



.....

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run every aspect of my life, from basic communicating, to
organising my Care Enablers, to writing emails.

.....

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APRIL 2017 VOLUME 31 NUMBER 1

THE JOURNAL OF COMMUNICATION MATTERS / ISAAC (UK)

Topics include: TOMS AAC outcome measures • AAC use in neurodegenerative conditions
• The case for transporting AAC • Longterm direct intervention • AAC & Chaucer • Food
choices in dementia • Health transitions in young people • Holistic approach to mounting



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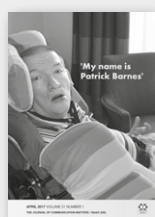
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Patrick is taking part in our social media AAC awareness & fundraising campaign '#My CommunicationMatters' which will go out on our Facebook, Twitter & LinkedIn etc. Want to take part? Please send us a photo and we ask you to answer the question 'I use my AAC device to...' for you to say exactly what you would like to say about what AAC enables you to do

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Co-chairs' Report

Toby Hewson & Ruth McMorran

It's hard to believe that we are already half way through our first year as co-chairs.

We're really pleased to welcome a new co-opted trustee to the Board. Oliver Lee is a Speech and Language Therapist at Rookwood Hospital in Cardiff (National Electronic Assistive Technology Centre). We are aware that the policies around and provision for AAC varies differently in all parts of the UK, Ollie joining us on the Board ensures we are now learning more about the situation in Wales.

It is good too that Jo Cope is going to attend the next few Board Meetings as a non-voting contributor. Jo is the administrator for 1Voice and her attendance at meetings will help to ensure that 1Voice and CM are able to work together in the lead up to the 2017 Conference.

Our review of the Memorandum and Articles of Association is now almost complete and the new documents are currently with the Charities Commission awaiting their approval. We hope the final copies will be signed at the May Board Meeting.

Toby has made a video for Communication Matters with ChariTable. In this scheme, when you book a table at any of the registered restaurants, £1 for every guest in your

party will be donated by ChariTable Bookings to a charity of your choice at absolutely no cost to you. Please choose to donate to Communication Matters! Take a look at Toby's film on YouTube - <https://youtu.be/vwfr9Sv2PtW>

We continue to explore the possibilities of CM hosting the ISAAC conference in 2022. A small working group of trustees is currently gathering the information required to submit a 'letter of intent' ahead of the May deadline. If this is successful we will be looking for CM members to join trustees to form a steering group to investigate all the implications of hosting an international conference before any final decisions are made.

Planning is now well underway for the 2017 Conference which will be held at the University of Leeds from Sunday 10th to Tuesday 12th September. The deadline for submission of papers is 28th April. The Abstracts Review Group meets on Tuesday 9th May therefore there will be no extension on this date. We look forward to receiving your abstracts.

For the first time, this year you will be able to register and pay online with your credit card or you can register online and then pay by cheque or bank transfer. Registration is open now.

Communication Access UK Update #CA-UK

March was a busy month of training and delivering information workshops as well as beginning to evaluate the first responses to the symbol consultation.

The survey is still live so please do take part if you have not done already! Deadline extended until 28th April! We have had over 1000 online opinions and more in hard copy with some new ideas.

Link to survey: <https://www.surveymonkey.co.uk/r/C7F9Z95>

Workshop in Leeds to train mystery customers

We now have 3 AAC users trained (and one pending) to be co-presenters of the workshops to businesses. They all have now completed mystery customer visits and have taken part in the pilot training workshops at Leeds University.

Pilot training at University of Leeds of 80 staff

We trained 80 staff in 4 workshops of 20 each. We had representatives from the hospitality, administration and security teams and the feedback has been very positive with a high percentage reporting how valuable it was to meet and communicate with someone who uses AAC. The university are now keen to organise further workshops to include other frontline staff.

Visits to FE Colleges

Beaumont College, Lancaster: Cathy Harris facilitated a workshop for 6 representatives from the student union to introduce the project and to encourage participation the symbol consultation. This was well received with lots of comments and ideas from the students and the support team.

Percy Hedley College, Newcastle: A meeting with 15+ staff from Percy Hedley and others from employment services was encouraging as we seek to link this project to existing structures. This was followed by a training workshop about CAUK and introduce mystery customer role for 8 AAC users with their support staff. It was good to be able to trial the revised mystery customer questionnaire.

Next

During April the focus will be on the evaluation of the survey results. The next meeting of the steering group is on April 18th at RCSLT.

Please contact us if you would like to work with us to facilitate a workshop for your school, college, service or team. accessproject@communicationmatters.org.uk

CM News



(Above) Nathan Popple, Catherine Harris, Sam Knapp and Helen Quiller trained 80 members of staff at University of Leeds in communication access (#CA-UK). The conference team have also had extra training this year.

(Below) CM supports the launch of the All Party Parliamentary Group on Assistive Technology (APPGAT). Unfortunately due to a clash with board meetings the co-chairs could not attend although a trustee and members were there in other guises. Here is Lord Holmes addressing the delegates. For more information <http://www.policyconnect.org.uk/appgat/about>



Reflections on embedding TOM AAC into the working practice of a specialised service

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Abstract

Aim

This paper shares a critical appraisal of the Therapy Outcome Measure adapted for AAC services (TOM AAC), based on Barnsley Assistive Technology Team's experience of trialling and implementing this over one year.

Activities

Barnsley Assistive Technology nominated a team member to act as "TOMS Champion". The TOMS Champion provided training to contextualise TOM AAC, initiated use of TOM AAC within the team and ongoing support with the aim of embedding this outcome measure into working practice. Guidance notes were developed and are now regularly reviewed. Quarterly sessions are held to encourage discussion and reflection of the experience of using TOM AAC. Processes are agreed, the inter-rater reliability of the team is monitored and complex clients are presented.

Findings:

This paper will critically appraise the use of the measure for this specialised service: highlighting areas of TOM AAC that work well and those where changes are proposed to promote more consistent use of the measure. Additionally clinicians' reflections of using this measure will be analysed and considered in relation to the

inter-rater reliability achieved by the team during this trial period.

Conclusions

This paper acknowledges that implementing an outcome measure requires time and commitment, but can be a crucial tool for demonstrating the value of your team. TOM AAC is well-evidenced and can provide a firm basis for monitoring client outcomes. However each service must carefully apply the measure to ensure it is used consistently and provides relevant data.

Introduction

The Measure

TOM stands for the Therapy Outcome Measure, a tool used by many rehab professionals to measure the impact of their interventions. TOM is based on the World Health Organisation's International Classification of Functioning, Disability and Health (WHO ICF, 2002). TOM enables the clinician to rate their client in terms of impairment, activity, participation and well-being. As part of the usual assessment procedure, the clinician identifies a "best fit" descriptor for each domain and applies an 11-point ordinal scale (0 = Severe; 5 = Normal; 0.5 score = slightly better or worse than the descriptor) (Enderby, John and Petheram, 2006).

This process is helpful because: it

acknowledges that therapy aims to impact on multiple areas of a person's life; it captures their situation before, during and after intervention; it provides a single, simple measure that broadly reflects their status; and it facilitates the evaluation of outcomes, an important aspect of clinical governance.

The Royal College of Speech and Language Therapists (RCSLT) recently carried out a project which outlined their outcome measure criteria, and subsequently identified TOM as the optimal model in terms of flexibility, compatibility, accessibility and ease of use. TOM also makes it possible to collate outcome data, and observe trends at a service, regional and national level (Moyse, 2016).

Since the development of the core TOM, a number of health, social care and education professionals have contributed to the adaptation of the TOM scales for particular client groups, and this now includes AAC (Enderby and John, 2015). Following projects commissioned by NHS Education for Scotland (2014), TOM AAC has been refined so that validity and inter-rater reliability are considered strong (Boa, 2014).

The TOM AAC differs from other scales because a range of impairment domains are rated. Additionally the activity, participation and wellbeing scores are first rated without AAC (ie. not using signing

Figure 1 – TOM AAC Adapted Scale (Enderby and John, 2015)

| <i>Impairment</i> (5 scores) | | | <i>Activity / Communication</i> (2 scores) | <i>Participation</i> (2 scores) | <i>Wellbeing</i> (2 scores) | <i>Carer Wellbeing</i> (1 score if relevant) |
|---|--|--------------------|---|------------------------------------|--------------------------------|---|
| <i>Physical</i> | | <i>Without AAC</i> | | | | |
| <i>Cognitive</i> | | <i>With AAC</i> | | | | |
| <i>Sensory</i> | | | | | | |
| <i>Speech & Language Output</i> | | | | | | |
| <i>Comprehension</i> | | | | | | |

systems or technology) and then with AAC (ie. signing system or additional technology). [Figure 1]

The Service

Barnsley Assistive Technology (BAT) Team are the specialised service (or hub) for the Yorkshire and Humber region. The team has been contracted by NHS England to deliver specialised Augmentative Communication Aid services, by undertaking specialised assessment of AAC needs and providing specialised communication aids where clients meet criteria (NHS England, 2016). The team has undergone a recent expansion to meet this remit and currently employs 13 clinical staff: Clinical Scientists, Occupational Therapists and Speech and Language Therapists. The team also provides specialised services for Environmental Controls (EC).

In view of this changing role, BAT was keen to identify a preferred outcome measure so as not to have an unsuitable measure enforced. The team was also motivated by the opportunity to compare outcomes with other similar teams. Prior to the development of TOM AAC, staff sought guidance from Professor Pam Enderby and members of a regional EC peer support meeting, and consequently adopted TOM, initially aiming to complete it during case discussions. However there was no form in place to record TOM consistently or to encourage completion outside of these meetings. When the team from Southwark kindly lent their TOM-related scoring form, BAT became able to complete and discuss their TOM ratings at team meetings, but it was still not yet clear how this fitted into procedure because there was not a corresponding entry on the team database.

Once TOM AAC was launched, the team found the process easier, in particular because the range of impairment scores meant that they no longer needed to try

and align their client's condition to the closest possible scale. The TOM AAC template was therefore added to the team database in mid-2015. It soon became apparent however that there was ongoing uncertainty around terminology, and for a short time the team opted not to do TOM, rather than do it inconsistently.

To rectify this situation, a "TOMS Champion" was nominated and given the task of monitoring use and reliability of TOM, discussing issues with the team and agreeing procedure. This was achieved by holding quarterly catch-up meetings; producing training materials and guidance notes which were disseminated to existing staff and incorporated into the induction process for new starters; liaising with authors and national networks; and co-ordinating database updates.

Activities

Over the course of one year between July 2015 and July 2016, team discussions led to agreed processes in the following key areas. This is a suggested procedure for BAT to trial and compare with other specialised services, and has been agreed with Professor Pam Enderby, the developer of the original measure:

- TOM should be carried out as part of the initial assessment, after all significant visits and at the final recommendations stage. Even if equipment is trialled or issued during the session, the initial TOM should be the measure prior to our intervention.
- We will use the TOM AAC Impairment descriptors to score clients using EC, but for Activity descriptors we will refer to the Adapted TOM Scales in Development for Environmental Aids (Enderby, John and Petheram, 2006); and Participation descriptors will be taken from the Adapted Scales for Equipment Services (Enderby and John, 2015). AAC and EC will therefore need to be scored separately.

- In order to compare our TOM ratings with other areas who are not using the AAC specific tool, we will also provide an overall impairment score, which is not an average of the other scores, but rather a score for the primary impairment necessitating our intervention (for example speech output).
- BAT will aim to specifically capture the change associated with the provision of specialised equipment. It will measure the benefit of our intervention with clients who do not ultimately meet specialised provision criteria, without taking credit for work done by local services prior to referral to this specialised service. Separate scores will be provided for the provision of specialised equipment and for any additional input provided in the episode of care that is not the provision of specialised equipment (for example guided assessment, advice about low-tech systems).
- Particular attention was given to the issue of what constitutes 'with AAC' and 'without AAC', with the team finding it especially difficult to categorise unaided systems or body language for example. It was therefore decided that the comparison would be between what the client is using or has access to at the point of referral (any unaided or aided system, including specialised equipment provided in a previous episode of care) versus what is added as part of our intervention in the current episode of care.

The processes described do not align with the terminology provided with the TOM AAC scale and this became confusing for the team. To ensure that clinicians remain confident and consistent in their use of the measure, the following amendments to terminology have been suggested and are due to be incorporated into the team database for trial:

NEW: A FREE MULTI-ACCESSIBLE AAC INTERFACE FOR LITERATE USERS

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"Lauren (15) is now able to access a
complex communication system set out
in a simple logical way with Mind Express,
giving her independence, control and a
better quality of life."

JUDY KING, INDEPENDENT SLT



"It is difficult for me to communicate verbally,
but I still think & I love to talk - and that's
where my Mobi 2 using Mind Express
comes in. By using it I can say what I need,
and what I want. My Mobi is my best friend."

HANNAH JAMES

FREE LOANS AVAILABLE: Find the AAC device that works for you.



Smart 3



Zingui 2



Tellus 5



Mobi 2

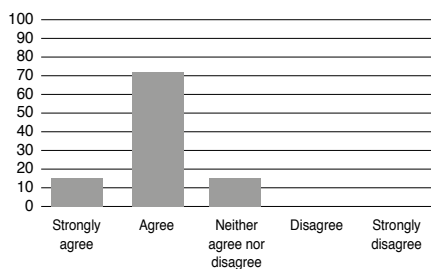


Allora 2

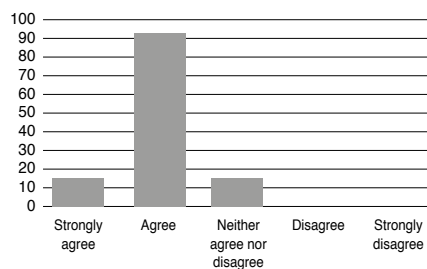
| TOM AAC Terminology | | Barnsley's Suggested Terminology |
|---------------------|---|---|
| Without AAC | > | Before Intervention |
| With AAC | > | After non-specialised intervention and/or After specialised intervention |

Figure 2 – BAT Questionnaire Results

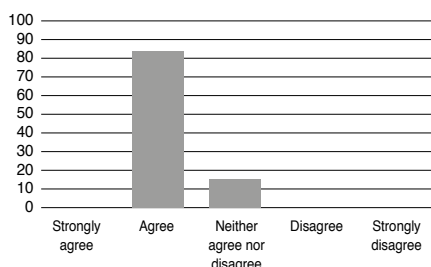
I have a good understanding about the background and principles of TOM AAC



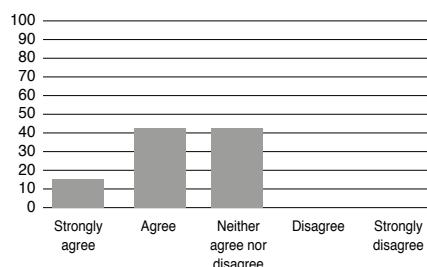
My use of TOM AAC is consistent



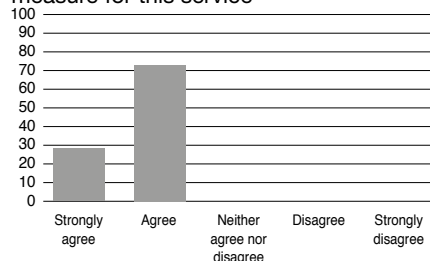
My TOM AAC scoring is reliable



I feel confident in employing TOM AAC



TOM AAC is an appropriate outcome measure for this service

**Figure 3 - BAT Inter-Rater Reliability Snapshot**

| Impairment | Range | |
|---------------------|-------|-----|
| | <=0.5 | <=1 |
| Physical | 100% | - |
| Cognitive | 91% | 9% |
| Sensory | 91% | 9% |
| Speech and Language | 45% | 55% |
| Comprehension | 100% | - |
| Overall | 70% | 30% |

| Activity | Range | |
|-------------------|--------|------|
| | <= 0.5 | <= 1 |
| Without Equipment | 60% | 40% |
| With equipment | 75% | 25% |

| Participation | Range | |
|-------------------|--------|------|
| | <= 0.5 | <= 1 |
| Without Equipment | 91% | 9% |
| With equipment | 100% | - |

| Wellbeing | Range | | | | |
|-------------------|--------|------|--------|------|-------|
| | <= 0.5 | <= 1 | <= 1.5 | <= 2 | > 2 |
| Without Equipment | 50% | 25% | 12.5% | - | 12.5% |
| With equipment | 66% | 17% | - | 17% | - |

85% of scores within 0.5 of the median scores = very good reliability.
85% or above within one point = good reliability
(Where scores provided; Carer well-being not scored by assessing clinician)

> Nearly!

Findings

Clinician Reflections

At the end of the year, team members were asked to complete a questionnaire about their experience of using TOM AAC, acknowledging that the team's use of it evolved in that time. [Figure 2]

Inter-Rater Reliability

A snapshot of the team's inter-rater reliability was calculated for comparison with clinicians' sense of their own confidence and reliability. The team were presented with a spoken case study of one client who had recently been seen for initial assessment. [Figure 3]

Even though the majority of the team agreed that they had good understanding of TOM AAC and felt that they were applying it consistently and reliably, some discrepancies are apparent. Together the team has identified some possible reasons for this.

- BAT was undergoing an expansion during this period, meaning that there were regular newcomers to the TOM procedure who were still consolidating the process.
- The inconsistent use of terminology as discussed above continued to cause confusion.
- There was ongoing debate about which domain would most appropriately reflect the impact of adjustments to specialised equipment.
- The option of Carer Well-being was not always being considered.
- The discipline or past experience of the rater was observed to influence scoring, particularly for Speech & Language or Comprehension impairment.
- Case histories are currently being presented verbally, whereas video footage is recommended.

Conclusions

Based on this team's experience, we conclude that it is fundamentally possible to embed TOM AAC into the working model of a specialised AAC service, but that some adjustments are necessary to ensure that it is being used consistently and providing relevant data. The implementation process has benefitted from the dedicated support of a nominated team member, which has enabled existing team members to adopt new procedures and new team members to routinely incorporate a form of TOM AAC into their practice.

Figure 4 - Clinician Reflections

Areas of the original TOM AAC that work well:

- 'Makes me question the value of my intervention'
- 'Helps me to consider if specialist AAC is making a significant change to a person's function'
- 'Considers a number of aspects therefore is relatively holistic'
- 'Provides data that can be used to demonstrate the effectiveness of the service'

Challenges in using the original TOM AAC

- 'The descriptions don't really fit my clients'
- 'Struggling with terminology'
- 'Confusing to measure when someone already has specialist AAC equipment in place at referral'
- 'Challenging to document if support given doesn't include providing specialist equipment'

Actions that have helped TOM AAC to become embedded:

- 'Simple and quick to use on the database'
- 'You are prompted to do it by the link at the bottom of the 'Visit' page'
- 'Information provided to support its use and integration into the database'
- 'The supporting documents and regular meeting are very helpful'

Adjustments suggested for our Specialist Service

- 'With/without equipment'
- 'Improve the descriptors-EC-orientated'
- 'Make the database reflect the discussions we have had'
- 'Make it a bit clearer on the scoring guidelines'

Suggestions to promote the continued use of adapted TOM AAC in the service

- 'Ongoing discussion and adaptations'
- 'Continued regular meetings to ensure consistency of use'
- 'Ongoing comparison of scoring'
- 'Use in conjunction with a patient-scoring outcome measure or client feedback questionnaire'

Figure 4 lists some of the comments made by team members when asked about their experience of trialling TOM AAC, and acts as a helpful summary of the associated rewards and challenges:

Evidently the implementation process is ongoing, and a number of actions are required before the team can be considered to be producing usable data. It is important that the team database reflects the final agreed procedure and that regular discussion continues in order to monitor consistency and inter-rater reliability.

Barnsley Assistive Technology also recognises the benefit of establishing consistency across specialised services as far as possible. The TOMS Champion is therefore forming connections with TOM representatives from other specialised services by attendance at events such as the TOMS CONNECT Conference which took place in Birmingham in November 2016, and regular meetings of the

Specialised Services TOMS Working Party. The working party has generated interesting discussion, and recently agreed aims of establishing a consensus for the timing and interpretation of ratings, collating a central data set and acting as TOM advisors to specialised services.

Finally it is important to acknowledge that TOM in isolation does not give a full picture of a service, therefore BAT has a long-term aim to complement this work by establishing procedures for goal-setting and gathering patient reported data.

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Factors related to high tech AAC use in adults with neurodegenerative conditions

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Chailey Communication Aid Service

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Introduction

The importance of augmentative and alternative communication (AAC) devices for people with communication difficulties is increasingly recognised, both low tech strategies (which are not electronic and include communication boards, phrase lists and A-Z charts) and high tech devices (which are computer based and produce speech). Such devices allow people to express their needs and wants, convey information to others, establish and maintain relationships and participate in the social conventions of politeness (Light, 1988).

The benefits afforded to people with communication difficulties who have access to a high tech AAC device include the promotion of a sense of self identify, enhanced self-image, social acceptance, improved involvement in decision making and self-determination (reviewed by Williams et al. 2008). In patients with Amyotrophic Lateral Sclerosis (ALS) improved ability to communicate has also been associated with improved quality of life, which was independent of the overall physical function of the patient (Felgoise et al., 2016).

Ball et al., (2004) have shown that in patients with ALS acceptance of high tech AAC is 96% with no participants in their study discontinuing their use of AAC. They term acceptance of a device as directly or indirectly agreeing to obtain a device, receive training and then using it voluntarily. Of patients who regularly used AAC they stated that many stopped using their high tech device in the last 2 months before they died and instead used low tech communication strategies with a

communication partner. Ball et al., (2007) reported all of their participants with ALS who had died used their devices in the last month of their life and of these nearly half used their device in the last week. Additionally nearly all of the participants reported a reliance on low tech strategies in addition to using a high tech device and all reported an increase in low tech strategies usage.

This level of acceptance of a high tech communication device reported by Ball et al., (2004) is considerably higher than has been reported in other studies. Other studies have reported much lower acceptance rates of high tech AAC. Mathy et al., (2000) reported that in a cohort of patients with ALS a quarter did not accept high tech AAC. Johnson et al., (2006) also stresses the importance of judging the success of a communication device, which she terms as the long-term use of one or a series of AAC systems with a majority of communication partners.

Successful implementation of a high tech communication aid depends on a range of different factors. These include factors relating to the person using the device, including: ease of use, both physical and cognitive, severity of medical condition at introduction of a device, cognitive abilities, fatigue and rate of disease progression. These factors are also dependent on those surrounding the person, including friends, family members and other caregivers: caregiver fatigue, attitudes of those around the client needing a communication device, response of others to the device, realistic expectations of the client and the communication

partner, skills and knowledge of caregiver and supporting staff, availability of technical support and the timeliness of referral (Beukleman & Ball, 2002; Lasker and Bedrosian, 2000; Baxter et al., 2012). Also, for each person with a communication device successful implementation is personal and will mean something different. Therefore, what one person judges to be successful may be judged a failure by someone else.

It should be noted that the literature concerning acceptance and factors that influence acceptance of AAC devices in patients with neurodegenerative conditions have focused on patient with ALS. Although factors concerning the people surrounding the person using AAC with a neurodegenerative condition other than ALS are most likely going to remain the same, condition specific factors such as access, ease of use of the device, cognition and fatigue are going to differ. In addition it should also be noted that studies reported in the literature are predominantly conducted in the USA where access to healthcare and funding for AAC devices is very different from in the UK.

Identification of whether implementation of a communication device is going to be successful or not will allow extra support to be put in place for clients and communication partners who may struggle before frustration develops and the device abandoned. It may be possible, where there are so many obstacles so as to make successful implementation unlikely, for more suitable low tech communication methods to be identified.

Aims

The purpose of the investigation was to determine if there was any pattern in which patients were using their communication device once it had been issued. This information will allow us to predict more accurately which patients may need extra support to use their devices to ensure that their needs are met.

Methods

Chailey Communication Aid Service (CCAS) was commissioned in 2015 by NHS England as a new regional centre to provide specialist assessment and provision of communication devices to adults and children with communication needs who meet the national criteria in Surrey, East and West Sussex, Brighton and Hove. Prior to the establishment of the hub Surrey and Sussex were acknowledged to have little access to AAC services. As soon as the service was commissioned referrals were accepted and patients were seen.

In 2016, as a part of service evaluation, adults and guardians of children who had been provided with a communication aid by the service at least two months previously were contacted. Responses from clients with a neurodegenerative condition were analysed for this study.

Patients were invited to complete a questionnaire that asked about device use, low tech strategies use, thoughts about different aspects of their device and also whether the device met their needs or not. To ensure that all clients who wanted to return the questionnaire were supported to do so, if questionnaires were not returned the referring speech and language therapist was approached and asked to offer the patient support to complete the questionnaire, if needed.

Information collected from the questionnaires was combined with data that we extracted from the clients' referral forms and assessment reports, regarding the clients diagnosis, condition severity at time of referral, disease duration, family support, living situation (e.g. with family or in a nursing home) and previous experience of technology.

Due to the rapid nature of disease progression in some of our cohort we also contacted referring speech and language therapists (SLTs) to ask whether clients who had died had used their device prior to their death and whether the device met their needs.

Results

Of the 51 possible clients on the CCAS caseload with neurodegenerative conditions it was not possible to send questionnaires to 21 (they either had no device, had not had their device for 2

months or longer or they had died). Of the remaining 30 clients to whom questionnaires were sent, 17 were returned, a response rate of 53%) as detailed in table 1. The responses and clinical data of the clients who replied are shown in table 2.

Table 1: Questionnaires returned by patient diagnosis

| | Replied/sent | Percentage replied |
|--------------------------------|--------------|--------------------|
| Motor Neurone Disease | 9/14 | 64% |
| Multisystem Atrophy | 3/6 | 50% |
| Multiple Sclerosis | 1/3 | 33% |
| Progressive Ataxia | 1/2 | 50% |
| Huntingtons Disease | 0/2 | 0% |
| Muscular Dystrophy | 1/1 | 100% |
| Progressive Neuropathy | 1/1 | 100% |
| Progressive Supranuclear Palsy | 1/1 | 100% |

Table 2: Results from questionnaires and clinical data

| Does your communication device meet your needs? | | Yes n=9 (all men) | No n=2 (1 man) | Sometimes n=3 (1 man) | Not needed yet n=3 (1 man) |
|---|---------------------------|----------------------|-------------------|-----------------------------|-------------------------------------|
| Diagnosis | MND | 5 | 1 | 1 | 2 |
| | Progressive neuropathy | 1 | 0 | 0 | 0 |
| | Progressive ataxia | 1 | 0 | 0 | 0 |
| | MSA | 1 | 1 | 1 | 0 |
| | PSP | 0 | 0 | 1 | 0 |
| | MS | 0 | 0 | 0 | 1 |
| | Muscular Dystrophy | 1 | 0 | 0 | 0 |
| Access method | direct access | 1 | 0 | 2 | 0 |
| | direct access + keyguard | 1 | 0 | 0 | 0 |
| | Switch scanning/stylus | 1 | 0 | 0 | 1 |
| | Stylus | 0 | 1 | 0 | 0 |
| | switch scanning | 4 | 1 | 1 | 1 |
| | eye gaze | 2 | 0 | 0 | 1 |
| Voice | No speech/anarthric | 5 | 1 | 1 | 0 |
| | Moderately unintelligible | 3 | 1 | 2 | 3 |
| | aphonic | 1 | 0 | 0 | 0 |
| Device use? | 10-25% | 4 | Not using | 1 | Not using yet |
| | 25-50% | 1 | | 0 | |
| | 50-75% | 2 | | 1 | |
| | 75-100% | 2 | | 1 | |
| Previous AAC use? | android apps | 2 | 1 | 0 | 0 |
| | iPAD apps | 0 | 1 | 1 | 1 |
| | Communication book | 0 | 0 | 1 | 0 |
| | A-Z chart | 1 | 0 | 0 | 0 |
| | nothing | 6 | 0 | 1 | 2 |
| Device introduced at right time? | Yes | 5 | 1 | 1 | 0 |
| | Too late | 4 | 1 | 2 | 0 |
| | Too early | 0 | 0 | 0 | 3 |
| Prior familiarity with technology? | Very familiar | 4 | 1 | 0 | 0 |
| | Some familiarity | 3 | 0 | 1 | 0 |
| | Not very familiar | 2 | 0 | 0 | 0 |
| | iPad user | 0 | 1 | 2 | 2 |
| | Tablet user | 0 | 0 | 0 | 1 |
| Living situation? | Nursing home | 4 | 2 | 1 | 0 |
| | With carers | 1 | 0 | 0 | 0 |
| | With spouse | 4 | 0 | 2 | 2 |
| | With son | 0 | 0 | 0 | 1 |
| Environmental control (EC) on device? | No | 4 | 1 | 2 | 3 |
| | Separate EC device | 1 | 1 | 0 | 0 |
| | Yes integrated | 4 | 0 | 1 | 0 |

Table 3 Device use of those clients who had died

| Used device? | | Yes n=10, 6 men | No n=12, 2 men |
|---------------------------------------|------------|-----------------|----------------|
| Diagnosis | MND PSP | 9 1 | 12 0 |
| Duration of device use prior to death | | 2.97 months | 2.84 months |

We also asked referring SLTs about the communication aid use of 22 patients who died whilst in possession of a communication device provided through CCAS. This data is shown in table 3.

Conclusions

From the sample of 17 patients 12 (71%) reported that their communication aids met or partly met their needs. This figure is within the range of acceptance reported by studies from the USA (Ball et al., 2004; Mathy et al., 2000). It should be noted that of the 12 people who found AAC beneficial only 50% has MND whereas the entire populations reported by Ball et al., 2004 and Mathy et al., 2000 comprised people with ALS.

One factor known to influence the acceptance of high tech communication devices is the timeliness of provision of a device. Three people (18%) reported having received their device too early and so were not using them. This does hint against the thought that people with a neurodegenerative condition should be given a communication device prior to needing one as at this stage the easiest method of communication a person can use is their speech. The CCAS cohort is small so this finding would need to be explored in a large group of patients. Further examination of these patients also showed that, when compared to the group, their intelligibility was moderate compared to the anarthria or aphonic voice of the rest of the group. Of the 12 people who found their device beneficial half felt that their device had been introduced at the right time and half felt introduction was too late. As CCAS is new many of the first patients who were referred may well have benefitted from AAC being introduced earlier but there was not a service for them to access prior to the commissioning of CCAS. The ability of CCAS to introduce a communication device at the right time for the patient also depended on the ability of the local therapist to identify when best to refer the patient for a specialist assessment.

Information was collected on what proportion of the day people used their communication devices. Of the 12 people who felt that their communication device met some or all of their needs, five used their device for half or more of the time each day. The remaining seven patients used their device for less than half the day but still felt that this duration of use met their needs. Interestingly one lady reported that her device met her needs but that she only used it for 30 minutes each day. This highlights that a successful implementation of a high tech AAC device does not mean that the client is using their device all the time, instead using it at certain times of the day when other strategies or speech did not work.

Johnson (2006) instead said that successful implementation of a device should mean that a person should use one or a series of AAC systems with a majority of communication partners. She included low tech communication strategies within this definition. It was found that very few of our patients had a low tech system in place. Review of the literature stresses the importance of the establishment of low tech AAC strategies in addition to the use of high tech devices. Ball et al., (2004; 2007) report that use of high tech devices stops just prior to death and that patients at this stage rely partly or totally on low tech strategies. Low tech strategies are also more efficient when the information to be conveyed is quick and is being conveyed to familiar communication partners (Mathy et al., 2000) and when patients want to maintain a social closeness Murray (2004). The scarce use of low tech strategies does represent a training need as high tech communication devices should represent one part of a total communication approach.

Other factors that have previously been related to whether a person accepts their communication device or not were also examined. It was found that people whose devices met their needs appeared more likely to

- Be diagnosed with MND, although the larger numbers of people with MND in the CCAS cohort does influence this finding;
- Have more severe speech intelligibility problems and so less able to rely on residual speech;
- Be more familiar with technology;
- Have integrated environmental controls on the communication devices. Of the people who thought that their device met some or all of their communication needs 5 had integrated environmental controls on the communication devices. Of the people who felt their devices did not meet their needs or that their device had been issued too early none had integrated environmental controls. This finding might reflect that the people who have devices that “do” more are then more predisposed to be accepting of their device and so use it more for communication. Although Chailey Communication Aid Service and the two Environmental Control Services covering Surrey, East and West Sussex and Brighton and Hove are funded separately the services do work closely together.

People who thought that their device only partially met their needs or did not meet their needs appeared more likely to be prior users of iPads and anecdotally people did find it difficult to transition from an Apple device to a Windows based device when needed.

Of the clients who were given a communication aid but then died the average time each had had their device was just 3 months. This may be an anomaly as the service was new and these patients may have been referred earlier if the service had existed. There appeared to be no difference in the duration that clients had their device before they died between those who used their devices and those who did not. We did not ask the SLTs whether the clients who were using their devices stopped using them in the weeks before they died, though, as patient contact during this time varied. It has been reported in the literature that clients with MND generally tend to stop using their communication devices a month before they die (Ball et al., 2007). We did find that the clients who did not use their communication device were more likely to be women.


Limitations

This investigation includes a small number of clients, although the response rate for the postal questionnaire was reasonable. Possible reasons for non-return were client fatigue and lack of support. To increase the chances of questionnaires being returned the questionnaire was kept short which in turn reduced the number of questions that could be asked. It is possible that there may have been a non-response error which occurs when the clients who did not respond were different from those who did.

The attitudes of people around the client using AAC and the level of support that they can offer were not considered. In residential settings and hospices where there are many communication partners support offered has been recognised as an area of need and CCAS is currently offering training in these settings.

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Transporting AAC

PATRICK BATES AND SIMON STEVENS

Email: pbeyepaint@gmail.com

Why is it important for self-directing AAC users to be able to use their devices within personal transport?

The requirements and expectations of AAC users with severe impairments have radically changed in the last ten years. Many of them are now considered to be able to 'self-direct' their lives including employing and managing their own personal assistants.

The rise of smartphones and tablets has made multimedia communication on the move a norm, and therefore there is consumer demand for technology, considered as AAC, to provide an equal range of features.

Many NHS providers of AAC require users not to use wheelchair mounted AAC devices in personal transport for health and safety reasons, based on therapeutic outcomes. However, denying self-directing users a voice in private transport, when they are the employer of the driver, raises fundamental 'choice and control' and safeguarding issues. If self-directed users can not 'direct' in personal transport, are they being denied their human rights and responsibilities?

This paper explores the practical, policy and wider implications of current NHS policy in this matter, and the broader issues regarding, the conflict between framing need of therapy, and the pursuit of normalised standard social outcomes. In examining the purpose of AAC, and whether the remit of AAC is still a singular valid service, the paper will conclude by

questioning if personal health budgets are a future solution to conflicting outcomes, putting the wishes of self-directing AAC users at the forefront.

INTRODUCTION

The central premise of this paper is, the provision of AAC equipment is not just providing individuals with a 'voice', but a tool, that is one of many components, that assists in providing individuals, with no verbal voice, the ability to live independently, and participate in their communities and society. This arguably includes being able to use AAC in private transport.

I have severe cerebral palsy and been non-verbal all my life. I have used many AAC devices, and I currently use an eye gaze. I live in my own bungalow, and I have a mobility vehicle. I employ my own care staff whom I require 24/7. I have an extremely active social life and lifestyle, travelling to different parts of the country on a weekly basis.

My friend, and disabilities consultant, Simon Stevens, assisted me with writing this paper, although most of the content is my initial ideas. I am certain that everybody would agree that any low tech communication method, between myself and my care enabler via the rear view mirror is highly dangerous: so as I will explain later, it is weighing up the risk factor, of using my Eyegaze in my van.

This paper will challenge the regimes of the NHS in comparison with the rights of

individuals to live independently. It also highlights the conflicts between the medical model and social model regarding Speech and Language Therapy Services (SLTs) and AAC users.

AAC TAKES THE LEAD: HEADING TO A NEW PUB

A few months ago, I went out for a meal at a new pub, in a village near Coventry, with a friend, who is also disabled. We all went in my vehicle to the restaurant, with my care enabler driving.

Out of the three of us, and as someone an outsider may perceive as the less capable, I was the only one who knew where we were going. My friend trusted my care enabler and myself & simply followed our directions. So it was important I had access to AAC device, as I was the most confident in the vehicle.

If because of policies and procedures of the NHS, I had been denied, the ability to have, a voice, in my vehicle, I would have had to work with my care enabler, to pre-set the satnav, and we would all have been dependent, on their ability to obey the satnav, assuming it took us to the right place. If we have got lost, and ended up discussing what had occurred, then I would have been frustratingly disadvantaged.

I believe the episode gives an example of why it is important for AAC users to have the ability to use their devices in their own and other vehicles.

PURPOSE OF AAC

It is often assumed that the purpose of AAC is to provide people with a 'voice'. However, a voice can only be seen as a tool that assists people to participate in daily activities, including family life, leisure, education, volunteering, and paid employment. However, there appears there can be a difference of opinion between what SLTs see as the purpose of AAC, and what action users consider being the purpose. A central aim of the paper is to discuss this conflict of a real life example regarding using an AAC device with a vehicle.

THE PROBLEM: HEALTH VERSUS SOCIAL OUTCOMES

The incentive for the paper came from, the fact of, my local AAC assessment centre, who has provided my Eyegaze device, told me explicitly that I was not permitted to use the device in my vehicle, due to, 'safety reasons'.

Clearly, I have not been following their instructions, as I need to keep my independence. However, as I started to ponder the issue, it made me consider the conflict between health professionals' focus on health outcomes, compared with the social outcome, that people who use AAC require, especially those who can self-direct their care support.

The outcomes of having an AAC device can be split into health, and social outcomes. The assessment criteria for an AAC, by an SLT will often solely be based on health outcomes. This firstly, includes having an alternative method of communication, to replace or complement limited verbal communication, so, a 'patient' may be able to communicate with family, friends and professionals to ensure a quality of life.

I often go on long journeys with a single care enabler driving me, so the need to convey basic care needs become vital, i.e., the need to stop for the toilet or a drink, and to check if my care enabler is ok. The SLT could argue it is the care enabler's responsibility to look after me, within the Medical Model approach. However, throughout this paper, I will be focusing on self-directing care, thus I need to have access to my AAC device, thus, I am coming from a Social Model approach.

While these outcomes may be important, for many AAC users there will be a range of social outcomes, which assists to facilitate their education, employment, leisure and other outcomes. Social outcomes also,

include accessing the community through public or private transport. Therefore, in this context, my ability to be able to navigate in my vehicle becomes relevant.

RISK ENABLEMENT AND MANAGEMENT

The restrictions set by the AAC technology team is often based on risk evasive practices, built up over many years with a heavily bureaucratic NHS. The life opportunities and experiences, of lifelong AAC users, have radically improved, over the last 40 years, and their expectations for a 'normal life' has increased.

While AAC users need to accept, there are always risks to anything they do, the focus should be on support used to manage the risks, within a culture of risk enablement. This would include understanding the consequences of one risk over another. So while there may indeed be some risk of greater harm by using my AAC device in my vehicle if I was in a road traffic accident, I would be at significant risk of being vulnerable to the wishes to my personal care staff if I did not. I am therefore taken the decision with the least risk.

It is important to understand, and appreciate, that not all AAC users, will have the 'capacity', to take on decisions about risks, and that others, including SLTs, may need to decide them on their behalf.

PUPPET MASTER VS. THE PUPPET

Historically, even when AAC users were presumed to have the capacity, it was assumed they were looked after by their families, directly or indirectly, and therefore did not take responsibility for managing their lives. Advances in social care, as well as other factors, mean more AAC users like myself can 'self-direct' our support and our lives.

This means that we have become the puppet masters, for our own destinies, often by directly employing and managing our own personal care staff, instead of puppets whose lives are controlled by others. Having suitable AAC devices wherever and whenever we require it, including in private vehicles is part of this picture.

HUMAN RIGHTS IMPLICATIONS

Although not directly linked to the Human Rights of the AAC user, in the Communication Matters aims, it clearly states that it is the AAC user right to have a voice, at all times. There is a mismatch of the aims here, and surely to fulfil this correctly, changes need to be made within

services to honour that voice.

When we talk about having a voice, it is important to know what we mean. Someone's voice is not just the physical means to expressing words in a verbal setting, but also the social and human right to voice thoughts, feelings and emotions in order to participate fully in society.

Sometimes, SLTs and others seem to feel, so long as someone can say, yes or no to the questions of others, and inform people when they need the toilet, or to perform another essential activity, their job is done. I would argue this is not good enough and that AAC users should have the technology, training and encouragement to have a full voice.

RIGHTS AND RESPONSIBILITIES.

It is important we frame the context of the paper and the subject regarding rights and responsibilities. Both SLTs and AAC users have rights and responsibilities that need to be balanced.

SLTs have an obligation to provide users with appropriate AAC device & could expect users to use them in the way they intended. AAC users, in turn, have the right to expect SLTs to provide them with appropriate AAC device, but they have a responsibility to ensure they use their devices safely and appropriately. When AAC users can take responsibility for their devices they have the ability to take appropriate risks at their discretion.

This interdependence of rights and responsibilities between SLTs and AAC users, can work well, unless SLTs do not permit AAC users to take responsibilities concerning using their AAC, based on a level of distrust without the understanding of individual circumstances (like not permitting AAC users using their devices in vehicles). It is important to note as discussed previously is that not every AAC user has the 'mental capacity' to take the relevant responsibility.

THE SOLUTION? PERSONAL HEALTH BUDGETS

Personal Health Budgets (PHBs) is a relatively new concept, that is born out of the movement towards direct payments, and personal budgets within social care. They are payments paid to an individual, or someone on their behalf like their family, as an alternative to direct services or provision. PHBs have been popular with patients using NHS Continuing Care who wished to employ their own personal assistants instead of relying on care

agencies. However, PHBs have not currently been used much for other regards reasons.

NHS England, the body that has overall responsibility for health in England, plans to expand PHBs to has many services as they are suitable for, which could include AAC. This means that AAC service users could receive one-off payments to purchase their own AAC devices. It is important that the payments provided covers insurance and lifetime technical support.

Because the user has, in this scenario, purchased the AAC device themselves, they have sole responsibility for their device and can take any risks they want without the interference of the NHS team, understanding if they break the device, it may not be as easily repaired or replaced. This means using an AAC device in a vehicle becomes a personal choice and viable.

While AAC may already on paper be able to obtain a PHB to purchase an AAC device, it may be a few years before the systems to do this are in place, and it becomes a norm.

NORMALISED SOCIAL OUTCOMES

A core principal of the paper is 'normalised social outcomes' which is key to the inclusion and liberation of people with impairments. The principal is that people with impairment should be able to take part in the same activities as their non-impaired peers, regarding age, resources and cultural background. This is not a right to do these activities since the individual must be able to have the financial resources for them to do the activity themselves, where 'the state' pays

any additional costs like having a personal assistant.

Normalised social outcomes also mean that it should be assumed people with impairments take part in the same activities as non-impaired people if they so wish. This means, if an AAC user has a private vehicle, either funded by Motability or privately, they will not just use it to go shopping and to hospital appointments, but also college, work, restaurants, theatres, theme parks and so on. Having access to their AAC device in their vehicle keeps their autonomy and the ability to be spontaneous like their non-impaired peers.

WAYS FORWARD

I believe that this paper has successfully proven that it is appropriate for AAC users to have full access to their devices in their vehicles, so long as they are willing to take on the consequences of doing this. The problem is convincing SLTs & others who are responsible for providing AAC devices that they need to make the need for users to use their AAC device in their vehicles if they wish and it is appropriate.

We argue that the primary barrier is the long-standing power relationship between SLTs and AAC users within current health services, where SLTs have the 'upper hand'. Moving towards co-produced plans between AAC users and SLTs would require a significant cultural change in the way the services and AAC users work together. There needs to be a fundamental shift in the conceptual view of AAC devices within the NHS itself, away from the Medical Model towards what AAC users want, adopting the Social

Model approach, working with those AAC users who are self-directing their care, to assess together the 'risks' of using their AAC devices in their vehicles.

The assessment could specify the individual rights and responsibilities of both SLT and AAC user, as well as identify the relevant risks and more importantly, how to manage the risks. This could be regarded a risk enablement tool, as opposed to a risk aversive one. I think self-directing should be offered the opportunity to sign a disclaimer as this is important in these days of our culture, together with the Personal Risk Assessment. Another solution not already discussed are 'personal risk assessments'. These assessments would be carried out by SLTs to assess individually the risks associated with how a particular AAC user intends to use their device.

Personal Health Budgets could be an ideal solution to this. It may take years for services to set up the systems and procedures required to provide PHBs, and therefore AAC users may have to fight hard to obtain one until this happens.

Finally, it should be hoped that papers like this one could raise debate and discussion to both the understanding of SLTs and AAC users of the importance of having access to devices in vehicles.

While this is a fairly controversial subject, but I feel with some sensible risk assessment, on both sides, we can overcome this problem and others in the same arena.

REFERENCE

<https://www.england.nhs.uk/healthbudgets/>

Small Grants from CM

From time to time, Communication Matters offers small non-recurrent grants of up to £200 to applicants in the UK.

One area that CM Trustees would consider for support would be for attending an event in a country where AAC is less well developed. One such event coming up next year is the ECE-AAC conference, taking place in Bucharest in July 2017.

If you would like to present at this conference, applying for a small grant to help with associated expenses is something you could consider.

You can find out more here:

<http://www.communicationmatters.org.uk/funding/CM-grants>

Implementing a communication system; the case for regular, direct long term intervention

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In a time when resources are stretched, it is essential to be able to provide evidence for the effectiveness of treatment and to manage expectations of how long it may take to implement an approach. This article will describe how 3 approaches were used with William* and how it took over a year of therapy before he showed observable progress in his communication skills and was able to intentionally use a communication system.

William is a 14 year old boy with autism and complex challenging behaviour. He attends a secondary special school and he requires a high level of adult support. In October 2014, I was contracted to provide direct speech and language therapy input once a week for 45 minutes, following a request from the local authority to meet the requirements of his statement of special educational needs. At that time, there had been discussion as to whether he required regular direct intervention as he was not making progress in his communication skills. William's previous speech and language therapist had recommended that, as he was making limited progress, the focus of intervention should be on working with him in class and providing more of a consultation model where advice is given to class staff rather than direct work.

When I first started working with William, he was able to communicate a few single words using signs and symbols and he was extremely challenging to engage in therapy. He had previously used Picture Exchange Communication System (PECS) however this had had limited success and staff were mainly using the PECS cards

for 'now' and 'next'. His interests were limited to blowing feathers and listening to music. William's behaviour tended to go in cycles and over the winter he would become extremely agitated and aggressive towards himself and others. He found staying in class difficult and therapy sessions would take place wherever he was including on the stairs, outside and in the corridor.

When I first observed William, my immediate goal was to provide him with a means to communicate effectively. Having used the Language Acquisition Through Motor Planning (LAMP) approach I was keen to use this with William. The LAMP approach is made up of 5 elements which are auditory signals, natural consequences, consistent and unique motor patterns, shared focus and readiness to learn. See Figure 1. The LAMP approach was developed by John and Cindy Halloran and the software for voice output was previously only available on specific communication aids such as the Accent. This meant having to borrow a trial device from Liberator and then a lengthy process to apply for funding, often resulting in parents having to raise thousands of pounds themselves, as they had seen how effective the system was and didn't want to wait. Recently, the app (LAMP words for life) became available which enabled LAMP to be accessed on the iPad and, at around £200, was more affordable for families, schools and local authorities who already often had iPads.

It is important to note that LAMP words for life (WFL) is not an app that you can load up, hand to the child and leave them

to it if you want the system to be used over time. Naguib Bedwani et al (2015) found positive gains using LAMP, however they found that it was important that the child and family were supported by speech and language therapy and technical support for long term success of using the system. I have also found this to be the case as staff and families can find it difficult to model the learning without support and they need training on how to use the LAMP approach, which is tailored to each child's individual needs.

I wanted William to use LAMP WFL on the iPad, as my experience of using the LAMP approach, and my initial assessment of William indicated strongly that this was an approach that could work for him. He had significant sensory difficulties and he needed a system that was easy to use and still gave him access to a wide range of words. Due to his challenging behaviours, I felt that it was important that William could say core words such as 'stop' and that he was able to do more than requesting. I felt that having access to a range of core words would enable him to move towards autonomy, in that he could tell us what he wanted to say, rather than what was on his PECS book or what I had programmed into a device. At all times the LAMP ethos of presuming competence was also uppermost in my mind as William's 14 years of life experience could not be underestimated and he needed a system that could reflect that.

Once I had decided that LAMP was going to be the approach I wanted to use with William, and that my ultimate goal would be for him to use the LAMP WFL app as his

primary communication method alongside signs, I started direct weekly therapy with him. I was acutely aware that I was not going to be able to hand over my iPad to William and he would instantly use the app. My experience and the research told me that if William was going to use the app effectively and functionally, he would need direct, regular input and that it would take time. At that point I hadn't appreciated that it would take over a year and four attempts to reach that stage, but I was fortunate to be in a supportive school with great staff who also believed in William's potential.

Speech and Language Therapy sessions began by working on William's interaction skills using the Floortime approach and Ayres sensory integration theory to prepare William to be ready to introduce the LAMP app. Both of these approaches sit comfortably within the 5 elements of the LAMP approach (see above) particularly in readiness to learn and shared focus. If William was not able to tolerate people being near him or able to attend to the iPad he would never be able to access the app.

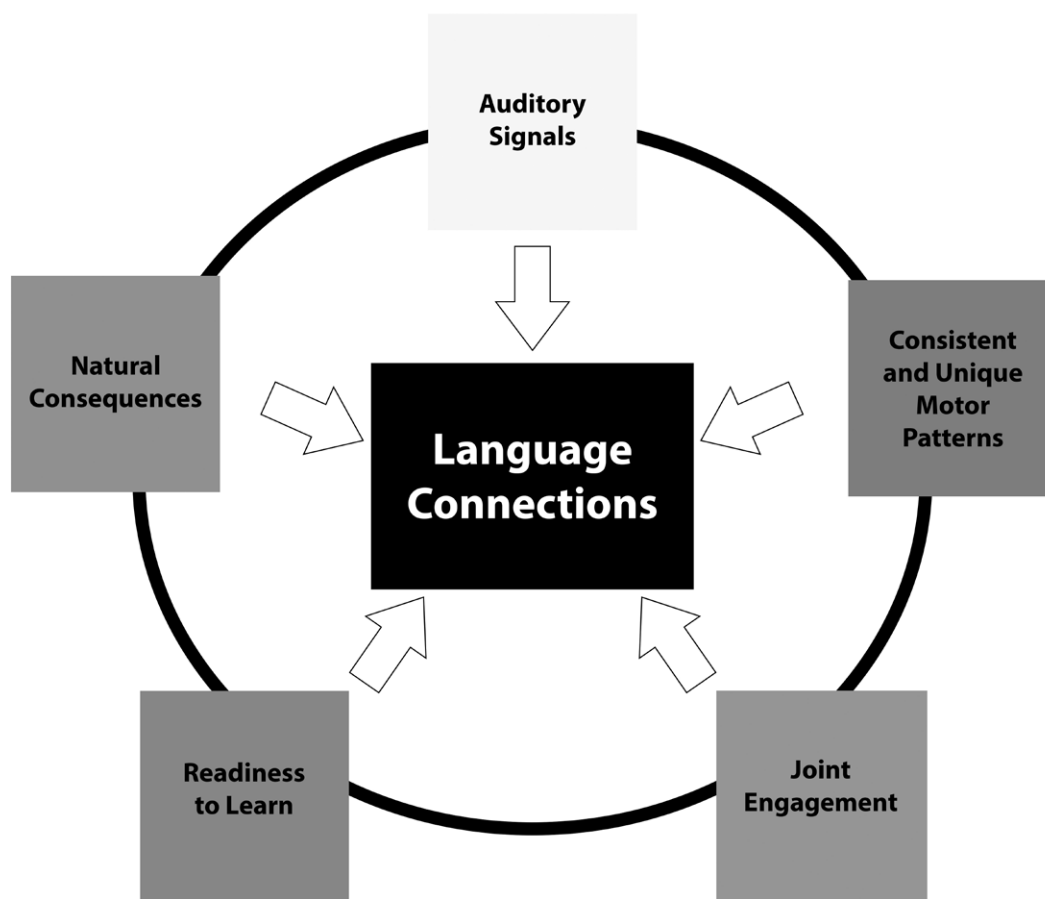
The Floortime approach forms part of the DIR model (developmental, individual differences, relationship based) and was created by Dr Stanley Greenspan and Serena Wieder. It shares similarities with Intensive Interaction in that it is play based, developmental and tailored to the child and their abilities. The book 'Engaging Autism' talks about how the model "allows us to integrate emotional, social, intellectual, and educational goals for each child" (page 41). William needed support to be able to tolerate interaction and as such we worked on milestone 2 (intimacy) which helped William to be able to build a relationships with others.

William also demonstrated significant difficulties within his sensory system which had been previously addressed with a sensory diet by the Occupational Therapists working with him. Due to issues with local provision, William had had a number of different occupational therapists and he had not had the opportunity to develop relationships with them. Having attended training on Ayres Sensory Integration, I was keen to provide strategies to support him to be calmer

in my sessions mainly using proprioceptive input also known as hard heavy work. Ayres Sensory Integration theory was developed by Dr A. Jean Ayres and she states "because speech and language depend upon many sensory integrative processes, they are apt to develop slowly whenever there is irregularity in any aspect of sensory processing." (Page 52). William was an excellent example of this and why it was crucial to work on his sensory system first. I believe this is an element many speech and language therapists have not been able to implement in therapy but, without it, it can be extremely difficult to move beyond the challenging behaviours.

In March 2015, after 4 months of input, I made the first attempt at using the LAMP WFL app. The app was set in vocabulary builder with 6 squares showing (more, help, stop, go, on, off). William threw my iPad and showed very little interest in the app. At this point he had begun to show more interest in single voice output switches if they had music on them. In June 2015, William was beginning to maintain short interactions with me

Figure 1



and he was less aggressive. The app was offered on a few occasions but he showed no interest. By October 2015, William was much more tolerant of interacting with me in sessions for longer periods of time. He would occasionally sign 'stop' and would press stop once on the app with considerable prompting if it was only a single step. He was beginning to show more interest in the app at this point, however over the next two months his behaviour deteriorated again and progress plateaued. Then, in February 2016, after over a year of input, William was offered the app and he began to use it spontaneously to say 'stop' and 'more'. Within 10 minutes he was able to use the full version where he had to press two squares to say 'stop', 'go' and 'more' and would look at the adult to respond. It was clear at that point that William was able to understand the function of the app and communicate with the adults to ask for more of the activities he enjoyed but he also had a surprise for us. During that session, William chose

his music from the pictures on a page and one song came on much too loud. I said 'oh that's too loud' and modelled it on the app. William turned down the music, looked at me and then independently pressed 'loud' on the app and smiled. It was at that point that I knew that he was on his way to being an effective communicator. Since then William has continued to make steady progress. He is using the LAMP app in class and is beginning to use it at home and his range of words continues to increase. He is also more interactive with others, his behaviour has improved and he is interacting appropriately with many more people.

As therapists, we are often under pressure to provide more input with less resources. As such we may advocate indirect work by training others and have only one opportunity to trial an aid or system. William is an example of why, for many children, we must advocate for direct, regular input over potentially a long period so that we can lay the foundation

skills needed to successfully implement AAC and not settle for providing what we know is not clinically effective. It is also important that we give children more than one opportunity to trial a system such as LAMP before we dismiss it as not being suitable. We should be thinking "not yet" instead of "not ever" and always, always presume competence.

*Name has been changed.

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'Bars, beer and brawls – AAC in Chaucer's Canterbury Tales'

HELEN DUNMAN

Chailey Heritage School

Email: helenmarydunman@hotmail.co.uk

I teach drama to pupils between the ages of 16 and 19 at Chailey Heritage School. Having successfully taken part in the Schools' Shakespeare Festival the year before, I was keen for my students to take part in another area of drama, equivalent to those studied in mainstream by young people of the same age but presented to them in an accessible way.



Aim

My aim was to devise a project around Chaucer's *Canterbury Tales* which met the needs of a wide range of students and led to progress in communication for each individual's.

The group

The students were all aged between 16 and 19. All had severe physical disabilities and complex sensory and medical needs. Learning needs ranged from PMLD to SLD. Five students used lo-tech AAC, six used no-tech, and one used high-tech.

Research

Having decided to tackle Chaucer, I then needed to think about how I could bring this to life for my students and create another 'world' for them. I got permission to transform our beautiful school chapel into a mediaeval pub and then set about researching how a Chaucerian pub might have looked, smelt and sounded. They were fairly rough places where people of all ages gathered to drink beer (even babies!), maybe eat something such



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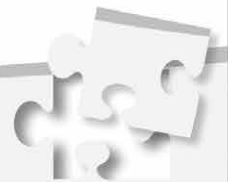
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Roadshows 2018

The CM Office staff and trustees are beginning to plan our 2018 Roadshows. From January 2018, we will be introducing a payment of £10 for a place at a Roadshow, this is due to increased costs and an increasingly high dropout rate on places booked and confirmed on the system.

There will be a reduced charge of £5 for those who are members of Communication Matters, PwuAAC and their family members will also be charged £5, one accompanying personal support assistant will be eligible for a free place.

This fee will be non-refundable but will be transferrable. Attendees will be able to register and pay for Roadshow places on the Communication Matters website. It will be possible to make these payments online. The Board of Trustees thank everyone for continuing to support Communication Matters by attending Roadshows across the UK.



We met as a group in the school hall and got changed into our costumes (staff as well as students). I would change into my costume and become Harry Bailey the landlord as I did so, changing my voice/ accent and also speaking the odd line of Chaucerian language to mark out a difference/another world. I had also learnt during the School Shakespeare festival that people of all abilities can enjoy the rhythm and sound of language even if they don't understand every word that is spoken. I then gave out objects of reference to the students with PMLD, so they might begin to anticipate what might be about to happen next. Max had his own pewter tankard which he usually clung to and sucked throughout the session, Rosie had a real piece of old sheepskin which she wore right around her shoulders.

We would then process to the 'pub'. I explained this to the students in the following way: - *'We are travellers going on a long trip to Canterbury, a special place. It will take us many weeks to get there, on the way we will be stopping off at pubs, we will have a chance to drink, get warm and share stories.'* One of the student's with ASD was initially upset that drama was happening in a different place to our usual drama space, but it turned out he could be lured up to the chapel quite happily if he led the procession with a suitable song that we taught him. Once at the pub 'Harry' would welcome the 'Pilgrims' and direct them into one of 3 groups. A colleague who is a PMLD specialist gave me some training, which I cascaded to staff regarding how students should be facilitated into REALLY exploring a sensory item. This can make all the difference in a student feeling motivated to communicate that s/he would like 'more' of something. So students who went to the bar area had a pewter tankard sluiced in beer, especially around the rim, held to their lips for some time so they could put their tongues out to explore, feel it on their lips etc. Students who went to the kitchen area had their hands immersed in cooked and uncooked porridge. The groups would rotate every 20 minutes. We finished each session by gathering around a fire pit for a 'chat' or to share a story (The Miller's Tale). I would sometimes ask AAC users to prepare a question for 'Harry' and it was at this time that they asked 'him'. Students showed keenness to ask Harry questions as he was rude, cheeky and unpredictable - he might throw them out of the pub, if he didn't like the question. Big Macks were also used throughout the session,

as basic porridge with pulses and more often than not a fight would break out. Also there were no pub loos and people didn't usually bother to go outside, so you get the picture!

I decided to set up 3 basic areas in the pub, a bar with real beer and pewter tankards, a kitchen with cooked and uncooked porridge and uncooked pulses, and a hay area, where students had their shoes and socks taken off and experienced putting their feet onto a cold tray covered in hay, to simulate walking barefoot in the pub.

To create interesting smells I threw beer on the floor every week and then covered it with sawdust and hay and had horse manure in a plastic box, which was unleashed before every session! The smell was quite pungent as we came in and a great sensory cue for the young people who had visual impairments.

The session format

I repeated the session in the same way every week, which was helpful for our students who need continual repetition to consolidate learning.

to enable communication in storytelling, to provoke a reaction from someone. Our early VOCA user chose to use it to say 'You pig' to another 'punter' (staff member) who reacted by starting 'fight' with him and they both got 'thrown out'. This was motivating for him to get an immediate and satisfying reaction to his communication. I would also throw out disgusting facts during the session which I would ask students about at the end eg. 'What was different about a mediaeval pub, compared to a pub now?' And expect an answer using AAC eg. 'Baby beer' referring to children drinking. Students with PMLD were helped to explore and respond to sensory items.

Results

Each student had their own communication target. These included 'To initiate a conversation using AAC', 'To ask/answer questions using AAC' or 'To indicate 'More' to something'. All these were taken from their communication profile targets ('My Next Steps') and incorporated into the drama so students wouldn't necessarily know they were 'working' (not always an appealing word to a teenager!). I noted improved outcomes for all students in their communication. Support staff were also very vigilant in recording student responses and in looking for patterns and consistencies. AAC users gave clear communication choices to ask and answer questions to 'Harry', often managing to link 2 symbols together eg. 'What eat?', 'What wear?' which is often challenging for our students. Students who find it difficult to press a Big Mack really tried hard to hit it and communicate and did this successfully. Students with PMLD showed increased responses and some showed consistent yes/no's to certain objects and indicated a positive response to 'more'. Two PMLD students for example, showed a smile and head up when the beery tankard was put to their mouths and 1 made a vocalisation to indicate pleasure. Towards the end of the project (10 weeks) these two were consistently showing a positive response when asked 'More'. Their responses were quite different to the porridge and hay areas eg. head down, no smile, no vocalisation. Our early VOCA user managed to initiate a conversation with no prompting, four times. One student who has PMLD and ASD, indicated resistance to being in a group less familiar to him at the beginning. He walked to a corner of the room, lay on a beanbag, pulled his cloak over himself



and did not want to get up. His TA supported him in coming up to the 'pub' a few weeks later and he walked around, stopping from time to time to look at the lines of the radiator. By the end of the project he was beginning to explore some sensory items presented to him. He showed interest in the group gathered around the fire. With no pressure, he walked to the circle, sat on a chair and remained still while we told the 'Millers Tale' – huge progress!

Conclusion

Providing an immersive sensory dramatic 'World' for students with complex communication needs can lead to increased communication and progress in each learner's individual communication journey. Whatever their disabilities, teenagers are teenagers and need a fun, stimulating, maybe even scary scary, project that they enjoy being part of, where they are not thinking necessarily about 'Work'. They need to be motivated to communicate, and we need to find the best motivators for each of them!

“Will anyone listen to us?”

What matters to young people with complex and exceptional health needs and their families during health transitions

MARGO MACKAY AND JOAN MURPHY

Talking Mats

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Background

Times of transition of any kind for young people are highly significant but for young people with complex health needs, the transition from children's to adult health services is particularly challenging.

CEN, the Clinical Network for Children with Exceptional Healthcare Needs, commissioned Talking Mats to find out the views of young people with complex needs and their parents about what matters to them at a time of transition in health services from children to adults. The literature suggests that we cannot assume that there will be consensus between parents and children or professionals and families about the needs of children. Listening to the perspectives of children and young people can be challenging since often the nature and complexity of their health condition includes significant communication impairment. The perspectives of the young people were considered to be vital to this study and we wanted to capture their experiences, record their voices and use the information to help us understand the reality of what matters to children and young people themselves.

Methods

The Talking Mats team met with the CEN team to determine the symbol sets which would be the basis for the Talking Mats discussions. We agreed on 2 main topics relating to health care services

- i) At the GP surgery and
- ii) At hospital

Talking about transition and future

wishes can be difficult for us all. To do so you need language and cognitive skills to be able to conceptualise the future. In order to think about the issues around transition, the primary focus needs to be on the present. We felt that if we could identify the aspects of their current lives and experiences that were going well, and not so well, we could extrapolate from this. Our pilot interview confirmed a practical focus was best and we made the topics and options as concrete as possible by relating them to actual situations. We interviewed 4 young people to get their views.

Findings

PAEDIATRIC SERVICES:

The participants' experience of paediatric services at the children's hospital was generally seen as good and the reasons for attending were either for planned admissions or for outpatient appointments. The journey to the children's hospital was fine, although having to wait for appointments as outpatients was mentioned as a problem. All the young people were clear that they needed to have their Mum with them and they wanted to have their own things for comfort. They felt the staff were generally good, although they mentioned that some didn't listen to them and some used difficult words.

GENERAL PRACTITIONER:

For those who had had contact with their GP they indicated that they liked their GP but that sometimes the GP talked to their Mum instead of them and they wanted to be included more. One young person said

that she preferred the GP to talk to her Mum who would then explain things to her later. Others felt that there were too many other health centre staff and that they could be a bit overpowering. They all thought the journey to the GP was fine and one young person liked that the GP visited at home.

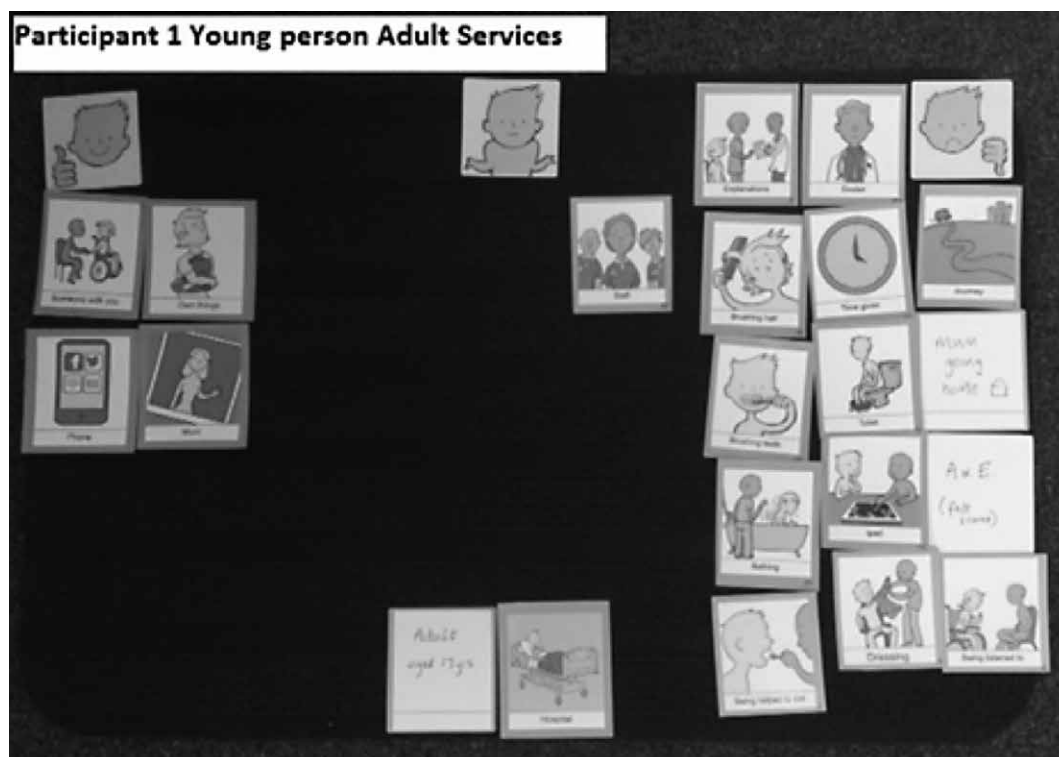
All but one young person had not yet experienced an adult hospital but all said if they had to go they wanted their Mum to be with them.

The following case study highlights the issues surrounding an unplanned admission to an adult acute hospital. The young person's name has been changed to protect confidentiality. This is her story -

Rosie has quadriplegic cerebral palsy. She has to be fully supported in her wheelchair. She is unable to care for herself and relies on her family and carers for all her day to day needs. She has a full and active life and goes to college 3 days a week. She enjoys meeting people, has an interest in beauty and trips out. She can speak in a quiet voice and is a competent communicator.

When she was 16, she had a planned admission for a surgical procedure in the children's hospital. The operation was successful and she was sent home for 6 weeks in a spica cast. Whilst at home she suffered complications from the surgery and had to be readmitted to hospital. She had just had her 17th birthday. The journey to hospital in the ambulance was "horrendous" as there were no adaptations and she

it was refused and was told that this was because they didn't have enough staff on duty to clean her up. Her mum had to fight to reverse this decision and eventually an auxiliary was sent from the children's ward to help them. On admission to the ward, Mum had to explain the situation in detail to the nurses and doctors as they had no access to her previous medical



history. A specialist learning disability nurse had been due to visit to make a 'Health Passport' for Rosie but this had not yet been completed. This document should contain information about care needs, history and requirements. It is possible that if that had been in place it would have helped to reduce some distress and anxiety. Whilst children's hospitals have facilities to enable parents to stay with them this is not the case on an adult ward and after sitting up all night in a chair, Mum decided she must go home to get some things for Rosie. On her return at 2pm she found her daughter in distress and Rosie's breakfast and drink still lying on the table in front of her. Rosie had been put in the single room furthest from the nurse's station and she could not get help as she cannot shout or use the buzzer. No-one on the ward seemed to know anything about her and she had received no personal care. Mum managed to get her discharged after three days.

On returning home, Rosie needed someone to pass a naso-gastric tube but, as she was now 17 years old, the children's community nurse could no longer come round to do it. She was told that there was no one in the community trained to do this but that if she returned to the hospital someone in the renal ward may be able to do it within 24hrs.

Rosie's experience of transitioning to adult services left her feeling frightened and confused. Her mum explained that it was like going from one end of the scale to the other.

"She went from being a child to an adult within days. We were cushioned from reality - we expected the best because we were used to the best".

Mum and Rosie have been allowed to return to the children's hospital for the time being.

In this mat Rosie shares her positive experience of the children's ward and her next mat captures a very different experience following her emergency admission.

Discussion

The parents in this study all want to be active participants in the process of transition. Many give up their own employment to facilitate a smooth transition for their children. They are dealing with numerous professionals and some feel that, with

the transition to adult services, it is like putting the clock back to the early years when countless agencies were involved. Parents bring a great deal of knowledge and expertise to the process and many had devised their own solutions. There is a great deal of resilience and determination to get the best outcomes for their child. The actual detail of these outcomes are highly individualised and linked to unique environmental and personal factors. However this takes time and energy and there is very little recognition for the work that they do.

Children's hospitals are used to dealing with the significant health care needs of children with complex needs, but most adult units do not have the specialist training or specialist equipment to manage complex mobility needs or healthcare procedures. The staff appear not to be trained to deal with the physical needs of these young people such as involuntary movements, feeding or moving and handling. The general feeling is that parents need to be listened to more as they know their children best. Parents want staff to use their skills and knowledge but to also recognise that parents need support at times of particular crisis, not just off-loading the weight of the personal care onto parents who are already exhausted.

The overall feeling was that the paediatric services had, on the whole, worked well but that for those that had experienced the transition to adult services, it had been dramatically worse.

For those who had not yet experienced adult services there was a lot of anxiety and fear that adult services would not be able to provide developmentally appropriate care and indeed lacked the resources and trained staff to maintain and support a smooth transition.

Rosie's story illustrates dramatically what can go wrong and highlights the gaps in the process.

The families in this project gave us clear views about the problems and some thoughtful suggestions, including:

- Courses for parents on transition
- More specialist nurses e.g. transition nurses, acute liaison learning disability nurses
- Start preparing early – at least 2 years
- Transition wards for young people
- Training for doctors and nurses about complex needs

- More respite, not less
- Emotional support for parents
- Longer appointment times
- A hotline to GPs

Conclusion

The transition from children's to adult services for young people with exceptional needs and their families is complex and fraught with concerns and fears. This study collected the views of a small number of young people and their families who are experiencing this transition in Scotland.

Professor Steve Field, (Chief Inspector of Primary Medical Services and Integrated Care) in the Foreword to the Care Quality Commission report said:

"A system-wide change is needed to achieve a joined-up approach... each part of the system at every level, needs to work together... we have put the interests of a system that is no longer fit for purpose above the interests of the people it is supposed to serve"

We need to be courageous and determined to see change occur. It is easy to make excuses about not having the time, the resources or the skills. Caring for the most vulnerable has to be made a priority and we hope that this small project will go some way in answering the question posed by a father – *"Will anyone listen to us?"*

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'I don't enjoy food like I used to'

The views of people with dementia about mealtimes

JOAN MURPHY

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JAMES MCKILLOP

Scottish Dementia Working Group

Background:

Mealtimes involve two of our most fundamental human needs, the basic physiological requirements for food and drink and interpersonal involvement (Shune, 2015). Mealtimes are particularly important for people with dementia as they may develop difficulties both with eating as a source of nourishment and with the social aspects of mealtimes. They may experience a loss of appetite, dehydration from not drinking enough, changes in taste, difficulties with different textures, problems with cutlery, worries about where they eat etc. (Markson, 1997). It can be distressing for all concerned and can have serious implications for a person's health and well-being (Maher, 2013).

However, it is crucial to find out the views of the person with dementia themselves as carers may often not realise the difficulties or may make decisions for the person. Wherever possible it is important to involve the person with dementia and give them decision-making power to decide what, where and when they would like to eat.

The Talking Mats team have developed a resource specifically around Eating and Drinking which includes 68 symbols divided into three main topics – Meals, Impact on Health and Things that might Help.

The resource can be used to help people discuss different aspects of mealtimes and food. It is particularly useful in helping people understand the effect that

their eating and drinking difficulties can have on their health.

Aim of project:

Talking Mats received funding from the Miss EC Hendry Charitable Trust to gather information from the first-hand experience of people with dementia about changes in their eating and drinking.

Methods:

Joan Murphy led the project and was supported by James McKillop, a member of the Scottish Dementia Working Group, which is a national campaigning group, run by people with dementia. James is very familiar with Talking Mats and suggested the idea of investigating the views of other people with dementia about eating and drinking difficulties in a group situation.

We ran three focus groups as this is a method previously used by the Talking Mats team and found to be a successful way to allow people with communication and/or cognitive difficulties to express and share their views. A selection of symbols from the Talking Mats Eating & Drinking resource was used to stimulate and focus discussions. We collated and analysed the results of the discussions thematically.

Findings:

Figure 2 is an example of one participant's mat about meals.

Those participants who had more advanced dementia found it harder to express their views but all appeared to enjoy the discussion and sharing their

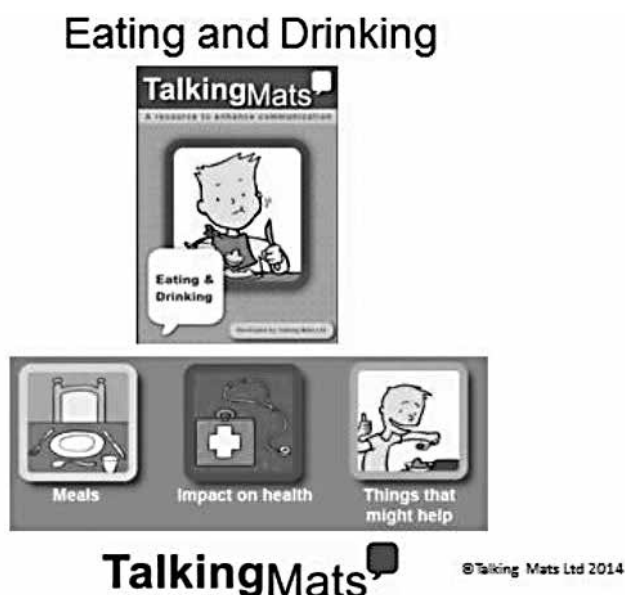


Figure 1

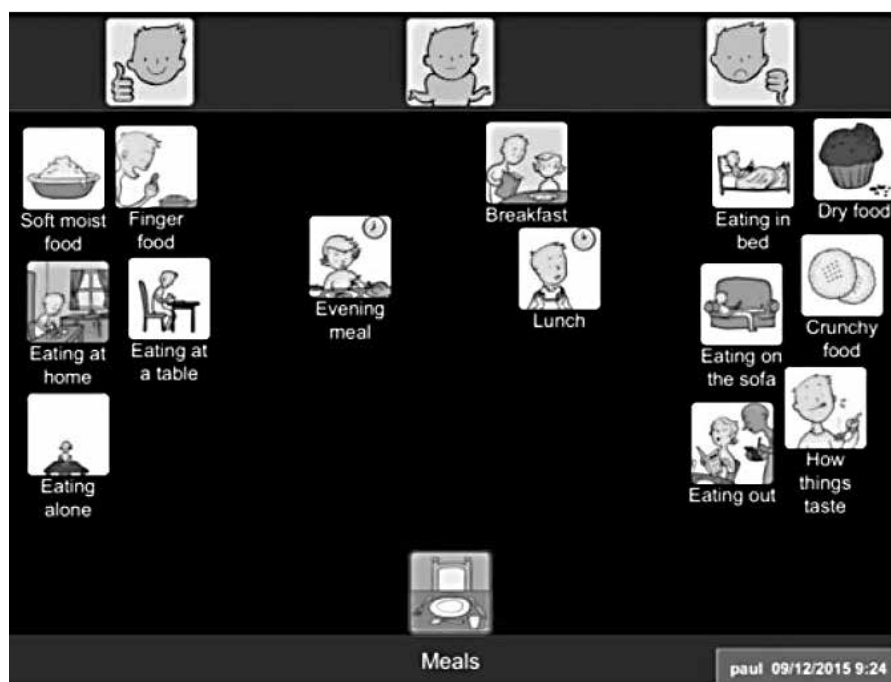


Figure 2

views with each other, sometimes agreeing, but not always. The following themes emerged from the discussions:

Mealtimes

For several people, their experience of mealtimes had changed since their diagnosis of dementia. Several said that they now skip breakfast and sometimes lunch

- *I just went off it [breakfast]*
- *Sometimes I'll take it [breakfast] sometimes I don't – I try to have it*
- *I can take it or leave it*

Where to eat:

Some found it more difficult to eat out since their diagnosis for various reasons including noise, distractions and unfamiliarity.

- *I can get embarrassed*
- *I don't like eating out now. It's too noisy for me*
- *I have difficulty with strange knives, forks and spoons – makes me slower and food gets cold and less tasty*

Whereas others really enjoyed going out

- *I do enjoy all these cafes. It's great having company. You feel you're not alone.*

Changes in taste:

Almost all the participants talked about how their taste had changed both for food and drink.

- *I don't enjoy food like I used to*
- *Tastes have changed – I used to eat*

potatoes and mince for breakfast, dinner and tea [laughs] but its not the same

- *I can't describe exactly what it is, but it's the tongue. I can't clean it, I can't get rid of it*
- *It's just a bland taste*

Some families had overcome the problem of lack of taste by going for more strongly flavoured food.

- *I now like tasty food*
- *We've got the time now that we didn't have and can concentrate on [cooking] with flavours and different recipes*
- *She adds peppers and spices to my mince now*

Appetite:

This was another aspect that had changed for most participants

- *I rarely feel hungry. Looking at the mat I can tell my eating and drinking isn't good*
- *I always used to like my chuck – I'm getting smaller portions now.*
- *I just tend to consume the food rather than enjoy it.*

Remembering to eat or drink:

Another key factor reported by most was the problem of forgetting to eat and drink

- *I don't drink enough – I keep forgetting*
- *I'm forever getting rows for not eating enough*
- *My husband leaves food out for me to make sure I eat it.*

Thirst:

When asked specifically about drinking, thirst was noted as a significant change since diagnosis

- *I'm a lot thirstier now*
- *I drink a lot and I go to the toilet a lot*
- *I do get a dry mouth*

When discussing how they felt the changes in their eating and drinking had affected their health, three main issues were noted by all the participants.

Energy:

They all acknowledged that this was poorer than before their diagnosis

- *My energy's not good*
- *When my grandkids are up I have tremendous energy. I've always said, when they come up I feel like 19, when they leave I feel like 90. But mostly every day, not a lot of energy.*
- *Very, very bad*

Concentration:

Similarly, they all felt that their ability to concentrate was affected

- *It's poor – I need to have a variety of things to do*
- *Don't think I could watch a whole film*
- *I never thought of that before until just now. This (symbol) has never left my hands since I picked it up and now I can understand what we're still talking about and what I want to say.*

Sleep:

Sleep was a topic that the participants added and several wanted to talk about it. For them there seemed to be a connection between sleep and eating and drinking.

- *I'm getting terrible dreams*
- *I don't sleep anywhere as much as I should*
- *I sleep too much*

Things that might help

During the course of the focus groups participants discussed ways that they had found to help with eating and drinking problems. Several ideas were shared such as:

- reducing distractions like TV and noise when eating
- avoiding difficult food
- having more time
- getting involved in cooking with a partner
- adding additional flavour to food
- having food which looks attractive

- having smaller meals
- having medication in liquid form rather than as tablets
- being reminded by others to eat and drink
- going to familiar cafes or restaurants when eating out
- having own cutlery when eating out

Discussion:

The social aspect of eating and drinking also changed for many of the participants and, given the importance of social engagement for quality of life it is important to be aware of the effects of changes in eating and drinking on mealtime dynamics. For some it may be that they are now less interested in the social aspect of eating with others at home. Others found it hard to eat out because of distractions

Almost all the participants talked about how their taste had changed both for food and drink which in turn affected their appetite. Some families had overcome the problem of lack of taste by going for more strongly flavoured food. When asked specifically about drinking, thirst was noted as a significant change since diagnosis

Three additional health issues which the participants felt were connected with eating and drinking were poorer energy levels than before their diagnosis, reduction in ability to concentrate and changes in sleep patterns.

- Dementia & Sensory Challenges - Life Changes Trust (2014)
- Eating Well with Dementia A carers' guide (2014)

- Let's talk about dementia: speech and language therapy in dementia (2015)
- Communication and Mealtimes Toolkit (2012)
- Talking Mats Eating and Drinking Resource (2014)

We are very grateful to the Miss EC Hendry Charitable Trust who funded the project.

We are also indebted to the people with dementia who took part and their families who supported them. Thanks also to the Dementia Centres who organised the groups and provided their premises for the focus group meetings.

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- Talking Mats Eating and Drinking Resource* (2014). <http://www.talkingmats.com/product/talking-mats-and-eating-drinking/>

CALL FOR NOMINATIONS 2017....

The Alan Martin Award

Presented annually at Communication Matters Conference for significant contribution to the Arts by someone who uses AAC

The Background to the Award

This award, first presented in 2013, is in memory of a remarkable man who was amongst other things a dancer, a musician and comedian who worked for the inclusion for all people within the arts whatever their disability. For 16 years Martin attended and presented at CM conference. Sadly he passed away in December 2012.

Alan often told the young people who he worked with:

"Never let anybody tell you that you can't do something because of a disability."

So far the award has been presented to poetry, drama and photography.

Barry Smith received the award in 2013 for his poetry. The breadth of his work gives a real insight into the life and experiences of people who use AAC and have physical as well as communication challenges in their life. There is an interview with Barry in the CM Journal Vol 29 (2) 2015 and his poetry is on the CM website.

Kate Caryer received the award in 2014. Kate is a writer, ex Channel 4 continuity person and actor. The Unspoken Project CIC brought 'Speechless' to the stage at conference 2016. A summary of a video of the premier will shortly be available as an educational resource on the CM website.

Sam Knapp received the award in 2015 for his creative photography. Sam has a website where you can buy his work. He does photo booths, landscapes and street photography. Twitter @Samknapp
<http://www.samknapp.photography/>

Jemima Hughes won the award in 2016 for her work with animations over several years. Her work can be seen on YouTube at <http://randomacts.channel4.com/post/149327322436/first-acts-jemima-hughes-imagination-a>

<https://www.youtube.com/watch?v=kYHm1ZviwJM>, https://www.youtube.com/watch?v=X8TDk_QjLqY

What Art form will the award go to in 2017?

Please send your nominations to the office by post or email at manager@communicationmatters.org.uk with a short explanation of the reason why you think this person would be an ideal recipient of the Alan Martin Award. Please attach an example of their work if possible. The award will be judged by the Trustees (& hopefully 1Voice Trustees as happened last year). A shortlist of 3 will be drawn up and the final decision will be announced at the conference on Tuesday afternoon plenary and awarded by the last year's winner.

Rules:

The person must be 18 or over.

The person may be amateur, be in arts education or gain income from their Art.

Any form of creative output can be considered.

The person should not have received the Alan Martin Award before (in the last 5 years).

Closing date September 1st.

The drive for a holistic approach to mounting communication equipment

ESTHER DAKIN AND BILLY HUNTER

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Smile Smart Technology Ltd is one of our organisational, supplier members.

Abstract

Collaboration between professionals to provide effective mounting is essential to establishing maximum capacity for user independence.

This article will emphasize the 'nexus' quality of mounting and its now pivotal role in the growing interdisciplinary world of contemporary assistive technology.

Introduction

The progress in technological advancement and complex provision makes the need for a co-ordinated approach to mounting increasingly crucial. Whether using mounted devices for teaching, access or environment, the fundamental tenet of today's mounting theory must be to enable the greatest access, with the least encroachment upon the natural movement of the individual. Product advancements now require greater communication between practitioner teams to fully support users through effective installation.

In this article we encourage the move to using the most discreet mounting options available, with the practice of 'minimal mounting'. We champion the notion of 'NEAT, DISCREET & PRACTICAL'.

Product

The move to lighter-weight mounting systems as pioneered by the German manufacturer, Rehadapt has led the way to enabling 'more amenable' optimizations of function. First brought into the UK in early 2009 by Smile Rehab,

now Smile Smart Technology Ltd, the Rehadapt mounting systems are lighter weight than previously available on the market and highly versatile. This range allows the mounting of a wide range of products, from a sizable Tobii I-15 down to the delicacy of a Mo-Vis joystick with the least encroachment upon natural movement.

Prior to the advent of Rehadapt's emergence into the UK market, the dominance of the Daessy mounting system had been borne out of its superb sturdiness and robust nature, which it continues to provide today.

Another strong line is Mount 'n' Mover from the USA. A highly sophisticated mounting system for electronic devices that allows for considerable customization and has compatible adapter plates to work with existing Daessy hardware. These are a strong product for those requiring particularly high levels of position provision.

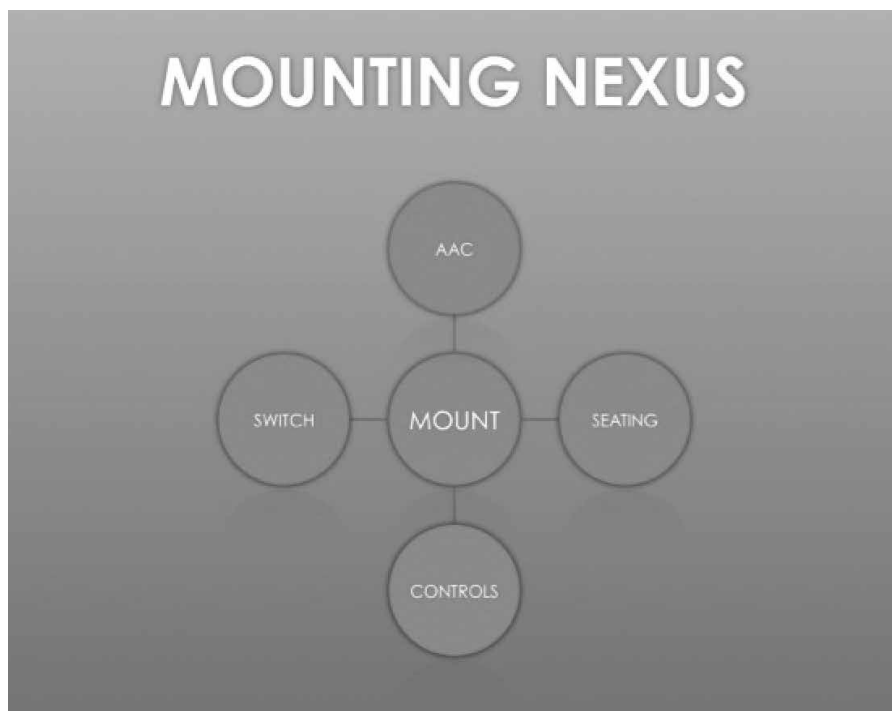
'Minimal mounting' is arguably driven by the natural response to developments in lighter-weight and streamlined AAC devices. The extraordinary advances that now allow access to communication through technology as diminutive as iPhones, can transform lives, *if mounted correctly*. The incentive to use the Rehadapt system in these cases is two-fold, as there is minimal mount to impinge upon movement or sight, and its versatility allows for accurate adjustment without excessive weight or metalwork to surround a small sleek object. Where larger devices are used, the high-tensile

strength, combined with adjusting clamps provide steady support and versatility.

Head switch mounts have been an increased focus area at Smile Smart Technology as Roger Dakin believes that to motivate effective switch use, 'comfort is king'. His new 'Softytots' that soften the impact of switch use of Pico and Buddy Button that can be wiped clean and dried, have shown to be great incentives, particularly for comfort to the delicate head region and facial skin.

Coupled with the also new, 'Flexirods' that flex gently as pressed and immediately return to position, there is a new more pliant and encouraging experience in switch access - made possible by 'minimal mounting' and strongly empathetic design.

From 2009, the challenges of adapting imported products to the UK market was a team effort between Smile and Rehadapt. Despite the flexibility of all systems, it is the skill of the installer that defines the practicability of the mounting solution. Many of the AAC Specialised Services excel in good installation practice and their collaboration with engineering partners ensure optimum results. Experience has shown that the very nature of specialist mounting requires high-levels of installation knowledge and that where these services are not used problems most often occur. This wastes time and budgets. If mounts are not installed well, device use is impaired, either through poor access or excessive additional mounting - leading to 'the Christmas tree effect'.



In this process, if the seating is correct the initial stage one is complete. Stage two is ensuring good access and positioning of the device. If the user intends to operate switches, either by head operation, hand, knee, feet or other means, it is imperative that the switch or switches are sited where they might be easily be set up and operated on a continuous basis, with trouble free operation. Ensuring switches are sited so as not to make them liable to damage or inadvertently disconnected by care staff during the various day-to-day routine is a key factor in siting switches. A primary question that should be considered is: are the switches comfortable? because hitting your head against a piece of cold, hard plastic when your tone goes high (episodic dystonia) is painful and yet completely preventable. Discomfort and pain of this kind is the main disincentive in access to this type of control. Having sufficient empathy with the user is key to success. Equally, ill-positioning may also lead to unintentional operation which additionally gives rise to great frustration and anger by the user.

Therefore the practice of good 'minimal mounting' requires specialist mounting installers to achieve a 'NEAT, DISCREET & PRACTICAL' result.

Practice

Strong communication between the user, care team and specialists is the key component to the installation process. As the mounts themselves are the technical nexus between device, seating, controls and switches, so equally is the good communication between all involved to facilitate a comfortable and encouraging installation.

To expand upon this further, we press for the need to reform the regressive perception of wheels and health on the one side of support against speech and education on the other. Progressive provision for optimum care requires an essential shift to maintain momentum with the technology we use, for a collaborative 'holistic' approach and a move away from now outdated divides.

A message from Roger Dakin

'The mounting of communication equipment onto wheelchairs has historically been a somewhat hit and miss affair, with all parties making their best attempt and with varied levels of success. Depending upon the variance of who owns the wheelchair, who installs the mount and who does the final setup of the device – it can be a lengthy and time consuming process. Any user wishing to make use of a

communication device is also subject to the skill of the seating supplier, prescribing Occupational Therapist or Physiotherapist, all of whom create the correct postural support with which to operate the device. If the client has too much postural movement, the switch positioning, or eyegaze calibration will be thrown into disarray, much to the frustration of the user, instructor or teacher who hopes for optimum use of the equipment at the earliest opportunity.

There are now many ways to mount switches other than having bespoke ironmongery welded and created by an engineering department. In the dark past it would seem that some engineers believed that humans were themselves machines and that all their movements were symmetrical, particularly with head switches. Today we provide more flexible engineering technology, with switches that can be



made soft to the touch [using Softytots], mounts that can be made to give under pressure and return to their original position [using Flexirods]. Their individual siting can be adjusted independently and can all be swung away when hoisting, so avoiding damage.

If direct switching is not called for then eyegaze may well be the desired mode of operation, which in turn requires a greater degree of accuracy in seating and mounting the device. To be able to set up and adjust an eyegaze device requires a considerable degree of skill on the part of the installer. Pivotal to the swiftly effective access to these highly progressive devices is the skill of those setting-up the entire user system. The more accurately that the whole installation process is accomplished, the sooner the client will start to use the device.

Unlike a floor or table stand, a mount fitted onto a wheelchair must also take into consideration the seating and positioning of the client, as I have already mentioned as their legs and arms are likely to hit or pull the mount accidentally through voluntary or involuntary movement. If the mount is to be fitted onto a powerchair the other fundamental concern should be how might the position of the mount on the chair hinder or impede the ability of the user to drive. As the user is driving or being driven the positioning of mounts and their devices should also be taken into careful consideration. They must be kept within the curtilage of the chair to avoid damage, as you could be forgiven for thinking that often mounts and communication devices are also designed for pushing open doors... which they are not!

In the dark age of wheelchairs, they were all made of tubular steel or aluminum with canvas seats and backs, very much akin to the style of a directors chair, seen on film sets. This design left little room to mount additional equipment and due to the weight of the early computers/or communication

devices, like early Liberators or Camelions, the centre of balance was paramount when fitting a device onto a chair. Since all this equipment was of its time, rules and procedures were created to ensure that the stability of the chair was not compromised and tests like stability decks were required. Slowly, as in motor car design, heavy structural steel has been replaced by light-weight structural aluminum, as used in aircraft design. This together with the remarkable reduction in size and weight of communication devices, has led to a far more user friendly approach to their mounting onto modern wheelchairs. The design of contemporary wheelchairs has also now taken into account fitting additional equipment onto the chair; the overall centre of gravity has been lowered and as such the mounting positions available are far more flexible.

The ideal mount is light and tight to the chair, the device is removed easily and stowed at the rear of the chair in a total of 10-15 seconds. Damage is reduced, vision unimpeded and there is little to hinder the driver. The same can be said for manual chair users and more so today, classroom chairs.

Since the advent of these lightweight mounts we have mounted devices onto classroom chairs and even buggies, enabling even the very young to get started on these new generation of devices such as iPads and their like upwards. The simplicity of their installation, light weight and low cost has improved the use of communication devices by an unprecedented degree.

With such wide access now available in AAC devices through technological advancements, the correct and lasting use of the devices themselves and the allied products, it stands to reason that we should be looking at the client in a more holistic way to ensure that each element is prescribed and operating correctly. Not as is often the case where we see the poor installation of one

part severely compromising the use of others. We should be free to discuss the client's needs as a whole and end the historical departmentalism of our area, with specialists each doing their own part in isolation. Too often it is only when the client is at the end of their wits with frustration that the holistic approach is taken. It would be far more cost effective in the long run and save a great deal of time and effort if we all worked together from the outset.

Today's communication devices provide the brightest access to the future that we have ever seen. Younger users have the most incredible potential today, all they need is great access to achieve great things.'

Conclusion

Interdisciplinary practice became a progressive movement in academia and industry some ten years ago. It is time that our industry and professions follow this mindset. Stronger and more inclusive teamwork is pivotal given the technological advancements that touch so much of an AAC user's life and those around them. An improvement in our professional collaboration is key to good mounting results, as mounts are the nexus that facilitates effective AAC use.

For further information visit:
<https://www.smilesmart-tech.com>

FOOTNOTE

Roger Dakin is the founder of SMILE and developer of the Smile Smart System and Platforms for neurodisability assessment and switch and control training using the theory of motivational movement by wheeled device. Billy Hunter is the Sales Manager at SMILE and has been with the company 10 years. Esther Dakin is Communications Manager at SMILE and responsible for research, legal and policy work.



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New Membership Rates Explained

The Board of Trustees are thrilled that CM continues to have a strong membership base. We are aware that over recent years, possibly since the inception of the 14 Specialised Services, that there has been a shift in membership patterns. In light of this, we have restructured our membership options as follows:

Individual: £65. Includes 3 issues of Communication Matters Journal, reduced rate at any Study Day organised by Communication Matters, eligible to attend the Communication Matters National Conference, and reduced rate delegate place at ISAAC Biennial Conference. Opportunities to represent CM at events across the UK (with paid expenses). Able to apply for small grants relating to work in the field of AAC.

CM Organisational (Types A, B & C): Same benefits as Individual membership, plus: eligible to apply to present at CM Roadshows (if supplier of AAC products, not just services), at the National Conference, reduced Communication Matters Journal advertising rate, and 1 reduced rate delegate place at the ISAAC Biennial Conference.

- **CM Organisational A:** £178. 2 sets of the CM Journal (3 issues), up to 3 reduced-rate delegates at any CM Study Day, and up to 3 delegates eligible to attend CM National Conference.
- **CM Organisational B:** £325. 4 sets of the CM Journal (3 issues), up to 6 reduced-rate delegates at any CM Study Day, and up to 6 delegates eligible to attend CM National Conference.
- **CM Organisational C:** £500. 6 sets of the CM Journal (3 issues), up to 10 reduced-rate delegates at any CM Study Day, and up to 10 delegates eligible to attend CM National Conference.

All types must include named members on the form.

People who use AAC/Family: Free membership for one year if new member (subject to availability); otherwise £21. Same benefits as Individual membership.

Full-time Student: £22. Same benefits as Individual membership.

Full-time Student (CM Journal only): £10. You receive the CM Journal but not the other benefits of Individual membership.

Retired: £48. Same benefits as Individual membership (available to people who have retired).

ISAAC Institutional: £336. Same benefits as CM Organisational membership A, plus: two extra delegates at the ISAAC Biennial Conference at reduced rate, and separate listing & reduced advertising rate in ISAAC Membership Directory and AAC Journal.

ISAAC Corporate: £667. Same benefits same as CM Organisational membership A, plus: separate listing and reduced advertising rate in ISAAC Membership Directory and AAC Journal, and reduced rate exhibition stand and advertising at ISAAC Biennial Conference and ISAAC co-sponsored events.

As with all changes, the board will evaluate the impact on the Charities key objectives and core values.

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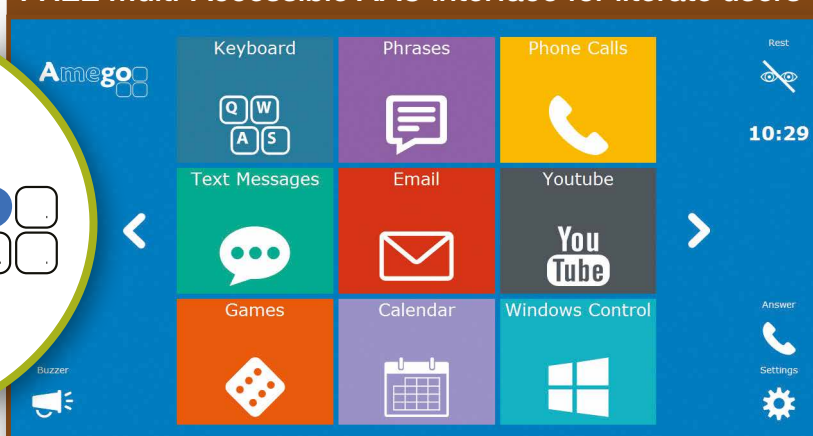
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