2017). This is likely to have resulted from utilitarian considerations of how to use limited resources to manage competing risks. Dysphagia is perceived by many HCPs to present a greater risk to patient/service user safety than communication disability, because it is associated with potentially life-threatening sequelae (Foster et al., 2016). However, people with communication disability have a legally recognized right to decision-making (including communication) support; this support would enhance engagement in treatment and lead to more positive health outcomes (Bunn et al., 2018).

Our findings confirm existing evidence about deleterious psychological, sensory, communicative and cognitive effects on professional-patient communication caused by the wearing of PPE (Banks et al., 2020; Marler & Ditton, 2021). These effects are compounded for people with communication disabilities, who may have concomitant cognitive difficulties and require supplementary, non-verbal information (e.g., facial expression) to augment their communication abilities. These effects are likely to be ongoing, as UK HCPs continue to be required to use PPE and apply social distancing measures. Our results also suggest that remote consultation methods, including telehealth, are not accessible to all people with communication disabilities,

because they increase the communicative and cognitive demands on this group, affect engagement, and present technological and financial barriers. These findings complement evidence from earlier studies including people with communication disabilities (Kong, 2021) and other populations (Banks et al., 2020; Parsons & Johal, 2020).

Some SLTs were no longer able to support other HCPs to create inclusive mental capacity processes for this population or were less able to involve family members as supporters, interpreters and advocates. This increases the risk that people with communication disabilities were denied opportunities to engage in autonomous or supported decision-making or that they made incapacitous decisions; best interest decision-making may not have included important considerations of individuals' values, wishes and preferences (Stewart et al., 2020). Of significant concern was our finding that some people with communication disabilities did not receive support to make decisions about DNACPR orders. This finding is consistent with evidence relating to DNACPR orders being made without adequate patient consultation for people with learning disabilities, who often experience communication disabilities (Care Quality Commission, 2021; Parsons & Johal, 2020; Ruck Keene, 2020; Stavert & McKay, 2020).

During the COVID-19 pandemic, new legal provisions were introduced in the UK to expedite transfer of care, in order to address resource allocation challenges. This meant that, in extreme circumstances, HCPs no longer needed to complete care needs assessments for individual patients/service users and could make care decisions without considering the wishes and preferences of these individuals or their advocates (Farrell & Hann, 2020; Ruck Keene, 2020; Stavert & McKay, 2020). Our findings suggest that these new legal provisions were implemented in some settings and people were not involved in decisions about their care. Decision-making in many instances may have adopted a utilitarian rather than rights-based approach; this may have placed people with communication disabilities at an even greater risk of experiencing reduced access to healthcare, including rehabilitation, and inferior health outcomes (Kong, 2021). We agree with other commentators (Ruck Keene, 2020; Stavert & McKay, 2020; Vicary et al., 2020) that a utilitarian approach to resource allocation has the potential to discriminate against those who may need support to make decisions or may not be able to make or voice their own decisions. Healthcare decision-making should be based instead on a human rights-based approach that is consistent with UK mental capacity legislation.

We acknowledge that SLTs based in England and those working with people with neurological conditions were over-represented in our sample, which has implications for the generalizability of our findings. A limitation of the survey method is that it relied on self-report and we were not

able to clarify ambiguous or incomplete responses. However, this method was considered to be feasible during the pandemic. Future research utilizing ethnographic or documentary analysis methods could provide a richer dataset to capture patient and HCP experiences.

CONCLUSIONS

In summary, our findings suggest the need for SLTs to support people with communication disabilities to engage in decision-making increased during the COVID-19 pandemic. Although the majority of respondents reported they were still able to offer support, the amount and nature of this support varied; in some cases, support was less robust. This is likely to have affected patients'/service users' ability to engage directly or through advocates in decisions about their care. Our findings lead us to suggest that existing inequities in the provision of care for people with communication disabilities in the UK were amplified during the pandemic. Speech and language therapy services and healthcare commissioners should work together to consider how best to ensure equitable service delivery to this population in ongoing resource-limited situations.

CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

ETHICS APPROVAL STATEMENT

This study received full ethical approval from Manchester Metropolitan University Faculty of Health, Psychology and Social Care Ethics Committee.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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REFERENCES

Banks, S., Cai, T., de Jonge, E., Shears, J., Shum, M., Sobočan, A.M., et al. (2020) Practising ethically during COVID-19: Social work challenges and responses. *International Social Work*, 63(5), 569–583. <https://doi.org/10.1177/0020872820949614>

Borrett, S. & Gould, L.J. (2020) Mental capacity assessment with people with aphasia: Understanding the role of the speech and language therapist. *Aphasiology*, [cited 2021 May 03]. 35(11), 1463–1481. <https://doi.org/10.1080/02687038.2020.1819954>

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.

Bunn, F., Goodman, C., Russell, B., Wilson, P., Manthorpe, J., et al. (2018) Supporting shared decision making for older people with multiple health and social care needs: A realist synthesis. *BMC Geriatrics*, 18(1), 165.

Care Quality Commission. (2021) Protect, respect, connect—Decisions about living and dying well during COVID-19. Available from: https://www.cqc.org.uk/sites/default/files/20210318_dnacpr_printer-version.pdf. [Accessed May 3, 2021].

Carragher, M., Steel, G., O'Halloran, R., Torabi, T., Johnson, H., Taylor, N. F., et al. (2020) Aphasia disrupts usual care: The stroke team's perceptions of delivering healthcare to patients with aphasia. *Disability and Rehabilitation*, [cited 2021 May 03]; 43(21), 3003–3014. <https://doi.org/10.1080/09638288.2020.1722264>

Centre for Workforce Intelligence. (2014) Securing the future workforce supply: Speech and language therapy stocktake. London, CFWI.

Chadd, K., Moyse, K. & Enderby, P. (2021) Impact of COVID-19 on the speech and language therapy profession and their patients. *Frontiers of Neurology*, 12, 629190. <https://doi.org/10.3389/fneur.2021.629190>

Farrell, A.M. & Hann, P. (2020) Mental health and capacity laws in Northern Ireland and the COVID-19 pandemic: Examining powers, procedures and protections under emergency legislation. *International Journal of Law and Psychiatry*, [cited 2021 May 03]. 7, <https://doi.org/10.1016/j.ijlp.2020.101602>

Ferguson, A., Duffield, G. & Worrall, L. (2010) Legal decision-making by people with aphasia: critical incidents for speech pathologists. *International Journal of Language & Communication Disorders*, 45(2), 244–258.

Foster, A., O'Halloran, R., Rose, M., & Worrall, L. (2016) "Communication is taking a back seat": Speech pathologists' perceptions of aphasia management in acute hospital settings. *Aphasiology*, 30(5), 585–608.

Health and Care Professions Council. (2020) Registrant snapshot – 3 November 2020. Available from: <https://hcpc-uk.org>. [Accessed October 6, 2021].

Jayes, M., Palmer, R. & Enderby, P. (2017) An exploration of mental capacity assessment within acute hospital and intermediate care settings in England: A focus group study. *Disability and Rehabilitation*, 39(21), 2148–2157.

Jayes, M., Palmer, R. & Enderby, P. (2021) Giving voice to people with communication disabilities during mental capacity assessments. *International Journal of Language & Communication Disorders*, 56(1), 90–101.

Kong, A.P. (2021) The impact of COVID-19 on speakers with aphasia: What is currently known and missing? *Journal of Speech, Language, and Hearing Research*, 64(1), 176–180.

Marler, H. & Ditton, A. (2021) "I'm smiling back at you": Exploring the impact of mask wearing on communication in healthcare. *International Journal of Language & Communication Disorders*, 56(1), 205–214.

McCormick, M., Bose, A. & Marinis, T. (2017) Decision-making capacity in aphasia: SLT's contribution in England. *Aphasiology*, 31(11), 1344–1358.

National Institute for Health and Care Excellence. (2018) Decision-making and mental capacity [NICE guideline NG108]. Available from: <https://www.nice.org.uk/guidance/ng108>. [Accessed May 3, 2021].

Office of Public Sector Information. (2005) *Mental Capacity Act 2005*. London, OPSI.

Parsons, J.A. & Johal, H.K. (2020) Best interests versus resource allocation: Could COVID-19 cloud decision-making for the cognitively impaired? *Journal of Medical Ethics*, 46(7), 447–450.

Ruck Keene, A. (2020) Capacity in the time of Coronavirus. *International Journal of Law and Psychiatry*, [cited 2021 May 03]. 70, <https://doi.org/10.1016/j.ijlp.2020.101560>

Stavert, J. & McKay, C. (2020) Scottish mental health and capacity law: The normal, pandemic and 'new normal'. *International Journal of Law and Psychiatry*, [cited 2021 May 03]. 71, <https://doi.org/10.1016/j.ijlp.2020.101593>

Stewart, C., Biegler, P., Brunero, S., Lamont, S., & Tomossy, G. F. (2020) Mental capacity assessments for COVID-19 patients: Emergency admissions and the CARD approach. *Journal of Bioethical Inquiry*, 17(4), 803–808.

The Scottish Government. (2008) *Adults with Incapacity (Scotland) Act 2000*. Edinburgh, The Scottish Government.

The Stationery Office. (2016) *Mental Capacity Act (Northern Ireland)*. Norwich, The Stationery Office.

Vicary, S., Stone, K., McCusker, P., Davidson, G., & Spencer-Lane, T. (2020) "It's about how much we can do, and not how little we can get away with": Coronavirus-related legislative changes for social care in the United Kingdom. *International Journal of Law and Psychiatry*, [cited 2021 May 03]. 72, <https://doi.org/10.1016/j.ijlp.2020.101601>

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