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Commentary for LDR

Commentary on: Evaluating service users' experiences of using Talking Mats [™]

Purpose: This paper provides some thoughts following on from reading: Evaluating service users' experiences of using Talking Mats [™].

Design/methodology/approach: This commentary outlines some considerations for the continued discussions about how to engage people who have profound and multiple learning disabilities.

Findings: The literature is not clear on the involvement of people with more profound and multiple learning disabilities, or for those who do not use much spoken language. Some papers have explored the notion of involvement and interpretation of pre-intentional communicators' desires and interests.

Originality/value: There needs to be a robust discussion across carer, academic and service user communities to consider what the communication rights and needs are for people who have profound and multiple disabilities.

Key words: *profound and multiple learning disabilities; pre- intentional communication; inclusion; communication rights; person centred planning; augmentative and alternative communication*

The paper "Evaluating service users' experiences of using Talking Mats [™]" involves service users with learning disabilities in supported discussions about their views of Quality of Support and Quality of Life in relation to their lives. Evaluating service user experiences, as well as exploration of views about person-centred active support (PCAS) is essential when enabling people who have learning disabilities to express their views, and to have a choice about events in their lives. Talking Mats [™] is one method which can enable someone to express an opinion more easily or to think about an issue which needs exploration or resolution through use of an alternative medium. Talking Mats[™] have been used for many different reasons to support people who have complex communication needs for counselling, discussing challenging scenarios such as transition, and participation in research focus groups (Brewster, 2004).

This study rightly suggests that good implementation of PCAS can lead to improvements in a person's quality of life and emotional well-being. Its findings indicate that participants were able to consider their quality of life and express their own views through use of Talking Mats [™]. However, although described as having moderate to severe levels of learning disability, the participants in this study were able to use symbols effectively as part of the Talking Mats [™] process, and could participate in discussions about PCAS. None of the participants had profound and multiple learning disabilities (PMLD). It is likely that people with PMLD would not be able to use Talking Mats [™] to express their views,

and the issue as to how to interact meaningfully with people who have this level of disability deserves greater reflection and discussion.

There has been some consideration about the best way to involve service users with PMLD, both in gaining an opinion about something in their everyday lives or making choices. Both Felce (2002) and Cummins (2002) considered whether it is actually possible to accurately obtain the views and thoughts of people who have PMLD without relying on the opinion of significant others in that service user's life to interpret their possible viewpoints through their preferred communication style. Ware (2004) expands on this and argues that a pre-intentional communicator may react to people and events, as well as showing enjoyment or dislike, but that these responses are not an indication of choice, or even of preference. Thus, these non-verbal attempts which could involve the use of facial expression, whole body movement or vocalisations, are reactions to various experiences and stimuli, rather than initiated communication attempts. In addition to this, families and very familiar carers may over – interpret non – verbal communication attempts adding meanings to an interaction event which may not be the viewpoint of the person themselves (Brewster, 2004).

Ware (2004) investigated how family members and staff interpreted the responses of a young person with PMLD in different contexts. Responses indicating dislike had a high level of agreement, but it was harder to gain a similar level of agreement when observing responses that indicated if a situation or activity was liked or enjoyed. Ware's example reminds us that even familiar people may interpret the same signals initiated by a service user differently. It is hard to predict what the outcomes of this could be, both for the person with PMLD as well as the communication partners who share his/her experiences.

Green, Gardner & Reid (1997) completed a small study involving three service users with PMLD which highlighted that if time was spent determining their happiness responses in a systematic way, then there would be an increase in happiness indices during everyday interactions for the service users themselves. Unlike Ware's findings, this study suggests that it can be possible to develop a level of consistency with interpreting service user responses during interactions.

These examples suggest that there are many factors to consider when interacting with people who have PMLD. One factor is that communication partners should be responsive and sensitive when interpreting and responding to people who have PMLD. In order to be able to do this, people need to have knowledge about how to be responsive, and to be able to use an alternative and augmentative communication system (Hartley Kean, 2016). Another factor is that for successful inclusion to be sustained in the lives of people with PMLD, there needs to be regular training, a long –term commitment to enabling outcomes from training to succeed, and partnership working across agencies to ensure all who have contact with service users have the necessary skills. People who have PMLD are rarely included in research because of the challenges of interpreting responses accurately. Cluley (2017) considered how to involve people with PMLD in a research project through use of Photovoice. Using an action research approach, six adults with learning disabilities, only one of whom had limited verbal skills, were encouraged to use a camera to record

images of home life, in particular meaningful everyday experiences. The images were then shared by the participants, but there were still limitations in that support was needed from paid carers to interpret the meaning of the images for all involved. Cluley (2017) states that research methodologies for people who have PMLD need to be mediated to enable engagement, but does acknowledge, as others have (Aldridge, 2007) that research has epistemological barriers for many people with learning disabilities.

Augmentative and Alternative communication (AAC) such as using symbols, natural gestures, voice out – put communication devices or signs can support both the receptive and expressive skills of children and adults with learning disabilities (Norburn et al, 2016). However, people with PMLD may not be able to understand and therefore not be able to initiate effective use of the main types of AAC available. Those who need alternative forms of communication support are often highly dependent on others who know and understand how to use AAC to access social and learning situations (Brooks & Meltzoff, 2005; Dalton and Sweeny, 2011). One problem may be inconsistency of use by communication partners, or difficulty initiating the AAC strategy by the service user themselves as the strategy may require facilitation and modelling to scaffold interaction (Hetzroni and Roth, 2003; Norburn et al, 2016). For children and adults who have more complex needs, there may be a requirement that support from others is available to ensure that the relevant AAC tools are present so that communication exchanges can take place (Harding et al, 2011). People who have PMLD are likely to have additional physical, visual and auditory difficulties which may present further challenges for the use of AAC equipment (Millar et al., 2006; Rowland & Schweigert, 2000). This is not to suggest that people with more complex needs should not have access to AAC, but there needs to be greater consideration given to the rationale that supports an approach, and how much it will support communication opportunities, choice and participation (Harding et al, 2011). There is also an often erroneous notion that introducing a form of AAC may be a solution to a person's communication difficulties which can help them to overcome barriers, and provide them with a "voice". Lack of consistent training, along with difficulties in establishing effective use of an AAC approach can lead to abandonment (Johnson et al, 2006).

What should we be doing to ensure that people who have PMLD are not excluded and have good quality communication and interaction experiences? Intensive Interaction (Hewitt & Nind, 1998) has addressed some of these issues as it uses core principles of early interaction to support enjoyment of being with and interacting with someone in a mutually satisfying shared experience. This can enable communication partners to develop confident and responsive ways to interact and be with a person who has PMLD. Another approach, the SCERTS (Social, Communication, Emotional, Regulation and Transactional Support) Model (Prizant et al, 2003) is typically used with people with autistic spectrum conditions. It includes important strategies which take account of an individual's sensory, environmental and communication needs, and is therefore person centered. Although SCERTS (Prizant et al, 2003) is aimed at those who have autistic spectrum conditions, there are many aspects of

transactional support within the approach which could be generalised to a PMLD population. In particular, supporting communication partners to modify and shape their interactive style using the SCERTS (Prizant et al, 2003) model could provide a positive and satisfying framework when spending time with people who have PMLD as it may reduce some of the limiting environmental and cultural challenges.

In conclusion, further exploration and discussion about positive person centered ways of including people who have PMLD is needed. It might not always be appropriate to attribute many meanings to responses to various stimuli and everyday contexts with this population. It may also not be appropriate to provide methods of AAC that communication partners are not committed to or confident to use. Neither is it appropriate to implement methods of AAC that service users cannot understand how to use, spontaneously initiate or use independently. To increase inclusion and to ensure that people who have PMLD are included in both our culture and our lives, there need to be clear discussions about which communication styles can support inclusion and enhance quality of life for all. In addition, there needs to be ongoing examination of what AAC support should involve and include, and whether such methods are effective if the service user themselves is unable to initiate communication using the approach.

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