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Children and adults with learning disabilities (LD) are at increased risk of poor health compared to the population as a whole (Public Health England (PHE) 2016). The Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD) report (Heslop *et al* 2013) highlighted that men died 13 years sooner than the general population, and women 20 years sooner. Eating, drinking and swallowing (EDS) difficulties, often termed dysphagia, are an important health issue for people with learning disabilities across the lifespan (Harding & Wright 2010, Howseman 2013, PHE 2016). A high number of people in the CIPOLD report had swallowing difficulties, but it was difficult to identify factors related specifically to dysphagia which caused death.

Interventions to minimise the risks of dysphagia focus on a range of strategies that support the process of eating and drinking including; modifying the texture and consistency of food and drink, adjusting posture, and specific strategies e.g. pacing (Harding & Cockerill, 2015). In the case of people with learning disabilities the recommendations will frequently be carried out by a carer, paid and/or family, at each mealtime. Written guidelines are also usually provided for carers as part of an overall mealtime careplan (Howesman, 2013).

Adherence to eating and drinking guidelines for adults with LD has been investigated (Chadwick *et al* 2006, Crawford *et al* 2007) with non-adherence to guidelines identified as a common problem (Howseman 2013). The main focus and outcome has been on developing training mechanisms to support knowledge, confidence and then adherence to the guidelines. Chadwick and colleagues (2014) provided training to three randomly assigned groups of carers and investigated their accuracy in thickening liquids, one strategy used in dysphagia management. The groups were given either; written guidance alone; written guidance plus training; or written information, training and the provision of Thickness Indicator Model (TIM) tubes. The training and training plus TIM tubes initially were significantly more accurate than those with written guidance alone. However, over time, only the training plus TIM group were significantly more accurate. This research has highlighted the need

to refresh and repeat training skills ongoing, and questions whether written guidance alone is sufficient. However the written information itself has been little investigated to determine how this could be adapted to improve skills.

Research indicates that written guideline are in use in clinical practice for adults with LD. Chadwick and colleagues (2006) highlight that SLT intervention 'culminates in a set of written guidelines'. Crawford *et al* (2007) report recommendations are summarised in a 'short guidelines sheet'. Despite this the content, format and delivery aspect of written guidelines is little known. There has been some discussion regarding the need to provide 'a step by step laminated list of recommendations for individual clients' (Crawford *et al* 2007). This point of care tool for mealtimes is highlighted in clinical practice; 'Mealtime Placemats' (Duffin 2010), 'Personal Placemats' (PHE 2016). These are a one page, typically double sided, laminated sheet that contain key recommendations regarding mealtimes, often supported by photos, images and simple language.

Written information has the potential to be a constantly available resource to support carers in carrying out recommendations, when compared with a training sessions or the support of specialist professionals. There has been no exploration of whether this aspect of clinical practice is evident in the area of child disability.

This small study sought to determine whether Mealtime Advice Mats (MAMs) are in clinical use within special schools in the UK. It also aimed to explore aspects of how they are created, used, monitored and supported.

#### Method

A questionnaire survey of knowledge and practice of mealtime mats was completed with ethical approval from City, University of London. The participants were fourteen SLTs working within special schools and thirteen school staff of one London special school. All participants had experience of supporting children with their eating and drinking who had a range of learning disabilities and needs.

The participants received a short presentation about the project, and then indicated interest. A week later they were provided with a link to an online survey (SLTs) or a paper questionnaire (school staff). The questionnaires were developed using the research base with a small group of SLTs assisting in its development. The data collected were mainly quantitative with some options for free text comments as appropriate. They focused on some demographic details e.g. professional role, questions regarding MAM use in their setting, the content and perceived benefits of MAMs and dysphagia training. A copy of the questionnaire is available from the researchers on request.

Data were then analysed using descriptive statistics with free text comments noted. Discussion between the researchers highlighted the important or common themes.

#### **Results**

### **Participants**

The number of participants was 14 SLTs and 13 school staff. The SLTs experience level ranged from 1-7 or more years' experience. The school staff included some with less than one year's experience but also those with 1-7 plus years'. The school participants worked in the secondary special school age range, with SLTs having a wider age range of clients.

The majority (13, 93%) of SLTs reported that they create MAMs in special schools. One SLT (7%)

Use of MAMs and Types of classification

reported providing a different form of written guidance. Similarly, 12 (92%) of Staff reported that they support children who have a MAM; one (7%) reported using an alternatively named document. All (100%) of SLT participants and 8 (62%) of staff participants stated they used an alternative name to Mealtime Advice Mat. A wide variety of terms were described, including multiple options by some respondents. There was an overlap in some of these terms within the participant groups, but no commonality between the SLTs and school staff (figure 1).

#### FIGURE 1 about here

Staff involvement in MAM creation

Only 3 (23%) of staff respondents reported involvement in MAM creation. They described working collaboratively with SLTs e.g. through observations, discussion and feedback on drafts.

SLT participants that created MAMs reported various other professionals involved in this. Those roles frequently highlighted were Occupational Therapist (12, 92%) and class teacher (10, 77%). Others included School Mealtime Support Assistant (SMSA) (8, 62%), dietician (8, 62%), learning assistant (6, 46%) and school nurses (4, 31%).

Information included in MAMs

SLT and support staff highlighted similarities when indicating the content typically included on a MAM. There was overlap in many topics, including; personal information; drink/food texture required; positioning and utensils required and communication.

There were differences between staff and SLT responses on some information topics included however. For example, SLTs reported a higher occurrence of information on 'signs of aspiration or difficulty' on MAMs (100%) than staff members did (8, 62%). Staff reported there was a 'photo of the student' on the MAM more often than SLTs (12, 92% staff compared to 7, 54% SLTs). Conversely, less staff reported that the information on a MAM depends on the child/student compared to SLT reports (3, 23% staff compared to 7, 54% SLTs) (Figure 2).

## Insert figure 2 about here

No staff responses (0%) indicated MAMs included 'other' information than the options given.

However, the SLTs (100%) suggested some additional aspects as standard elements of their MAM.

These can be summarised as:

- Physical prompts and oral preparatory recommendations, not described as 'procedural instructions'
- Information on the reverse of the MAM e.g. contact details of the SLT, a plan for review,
   version number and date.
- Signature by staff on the reverse of the MAM: for staff to confirm that they understood the information.
- Generic information on the reverse regarding signs of aspiration.

Information about where MAMs are stored

A majority (11, 85%) of staff reported that MAMs were displayed on the classroom wall. The majority (10, 77%) of SLTs reported that MAMs were kept in the student's school file (Figure 3). Both groups reported the MAMs were stored in multiple locations.

Half of the SLTs (7, 50%) reported MAMs as stored in "other" locations. These included the therapy file and with the Head Teacher. Others highlighted its use as a point of care tool e.g. in the kitchen (to advise on food texture), on the table or in the utensil box, to ensure its availability during mealtimes.

## Insert Figure 3 about here

The purpose of MAMs

When asked why they used MAMs, 10 (77%) of staff responses mentioned dysphagia and feeding safety e.g. aspiration, consistency of food, equipment and position. Staff also identified other factors related to the purpose of MAM use, such as information sharing between staff and when working with unfamiliar children, as well as MAMs being used to monitor change or improvement.

Across SLT participants who created MAMS, eating and drinking risks were also mentioned consistently (13, 100%) as a motivator. Additional similarities between SLT and staff responses were

noted. For example, both groups identified that MAMs are important for those supporting the child at mealtimes to develop an awareness or ability to support the child's needs, awareness of positioning or equipment and using MAMs as a reference for important information.

Ease and usefulness of MAMs and suggestions for further improvements

In response to how easy it was to use MAMs, no school staff participants indicated that it was somewhat or very difficult. Overall 10 staff (76%) reported they found the MAMs easy to use (6, 46%) or very easy to use (4, 30%). SLT responses ranged from somewhat difficult to very easy. Equivalent to staff reports, 6 (46%) of SLTs reported they felt MAMs were easy for people that support children with MAMs to use. However, distinguishing from staff reports, 4 (31%) of SLTs indicated people may find it somewhat difficult. Many staff (9, 69%) reported that MAMs were very useful and no feedback among participants (0%) indicated that MAMs were not useful. However 6 (46%) of SLT participants reported they felt the staff found the MAMs quite useful.

The staff participants (8, 62%) made suggestions to make MAMs even easier to follow, and 6 (46%) suggested how they could be more useful. The following themes were identified:

- Keep MAMs with the child's equipment, to ensure availability during mealtimes.
- MAMs used alongside 1:1 modelling.
- More information about the child e.g. their needs.
- More pictures on the MAMs, including food and drink consistency.
- More updates of MAMs in order to suit the child.
- Food preferences included.
- Video of correct techniques to use e.g. physical support and adapted language use.

All the SLT participants that use MAMs (13, 93%) made suggestions for what would make the MAMs easier to follow and more useful. Recommendations included:

- Simplifying language and avoiding jargon. Using 'if...happens...then...' in procedural statements.
- Consistency of language and terminologies e.g. texture descriptors.
- Use of visuals to reduce written information e.g. photos and diagrams, including textures.
- MAMs kept with the child's lunchtime equipment.
- MAMs in view during the meal e.g. not under the plate.
- Highlighting signs of generic risks.
- Talk through advice sheets with staff and incorporate the staff's viewpoint.
- Joint-working to encourage MAM use e.g. if staff directed by the head teacher to use the MAM daily, SLT met with staff to agree to develop the MAM, encourage use and document this with the staff's signature.
- The importance of training before using MAMs.
- New or temporary staff should be informed about the MAM prior to mealtimes. Permanent or long-term staff should inform and educate other staff on each pupil's EDS requirements.

## **Training**

All SLT participants (14, 100%) stated they provide training to support working with children with EDS difficulties. This was reported as provided in a variety of ways, including the use of 1:1 support through guided instructions and demonstration, live or video observation of mealtimes with feedback, and whole school basic training on topics e.g. aspiration, positive mealtime environments.

All the SLTs that used MAMS (13, 100%) said that training involved them. All SLT participants (14, 100%) indicated training is offered to class teachers, classroom assistants and SMSAs. Training also reportedly involved parents, other staff members (e.g. kitchen staff, healthcare assistant) and other HCPs. SLTs also reported on how regularly they deliver training (Figure 5). A majority (8, 57%) of SLT participants suggested 'other' timeframes than the options given, namely due to different groups

requiring a different frequency of training. For example, training will differ for new staff compared to staff with years of EDS experience.

The majority (11, 85%) of staff said they have received training about working with children with EDS difficulties. Many (8, 62%) said their training included the use of MAMs. Across staff reports, training was most frequently offered by the SLT.

#### Discussion

This is a small scale regional study and so the ability to generalise the results to the UK as a whole may be limited. However this small sample suggests that there is a frequent use of written guidelines by SLTs in special schools for children with dysphagia. The results also indicate that usually these take the form of a MAM, a one page summary of the recommendations supported with simple language and images. Despite limited guidance there is general agreement on the main aspects covered within a MAM, with some acknowledgement from SLTs that the guidance is tailored to the individual.

However there are variations in clinical practice, most notably in regards to the name of the document. There were twelve different titles used within this survey, with differences in terminology suggested by the individual participants and within the same setting. This variability in name is evident within the literature also; 'Mealtime Placemats' (Duffin 2010), 'Personal Placemat' (PHE 2016), or with the concept discussed but not given a title (Crawford *et al* 2007). Inconsistency in use of terminology could cause difficulties in clinical practice, for example on transition from one service to another, and in research if wanting to investigate this practice further. This is in contrast to the fairly consistent use of other terms within this population e.g. Communication Passport (Millar and Aitken 2003), a document to describe the communication skills of an individual and how to support them.

The difference in term also reflects differences in how the mat is utilised. The majority of respondents highlight the role of the MAM to provide information on safe eating and drinking practices and ensuring that information is provided to appropriate staff. However although the MAM is reported as shared and stored in various locations, e.g. classroom wall, school file, only half of the SLT respondents highlight its use directly at mealtimes e.g. stored with utensils. None of the school staff reported the MAM directly accessible at mealtimes, though some suggested it should be, as did some SLTs. Interestingly one SLT reported that allowing MAMs to be directly visible e.g. on class wall, had stopped in their setting for concerns regarding confidentiality. This raises an interesting discussion point regarding risk, confidentiality and dignity. There is a need to ensure information is shared to maintain safety, while supporting privacy.

Encouragingly, considering its importance reported by others (Chadwick *et al* 2014, PHE 2016), training was highlighted as a consistent area of practice by both SLTs and school staff. A range of training methods were utilised e.g. whole school training, one to one modelling and practical workshops, described as having an important role previously (Harding and Halai 2009). The frequency of training was not clear from this study, with the majority of SLTs indicating they offered a range of timescales for refresher sessions. This may reflect the flexibility of the SLTs providing different types and frequency of training for different carers. However considering that staff training effects may be lost by 3-9 months after the session (Chadwick *et al* 2014) it is an important avenue to consider in the future. The respondents also highlighted difficulties with training however e.g. one school participant had not received training. This may be explained by previous findings highlighting the issue of high turnover and absences of support staff (Chadwick *et al* 2006).

Interestingly school staff rated the MAMs more highly than SLTs when reflecting on their ease of use and usefulness. The SLTs and school staff were from different settings and so this may explain some of the findings. It might also be useful to reflect on previous research that although carers may have the knowledge, or in this case find the MAMs easy to understand, this does not necessarily relate to

high levels of adherence (Chadwick *et al* 2006) or to accuracy (Chadwick *et al* 2014). It may be that the SLTs are reflecting on their concerns regarding adherence and considering whether the MAM can be changed to improve this. The majority of SLTs monitor this adherence. Some report strategies previously described to try to encourage it e.g. signing after reading the MAM (Chadwick 2006), and also regular audits/observations of practice.

While acknowledging the importance of school staff adherence to dysphagia guidelines it should be noted that the majority of a child's mealtimes are spent at home. It is therefore interesting to note that only half of the SLTs, and none of the school staff, suggested that the MAM was stored at home. This study did not explore the reasons why parents/home carers may not be provided with the MAM which may be multiple e.g. MAM focuses on school seating and so not relevant to home setting. However as studies suggest unpaid carer adherence to advice is reduced compared to that of paid carers (Chadwick *et al* 2006) and the majority of mealtimes taken in the home setting, this is an area of research that should be prioritised.

This study indicates that written simplified guidelines are being used in practice within UK special schools. This is following good practice guidelines (PHE 2016) and should continue. However there is variability in both the name for the document and how they are utilised, despite commonalities in the areas of recommendations they support. MAMs are a simple and potentially cost effective point of care tool to reinforce eating and drinking guidelines. Ensuring they are both optimally understood and useful to carers is an important area that needs to be further investigated, which could culminate in guidelines for how to best create and provide such documents. They are an important part of guideline provision and should not be ignored as they are potentially one of the most simple and cost effective methods available. They can be utilised as a method for measuring adherence to guidelines by services, in an area that can have a significant impact on a person with learning disability's health and wellbeing.

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