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Book Review – Consent Support Tool: Including people with communication disorders in health research studies

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Book Review – Palmer R, Jayes M. (2020) Consent Support Tool: Including people with communication disorders in health research studies. J&R Press. ISBN 978-1-907826-46-7

People with neurological conditions such as dementia and stroke may experience difficulties with communication that can present challenges for researchers seeking consent for research studies. Communication impairment may be difficult to untangle from impairment in decision-making capacity, and so may 'mask' a person's ability (or inability) to provide consent. Whilst access to, and support from, speech and language therapists is invaluable in this context, such a scarce resource is rarely available for consent encounters. These challenges around gaining consent mean that many people who have impaired communication are excluded from research. This exclusion denies them the opportunity to participate in research, limits the generalisability of the research findings, and leads to a poorer evidence-base for their care. This book and associated materials, authored by two clinical academic speech and language therapists with experience in conducting research with adults with communication disorders, offers practical, evidence-based support to facilitate the involvement of people with communication disorders in research.

The book is aimed at researchers and healthcare professionals who work with people with communication disorders such as aphasia (receptive and/or expressive) and dysarthria due to acquired neurological conditions including dementia, as well as lifelong conditions such as learning disabilities – some of who will also go on to develop neurological conditions. It is intended to help researchers and professionals to identify the different communication abilities and difficulties that a person may have, and to make judgements about how best to provide information and support them to make an informed decision about participation. As a nurse who conducts research with people with impaired capacity to consent (including people living with dementia in care homes) and leads research to explore some of the ethical and practical challenges involved, I was interested to see how this book might address the existing gap in support for researchers.

The book is only 44 pages in length and is structured in 4 parts: an introduction to the topic and the purpose of the tool, a description about how the tool was developed and evaluated, instructions for

using the tool to assess communication abilities and difficulties, and how to tailor communication strategies using the information obtained. It contains examples of the different types of information sheets that can be developed using accessible principles to correspond to the different needs of people with communication disorders. It also provides a structured form to record the results of the screening process (Part 1) outlined in the book, and maps the results to the appropriate style of information sheets and other strategies to use when communicating with the person (Part 2). Hard copies of this form accompany the book which is supplied in a hard-shell storage case.

The introduction chapter provides a succinct summary of why people with communication disorders should be included in research, and how capacity to consent should be assessed. It also clearly lays out the purpose of the tool, including that while use of this tool this does not form such an assessment, it does support the process. Chapter 2 outlines how the tool was developed and evaluated with people with aphasia and mild-severe comprehension impairment. The details about its development are perhaps of less interest to most readers, however the examples of communication profiles and the recommended style of information for each level are very useful. As are the examples of how the tool has been used in existing research projects. Chapter 3 provides detailed practical guidance for administering the screening test of communication abilities and difficulties, including how to interpret each section (speaking, understanding, reading, and writing). It also provides additional factors and contexts which these assessments should consider, such as any co-occurring disabilities. This is complemented by Chapter 4 which then links the assessment findings with a range of communication support strategies, including which information sheet version might be most appropriate to use and how to facilitate conversation, using four case examples. Chapter 5 moves from information provision to how that information is understood and weighed by the person, and how they can be supported to make and express a decision. Again, practical tips are given and an example of an accessible consent form is provided. There is also information about the process and documents needed in circumstances where the person is assessed as not having capacity to provide consent for themselves. Additional links to resources and guidance are provided as appendices.

This short, well-referenced book will provide invaluable support and guidance for researchers and healthcare professionals seeking to involve people with communication difficulties in research. It bridges the gap between specialist speech and language resources and real-world consent processes for research involving people with conditions such as dementia. Some of the content is specific to England and Wales as it references the Mental Capacity Act as the relevant legal framework, and excludes clinical trials involving medicines. However, the underlying principles about assessing communication and capacity and the supportive communication strategies it describes are applicable to all populations. It would also have been helpful to have reference to temporal aspects of communication, such as memory, which will be especially relevant to people living with dementia or other conditions associated with memory-loss. The book does, however, provide an important and unique addition to the researcher's toolbox to ensure that people with impaired communication and capacity are provided with opportunities to participate in, and benefit from, research.

Victoria Shepherd is a Research Fellow at Cardiff University. Her background is in nursing. As an applied health researcher, she is involved in a wide range of clinical trials and other research studies with a particular focus on care home research. Victoria's current research explores the ethical, legal and practical issues surrounding the inclusion of adults with impaired capacity to consent in research.