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Talking Mats®
A study of communication difficulties
and the feasibility and effectiveness
of a low-tech communication framework

Joan Murphy
The studies presented in this thesis have been carried out at the University of Stirling.

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Nijmegen 2009

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This thesis is dedicated to Tom Fairie
Talking Mats
A study of communication difficulties
and the feasibility and effectiveness
of a low-tech communication framework

Een wetenschappelijke proeve
op het gebied van de Medische Wetenschappen

Proefschrift

ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de rector magnificus prof. mr. S.C.J.J. Kortmann,
volgens besluit van het College van Decanen
in het openbaar te verdedigen op vrijdag 19 februari 2010
om 15.30 uur precies
door

Joan Fairie Murphy

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Introduction
Introduction

This thesis presents a selection of research projects carried out since 1999 which describe the evolution and development of Talking Mats, a low-tech augmentative communication framework. It was designed to help people with communication difficulties to comprehend and consider topics of relevance to them and to then express their views in a way that others can understand. The thesis begins with a study which examined the communication of people with deteriorating speech and their partners, and their perceptions of their communication difficulties and the augmentative and alternative communication (AAC) systems offered to them. It progresses to an investigation of the feasibility of the Talking Mats framework with different client groups and culminates in two projects which studied the effectiveness of the Talking Mats framework.

The following case study illustrates communication difficulties and the use of the Talking Mats framework to help a woman who had aphasia after a stroke. It is presented with her permission.

Case study

Lindsay had a stroke which resulted in severe receptive and expressive aphasia and a hemiplegia affecting the right side of her body. On discharge from hospital she was referred to a community rehabilitation team. She used the Talking Mats framework at the beginning of her rehabilitation in order to understand and consider the options available to her, to express her views about them and to set goals. She used the Talking Mats framework again prior to discharge from the rehabilitation team to think about how successful she had been in achieving her goals. In the following verbatim transcription, taken from Talking Mats and Aphasia, Lindsay is talking about what it is like to have aphasia and how she used the Talking Mats framework to express her views on her communication and to help her set rehabilitation goals. Discussion takes place using photographs of her completed Talking Mats. She has two sets, including submats on her communication, which were done one year apart. She also talks about using the Talking Mats framework by herself as a tool for self management.
J What did it feel like to you – especially your communication – after you had your stroke?

L Well ... for me communication was so important. I always had a love of words and I was in a job where communication was so important ... um ... and ... um ... my body got better ... um ... but ... I'm blank ... um ... no ... I got frustrated and I got angry ... angry with people. They couldn't understand what I was saying but it was all up here (pointing to brain). There was so many things I couldn’t do. I couldn’t speak. I couldn’t understand what people ... All on the negative ... very few positive ... and seeing Talking Mats laid out ... it stopped the confusion in my mind because everything was all mixed up. I couldn’t focus on what was bad, what was good. This made me focus. There were some ... I was happy with ... and some ... most of them ... I was unhappy with but it just made me focus. And a year on and the difference ... I could point to a newspaper on the Talking Mats and I could say ‘I learned to read a newspaper’ ... slowly but surely ... and that was on the positive side of the Mat the next time I did it. And there could ... um ... spelling or reading a book ... I could point to them on the negative side and then do something about it. ... yes.
J I really liked that the second time you added in humour.

L Which ... there was no humour a year ago ... oh yes ... there was no humour in anything. You talked to me ... you know I was very, very depressed.

J You can almost see, can't you, there's such a lot more on the positive side ... and you added in about your poetry.

L Yes I did a lot of writing. I did a lot of poetry before my stroke and it never entered into the Talking Mats I did a year ago ... I couldn't think ... there's no words there ... but a year later words are coming back to me slowly ... slowly but surely I can write again.

J So you're writing poetry again?

L Yes.

J What about you taking control of your rehab?

L Yes ... I use the Mats a lot at home ... the actual mats I look at ... not every day ... and I say 'that's something I want to do' and I take ... take steps to do something about it.

Background

Communication

The Royal College of Speech and Language Therapists defines communication as the sending and receiving of messages between people. The message can be about information, ideas or feelings and can be conveyed by spoken or written word, or gesture. Facial expression, tone of voice and body language are also important elements of communication. Communication includes speech, language, reading, writing and social skills and is one of the most complicated skills humans learn. It needs not only many parts of the brain to work together, but also the 'physical equipment' for hearing and vision, and the oral mechanism to be in full working order. In addition, the right opportunities need to occur at the right time for communication to develop and be maintained.

Communication impairment

The Royal College of Speech and Language Therapists defines communication impairment as 'reduced or lost ability to communicate in the standard way'. It may be the result of a congenital condition such as cerebral palsy or learning disability, or an acquired condition such as motor neurone disease or stroke. It may affect
receptive language, expressive language, voice production, articulation, fluency, stress, intonation, non-verbal language (e.g. facial expression and gesture) and social language. It may be caused by a non-deteriorating condition, such as cerebral palsy, or a degenerative illness such as Alzheimer's disease. Communication impairment can be a hidden disability where the person has no other impairment, e.g. many people with aphasia caused by stroke describe the frustration of people thinking they are drunk because there are no physical signs of their disability. Conversely communication impairment can be more visibly obvious when associated with a physical disability such as cerebral palsy or motor neurone disease. Because the person often cannot express their needs or explain what they feel, communication impairment can be isolating, debilitating and distressing.3,4

Specific groups of people with disabilities who are likely to have communication support needs were listed in a Scottish Government review in 2007.5 Table 1 outlines these groups.

Table 1. Diagnoses which may result in communication support needs

<table>
<thead>
<tr>
<th>Aphasia following a stroke</th>
<th>Autistic spectrum disorder</th>
<th>Cerebral palsy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cleft lip and palate</td>
<td>Disorders of social communication</td>
<td>Deafness</td>
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<tr>
<td>Developmental language delay</td>
<td>Dyslexia</td>
<td>Dementia</td>
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<td>Friedreich's ataxia</td>
<td>Head injury</td>
<td>Hearing impairment</td>
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<td>Huntington's chorea</td>
<td>Learning disability</td>
<td>Laryngectomy</td>
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<td>Motor neurone disease</td>
<td>Multiple sclerosis</td>
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<td>Neurological disease</td>
<td>Specific language impairment</td>
<td>Stammering</td>
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<tr>
<td>Visual impairment</td>
<td>Voice disorders</td>
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</tbody>
</table>

However, estimates of incidence and prevalence of people with communication support needs are difficult to find. One estimate suggests that there are currently 2.5 million people in the UK with a communication impairment.2 Enderby and Pickstone summarise data on the incidence and prevalence of acquired communication and swallowing disorders from a number of different sources.6 They suggest an overall international prevalence of 1,193 per 100,000 (1.2%). This figure does not include people with either general or specific developmental difficulties or people with communication support needs associated with deafness, visual impairment or dementia. The highest incidence reported for acquired communication difficulties is stroke which can result in long-standing communication support needs. The conclusion of the Scottish Government Review is that a conservative estimate of the number of people with marked communication needs is in the region of 1–2% of the population.5
The impact of communication impairment
Communication is a fundamental aspect of all human relationships. While effective communication can improve a person’s quality of life, problems with communication can have a major negative impact which is not always in direct proportion to the severity of the impairment. For example one of my patients with minimal articulation problems following a mild stroke was severely distressed as he perceived it as a threat to his return to work. Another patient with no speech due to head injury accepted her situation and was comfortable using a low-tech alphabet board for her everyday conversations. It is clear that difficulties with either or both receptive and expressive communication can be not only frustrating but also incapacitating.

Personal accounts give a sense of how communication difficulties can impact on someone’s life. The case study presented at the beginning of this chapter showed how frustrating the loss of words can be for someone who previously had a ‘love of words’. The following extract shows the extreme effect that being unable to speak can have on mundane aspects of life that most people take for granted. A woman with a congenital disability wrote:

I know what it is like to be fed potatoes all my life. After all potatoes are a good basic food for every day, easy to fix in so many different ways. I hate potatoes! But then, who knows that but me? I know what it is like to be dressed in red and blues when my favourite colours are mint greens, lemons and pinks. I mean really, can you imagine?

Every day the person with communication difficulties has to make choices regarding when, how and with whom to interact and, unlike those who typically communicate via speech, the person with communication difficulties must often expend huge physical and emotional effort. However, for many, even this amount of effort results in an inability to understand and be understood. They may lose confidence and self-esteem which can affect their personal and social relationships. Their disability can reduce their opportunities in education and employment and it may prevent them from receiving health and social services. It may also result in a sudden or gradual restriction in their social networks. Consequently they may be unable to fulfil their roles as partner, parent, family member, colleague and/or friend. A woman who lost her speech following an accident wrote:

Speech is the most important thing we have. It makes us a person and not a thing. No one should ever have to be a ‘thing’.

12
Augmentative and Alternative Communication – AAC

Augmentative and Alternative Communication (AAC) is the term used to describe methods of communication which can be added to the more usual methods of speech and writing when these are impaired. \(^{11}\) AAC can help someone understand as well as express themselves and includes unaided systems, such as signing and gesture, and aided systems, ranging from pen and paper to the most sophisticated computer technology currently available. Most people who use AAC employ a combination of unaided and aided methods. Aided methods are usually divided into two groups: low-tech and high-tech AAC systems.

**Low-tech AAC systems**

Low-tech systems are defined as any system which does not need a battery or power supply to function. \(^{11}\) Low-tech AAC can take a variety of forms such as a pen and paper to write messages, alphabet charts, pocket-sized books, waistband communicators, aprons, t-shirts, small and large boards which can display objects, remnants, pictures, symbols, letters or words. \(^{12-19}\) They allow the non-speaking person to communicate either by listener-assisted scanning or by pointing directly to the symbols, letters or words with hand or eye gaze, or with an aid such as a pointer or light. There are many different symbol systems and as well as ready-made displays, software programs can allow the creation of individually personalised boards or books. Low-tech systems may be accessed by pointing or by listener scanning. The following is a description of how low-tech systems can be used:

> The person using a low-tech communication system relies on a technique described as ‘listener mediated’ output. Basically, the communication partner ‘reads’ what the user is indicating and translates or interprets. The low-tech user’s communication is thus jointly constructed by both him/herself and the communication partner. For many AAC users this joint construction with, and personal engagement of, the communication partner is one of the main benefits of using a low-tech communication system. The responsibility for achieving effective communication is shared. \(^{20}p^{21}\)

**High-tech AAC systems**

High-tech AAC systems are devices requiring at least a battery to operate them. Most now have either synthesised or digitised voice output and are generally referred to as Voice Output Communication Aids (VOCA)s. The quality of speech
available varies. They can be accessed simply by directly touching the device or indirectly by scanning which requires the user to activate a switch or switches.\textsuperscript{11} High-tech communication aids range in their sophistication from aids which can carry a limited number of pre-recorded (digitised) messages on a static screen to those which can convey a limitless number of messages using synthesised speech. Some aids have both options. A choice can be made between text- or symbol-based aids and many of the more sophisticated aids allow the user to switch between symbols and text and to move between different levels of vocabulary using dynamic screen technology. Some devices can be linked to a computer to produce text and voice output. A range of software is available both for symbol- and text-based voice output programs. Both computers and VOCAs can be accessed by directly pressing a key/square on a standard or modified keyboard, or for those with very limited physical abilities, through a variety of switches operated by any part of the body which can produce a reliable repetitive movement\textsuperscript{12,21,22}.

\textbf{Origins of AAC}

In 1985 the first edition of the AAC Journal was published. Its contents featured mainly low-tech AAC such as the transparency of Amer-Ind symbols\textsuperscript{23} the prevention of communication breakdown by users of communication boards\textsuperscript{24} and an investigation of how Blissymbols were learned by non-disabled people\textsuperscript{25}. Originally AAC was mainly used with people with cerebral palsy with little or no functional communication, then began to be used with people with acquired disorders\textsuperscript{26}. For people with no speech but intact literacy and language and adequate hand function, machines such as the Canon Communicator\textsuperscript{TM} were said to have made a great difference to their lives. This is a comment from one of the first patients I gave a text-based device to in 1986:

\textit{This has been a godsend to me – I can argue now – before I had to grit my teeth.} (printout on ticker tape on Canon Communicator\textsuperscript{TM})

In the 1990s, with the development of computer technology, the focus shifted to more complex high-tech devices with the anticipation that high-tech could almost seem like a ‘magical’ way to solve people’s communication problems. In 1991 David Beukelman, one of the leading experts in the field of AAC, discussed the magic and cost of communicative competence. He wrote:

\textit{For someone who is unable to speak, to ‘talk’ and someone who is unable to ‘write’ to place words on paper (or computer screen) is [not only] improbable, it is magical.}\textsuperscript{27 p.2}
Initially much AAC research examined AAC users and their aids in isolation and often focused on operational competence, e.g. evaluation of key-stroke savings and sentence length. The advances in computer technology, voice synthesisers and ways of expressing language through the use of picture symbol representation resulted in a rapid growth in the provision of AAC systems for people with little or no useful speech and provided the potential for improved communication to many people with speech disabilities.

However, people with communication difficulties may also have problems with motor control, literacy, language and cognition (e.g. people with cerebral palsy, stroke, learning disabilities) and the ability to operate high-tech devices added an additional challenge. Intervention decisions had to consider the cognitive, language and motor capabilities of the user and most people used a variety of AAC methods depending on the communication task, the time of day and their fatigue level.

Evidence on the effectiveness of communication aids

Despite an increase in the number of AAC systems being provided, their functional use in everyday situations is still limited and many users resort to their previous communication methods because of the difficulties of using their devices outwith the instructional setting. I therefore undertook a search of the research base to investigate aided AAC systems for which there is evidence of effectiveness.

Search methods

The literature search was last updated during January and February 2009 to identify all peer-reviewed journal articles which report on the effectiveness of aided AAC systems. Databases used were MEDLINE, CINHAL, BNI, EMBASE, PsycINFO, AMED, ERIC and Cochrane Library. Manual searches of articles in the AAC (Augmentative and Alternative Communication) Journal were carried out and further papers in the reference sections of located articles, which were not defined during the online database searches, were reviewed for additional sources. The search terms (free text) included ‘communication (aid or device or system or tool or method)’ in combination with ‘communication (disability or disorder or impairment or difficulty)’. All possible arrangements of the terms were included. Furthermore, for all databases equivalent index terms (e.g. MeSH for MEDLINE) were used in the search.
Introduction

The inclusion criteria were: peer-reviewed journal articles; presentation of empirical data on effectiveness; low and high tech communication aids; all ages; all communication disabilities; English language; published between 1985 and the end of 2008 (i.e. a 23-year period since the publication of the first AAC Journal). Exclusion criteria were: papers referring only to literacy; training or teaching methods; unaided AAC (such as gesture or partner interpretation); prototype devices which are not commercially available; facilitated communication\(^1\); positioning for AAC; telecommunications. Articles concerned with signing by the deaf community were also excluded as this group was not seen to be using sign as AAC but as a primary mode of communication. Non-systematic reviews were not included but references were screened for possible relevant papers.

Search results
From the original search a total of 211 journal articles were retrieved once duplicates were removed. On the basis of abstracts and, where necessary, full text review, 198 were excluded because they did not meet the inclusion criteria and 13 full texts were included. Table 2 summarises the papers retrieved in relation to author, year of publication, types of AAC, study design, population and objectives. The table is arranged with reviews first followed by primary research on children/adolescents, adults with learning disabilities and finally adults with acquired disabilities. Papers retrieved are listed at the end of this chapter.

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Type of AAC</th>
<th>Study design</th>
<th>Population (n)</th>
<th>Objectives</th>
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<tr>
<td>Reviews</td>
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<tr>
<td>Lancioni (2007)</td>
<td>High tech (VOCAs) and low tech (PECS)</td>
<td>Overview of 37 studies</td>
<td>People with learning disabilities</td>
<td>To compare PECS with VOCAs for the performance of requests</td>
</tr>
<tr>
<td>Schlosser (2006)</td>
<td>High and low tech Various types</td>
<td>Aided and unaided Narrative review of 45 comparative studies</td>
<td>People with learning disabilities</td>
<td>To compare AAC systems and methodological adequacy of studies</td>
</tr>
<tr>
<td>Bailey (2006)</td>
<td>High tech (VOCAs) Various types</td>
<td>Qualitative study using interviews</td>
<td>Special education teachers (6) Speech and Language Therapist (1)</td>
<td>To provide a view of AAC team members' perceptions of AAC device use</td>
</tr>
</tbody>
</table>

1 Facilitated communication is a process by which a facilitator supports the hand or arm of a communicatively impaired individual while using a keyboard or other devices with the aim of helping the individual to develop pointing skills and to communicate.
<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Type of AAC</th>
<th>Study design</th>
<th>Population (n)</th>
<th>Objectives</th>
</tr>
</thead>
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<tr>
<td>Buzolich (1991)</td>
<td>High tech (VOCAs)</td>
<td>Comparative case study</td>
<td>Children with cerebral palsy (3)</td>
<td>To explore the acquisition of the commenting function</td>
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<td>LightTalker™</td>
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<td>TouchTalker™</td>
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<td>AudTalk™</td>
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<tr>
<td>Clarke (2001)</td>
<td>High and low tech</td>
<td>Qualitative study using</td>
<td>Adolescents (6)</td>
<td>To obtain the views of young people about their AAC systems</td>
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<tr>
<td></td>
<td>Various types</td>
<td>interviews and focus groups</td>
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<tr>
<td>McDonald (2008)</td>
<td>High tech (VOCAs)</td>
<td>Follow-up study</td>
<td>Referrers of children with physical and learning disabilities (60)</td>
<td>To evaluate communication-aid targets</td>
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<tr>
<td></td>
<td>Various types</td>
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<tr>
<td>Sigafuos (2005)</td>
<td>High tech (VOCAs), low tech</td>
<td>Case studies</td>
<td>Adolescents with learning disabilities (2)</td>
<td>To assess students’ preference for type of communication aid</td>
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<td>(communication board)</td>
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<td>Thunberg (2007)</td>
<td>High tech (VOCAs)</td>
<td>Mixed methods case studies</td>
<td>Children with autism (4)</td>
<td>To investigate students’ communication when given a VOCA</td>
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<tr>
<td></td>
<td>Touch-screen computer</td>
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<td>TechTalk™</td>
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<td>Adults with learning disabilities</td>
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<tr>
<td>Lund (2006)</td>
<td>High and low tech</td>
<td>Longitudinal case studies</td>
<td>Adults with cerebral palsy (7)</td>
<td>To evaluate long term AAC outcomes</td>
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<td>Various types</td>
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<td>Stoner (2006)</td>
<td>Low tech (PECS)</td>
<td>Modified ABAB single-subject design</td>
<td>Adults with learning disabilities (5)</td>
<td>To investigate the effectiveness of PECS</td>
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<td>Adults with acquired disabilities</td>
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<td>Fager (2006)</td>
<td>High and low tech</td>
<td>Postal questionnaires</td>
<td>Speech and Language Therapist (3) views of adults with traumatic brain injury</td>
<td>To document AAC acceptance and use patterns</td>
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<td>Various types</td>
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<td>Happ (2004)</td>
<td>High tech (VOCAs)</td>
<td>Participant observation,</td>
<td>Adults in ICU (11)</td>
<td>To examine the feasibility of AAC</td>
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<tr>
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<td>MessageMate™</td>
<td>semi-structured interviews, questionnaires, and clinical record review</td>
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<td>Dynamyte™</td>
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</tr>
<tr>
<td>Ho (2005)</td>
<td>Low tech (Pictographic topic books and remnant books)</td>
<td>Comparative case studies</td>
<td>Adults with global aphasia (2)</td>
<td>To compare remnant and symbol communication books</td>
</tr>
</tbody>
</table>

VOCA = Voice Output Communication Aid; PECS = Picture Exchange Communication System; ICU = Intensive Care Unit

No randomised control trials were found, two papers were literature reviews and 11 were studies with empirical data. Although I have tried to define the design in the above table, it was not always clear what study design was used. Eight studies were either single case studies or studies with fewer than 10 participants. One study included between 10 and 20 participants and only two studies (apart from the reviews) described more than 20 participants.
Introduction

Reviews
Schlosser et al. carried out a narrative review of 45 studies of unaided and aided AAC interventions for people with learning difficulties. The majority of the studies focused on signing, treatment strategies or access methods and were therefore not relevant to this thesis. One section of their results referred to three papers which compared communication boards with VOCAs but the papers were described as having inconclusive findings as there were ‘methodological shortcomings’. These included the presence of several variables which obscured the results and inconclusive data as they were only collected post-acquisition of the VOCAs.\(^{45,p17}\)

Lancioni et al. carried out a systematic review of 37 studies between 1992 and 2006 to examine the similarities and differences between Picture Exchange Communication System (PECS) and VOCAs for students with learning difficulties and pre-linguistic behaviour. Effectiveness was shown by the ability of the students to make requests. The authors concluded that PECS and VOCAs are similarly effective systems for introducing students with severe learning difficulties to make requests. They urged caution as most of the papers reviewed involved a small number of students and did not provide any details about the individual performance, procedural conditions applied and intervention times.\(^{18}\)

Children/adolescents with learning difficulties and/or cerebral palsy (six studies)
Bailey et al. examined the perceptions of an AAC team (six teachers and one Speech and Language Therapist) on a range of devices used by students in junior-high and high-school settings. There was no clear definition of effectiveness but the results described common themes, such as ownership and independence in care of the device and the ability to generalise its use outside the classroom which the authors suggested indicated effective use. Barriers to effective use were described including time constraints, limitations of AAC device such as portability and durability, training needs, and conflicting views between professionals and parents.\(^{46}\)

Buzolich et al. explored the acquisition of the commenting function (e.g. this is fun; this is boring; I like this; I don't like this) among three children using high-tech aids in a group situation in class. The assumption of effectiveness was that the students would use a commenting function appropriately in an interactive context. They reported that all three children acquired the commenting function which enabled them to have a longer conversation.\(^{47}\)
Clarke et al. obtained views of six young adults and 17 children about their communication aids (18 high-tech and five low-tech). Although they had no specific definition of effectiveness they hypothesised that identifying the views of young people with communication difficulties forms an essential element of the process of outcome measurement in a general sense. They found that most children felt their AAC was useful to them. Some indicated positive attitudes when they felt that their AAC system improved their self image (other people thinking their AAC was ‘cool’) or their interaction (able to tell jokes). However, further analysis of opinions revealed that negative attitudes towards AAC systems were primarily associated with operational issues (technical skills required to operate an AAC system) and that others felt that using an AAC device presented negative self imagery and did not perceive a benefit in interaction.\textsuperscript{48}

McDonald et al. evaluated operational, linguistic, social and academic targets of 60 children, between the ages of three and 18 years who used VOCAs. Effectiveness was assumed to be attainment of targets after six months’ use. They found that 63% of the targets set were not achieved and that ‘despite the potential of VOCAs, they were often subject to non-compliance, non-use and abandonment’.\textsuperscript{39} p 227 The reasons given included inappropriate provision of equipment, the demands of the equipment and high support needs.

Sigafoos et al. examined self-determination in AAC by assessing how two adolescents with severe learning disabilities indicated their preference for either a high-tech or low-tech communication aid. No definition of effectiveness was provided but the authors measured how often the students chose a VOCA compared to a communication board to request a snack. They concluded that both students preferred the VOCA over the low-tech aid. They suggested that the choice-making approach described in this study may be one way to allow students with learning disabilities to be involved in deciding which AAC system should be provided.\textsuperscript{49}

Thunberg et al. investigated the effectiveness of communication of four children with autistic spectrum disorder in three different activities at home when given a VOCA. The authors coded communication behaviours which included engagement in activity, turn taking, communicative form, function and effectiveness. Effectiveness was defined as ‘when the partner’s response praised, repeated, commented on, expanded or answered the participant’s communication’. They found that communication effectiveness increased in all three activities with the introduction of a VOCA and that the rate of effectiveness increased most during ‘sharing experiences of the pre-school day’ compared to ‘story reading’ and
‘mealtime’. They concluded that in this study, VOCAs were most effective when used to fulfil the main goals and roles of an activity.50

**Adults with learning difficulties and/or cerebral palsy (two studies)**

Lund et al. evaluated long-term outcomes of seven young adults with cerebral palsy who had used AAC for at least 15 years. They used a range of standardised speech and language measures. They did not define communication effectiveness specifically but examined qualitative aspects of functional communication in terms of adequacy (understanding and getting point across), appropriateness (relevance), promptness (without delay/efficiency) and communication sharing (who carries burden). There were individual variations across all measures and no consistent outcomes across the group. They concluded that interaction is a stronger predictor than language skills for participation outcomes related to everyday life.51

Stoner et al. investigated the effectiveness of PECS with five non-speaking adults with learning disabilities. Effectiveness was not specifically defined but a participant’s response was scored ‘correct’ if s/he independently reached for a picture, picked the picture up, directed the picture toward the communication partner and released the picture into the partner’s hand. The authors concluded that PECS was a viable method for three out of five participants to express needs and wants.19

**Adults with acquired communication difficulties (three studies)**

Fager et al. investigated the perceptions of three Speech and Language Therapists about AAC use (17 high tech and 8 low tech) by 25 adults with traumatic brain injury (TBI). Their criteria for effectiveness were acceptance, implementation and continued use of the device. They found that there was general acceptance of AAC but the type of device used varied with the changing needs of the participants. Text-based letter-by-letter formulation on both high- and low-tech systems was used most and abandonment was due mainly to loss of facilitator support.52

Happ et al. investigated the feasibility of VOCAs for 11 temporarily non-speaking patients in a medical intensive care unit. They did not specifically define effectiveness but assessed changes in patient perception of communication difficulty after provision of a VOCA. They used the revised Ease of Communication Scale before and after introduction of the VOCA and found significantly less difficulty with communication after device use. In addition, five of the 11
participants demonstrated some independent use of the device. Participants initiated communication interactions more often when VOCAs were used than when communicating by non-vocal methods. They identified barriers to VOCA use such as poor device positioning, deterioration in patient condition, staff time constraints, staff unfamiliarity with device and complex message screens.\textsuperscript{13} Ho et al. examined the effect of remnant and pictographic books on the communication interaction of two adults with global aphasia. They compared three conditions: no AAC, remnant books and symbol books. They measured changes in participants' behaviour and described effectiveness as 'the partner's subjective feeling of how well the partner and participant communicated during the conversation'. Results suggested that participants initiated more topics and had fewer un-repaired communication breakdowns in both of the aided conditions than when no symbols were available. They also concluded that participants engaged in more pointing behaviour with remnants than with pictographic symbols, and communication partners' subjective evaluations also favoured remnants over pictographs.\textsuperscript{53}

Discussion
The review highlights the difficulty of obtaining evidence of the effectiveness or otherwise of AAC systems. There was a lack of agreed definitions for key terms, in particular the term 'effectiveness'. Each paper was examined to identify how effectiveness was defined but only one paper contained a specific definition of 'effectiveness' and had empirical data to support its conclusions.\textsuperscript{50} This lack of a definition is partly because of the range of abilities of AAC users and the different purposes of AAC use with different groups of users in different contexts. The retrieved papers had varying objectives and only two focused on a specific type of AAC system, namely PECS.\textsuperscript{18,19} Only two papers obtained the views from AAC users themselves.\textsuperscript{13,48} A substantial barrier to the development of stronger conclusions regarding the effectiveness of AAC systems is the extent of methodological limitations of many studies, including small sample sizes, lack of information about participants and AAC systems, lack of validated outcome measures and lack of comparative designs. This all suggests a lack of good empirical evaluation of AAC systems in real-life situations, a point emphasised by a number of commentators.\textsuperscript{35,55-58,59}
Communication purpose of AAC

In 1988 Light presented a seminal model which suggested four main purposes of human communication. These purposes are:
1. expression of needs/wants;
2. information transfer;
3. social closeness; and
4. social etiquette.

Being able to communicate needs or wants helps regulate the behaviour of others (e.g. getting food) and being able to transfer information (e.g. giving directions) enables one to share knowledge. Social closeness, which occurs through chatting or casual conversation, results in personal relationships with others being established and maintained. Social etiquette such as politeness, greetings and farewells can also affect the maintenance of relationships between people. The interplay between these four purposes of communication is complex and all are required for effective communication and for maintaining good human relationships. Light’s model of four main purposes of communication is still the key model used in the field of AAC.

I further examined each of the papers retrieved through the review on effectiveness of AAC (above) to identify the communication purpose of the AAC described in the studies. Out of the 13 papers, nine discussed the purpose of the AAC systems.

Lancioni’s review examined VOCAs and PECS specifically for the purpose of making a request (needs and wants) and commented that there are no reliable methods specifically designed to determine how people with communication difficulties really feel. The communication purpose described in Buzolich’s study was the acquisition of basic comments (social closeness) by three children. They were given simple one-message AAC devices and were taught to make an assertive comment or evaluation. The communication purpose in Sigafoos’s study of two adults with learning disabilities was to request a snack (needs and wants). Thunberg et al. studied four children with autistic spectrum disorder using high-tech AAC while carrying out three different activities with their parents. The purpose of the first activity was that the child should have a meal (needs and wants), the second activity was to read some books together (social closeness) and the third activity was to share experiences of the pre-school day (information transfer). In Lund’s longitudinal study of seven young men with cerebral palsy who had used AAC devices for at least 15 years, most used their devices for
confirmation or denial (needs and wants) and, less so, to provide information. Stoner’s study of the effectiveness of PECS with five adults with learning disabilities noted that the purpose of their communication was to indicate needs and wants. Fager’s study of Speech and Language Therapists’ perceptions of AAC use by adults with traumatic brain injury listed the following communication functions: relaying stories, writing, information, phone, needs and conversation. They observed that the AAC systems were used primarily to express needs. Happ’s study, which examined the use of low- and high-tech AAC with 11 intubated patients in an intensive care unit, found that they were used primarily to indicate emotion (social closeness) and needs and wants. Ho studied the use of remnant books and symbol books with two adults with aphasia and suggested that remnant books promote social closeness rather than symbol books which were used only for needs and wants.

In conclusion, the main purposes of AAC systems which are described in the journals retrieved from the literature focus primarily on the provision of needs and wants and, less often, on information transfer. Social closeness was only mentioned in three studies.

The Talking Mats framework
Talking Mats is an interactive low-tech communication framework designed to help people with communication difficulties of different ages and abilities to express their views about specific topics or issues. It can be seen to address three of the four communication purposes suggested by Light, namely expressing needs and wants, information transfer and social closeness. It comprises a low-priced textured mat and picture symbols which have Velcro™ attached to the back so that they can be placed on the Mat and moved around by the person with communication difficulties to reflect their views. Any symbol system can be used but throughout this thesis the symbols referred to are Picture Communication Symbols (PCS™).

Three sets of picture symbols are used – topics, options and visual scale:
1. **topic** – whatever participants want to talk about in relation to a specific issue. For example, activities, environment, relationships, self care, etc.
2. **options** – relating specifically to each topic. For example, listening to music, playing card games, visiting friends, etc.

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2 The Picture Communication Symbols (PCS) are ©1981–2008 Mayer-Johnson Co. and are used with permission – Mayer-Johnson Co., PO Box 1579, Solana Beach, CA 92075, USA
3. **visual scale** – in order to allow participants to indicate their general feelings about each topic and option. For example, whether they are happy, unsure, unhappy.

Once the **topic** is chosen, e.g. what do you feel about where you go during the day?, the participant is given the **options** one at a time and asked an open question, e.g. What do you feel about ...? They can then place the option symbol under the appropriate position on the **visual scale**. Participants are given as much time as they need to respond and blank squares are provided to add any additional options they want. Participants can shift the symbols until they are sure that the Mat represents their views. Once they have confirmed that they are happy with the completed Mat a digital photograph is taken to provide a record of their views. One topic is chosen per Mat to be completed and 'submats' can be used to explore options in more detail if wished.

The examples below help to explain the way the Talking Mats framework works. In the example in Figure 2 a young man with cerebral palsy was asked what he felt about where he spent his weekdays. He indicated that he enjoyed going to college, was not sure about attending the local day centre and did not want to stay at home during the day.

**Figure 2. Example of a Talking Mat on day placement**
Figure 3 illustrates the use of the Talking Mats framework by a man who has severe aphasia as a result of a stroke. He used the Talking Mats framework to express his views about his health, (the topic represented by a larger symbol with a red border). He used a five-point visual scale (yellow symbols) representing a range from very happy, content, unsure, anxious to very unhappy. He chose eight options (blue border). He expressed the following: he was content with his mood, his hand control and his eating; he was unsure about his general health and his medication; and he was anxious about pain control and mobility but most unhappy with his difficulty with communication. An additional option was added as he indicated with gesture that he had had a heart problem in the past that he wanted to note but was not unduly concerned about.

Figure 3. Example of a Talking Mat on health

The Talking Mats framework can help people arrive at a decision about their views by providing a structure in which information is presented in small chunks supported by symbols. It gives people time and space to think about information, work out what it means and say what they feel in relation to other options in a visual way that can be easily recorded by taking a digital photograph of the completed Mat.

The Talking Mats framework is different from other AAC methods in several aspects. Its purpose is to allow people, irrespective of age or ability, to understand, consider and express their views or opinions. It is not designed to be used for everyday communication but rather as a framework for specific situations and/or topics. It is not intended to replace other communication methods but to
supplement them. The Talking Mats framework is deliberately 'low tech', using inexpensive components and requiring no specialist equipment. The literature search found no other AAC systems which were designed with the same specific purpose as the Talking Mats framework. The only other systems which have any features similar to the Talking Mats framework are the Picture Exchange Communication System (PECS™)\(^62\), 'I'll go first'\(^63\) and 'Triangle'\(^64\). Like the Talking Mats framework, they use symbols which are not on a fixed display. However, PECS's purpose is not to allow people to express their views but is specifically designed to teach people with severe cognitive impairments to exchange symbols for objects in order to initiate or respond to a request\(^18,19,62,65,66\). 'I'll go first' and 'Triangle' have been developed specifically for use with children. 'I'll go first' is designed to support and promote disabled children's participation in reviews. 'Triangle' gives information and guidance about communicating and consulting with disabled children and young people and has developed image-based vocabulary to help children communicate about a range of issues. There are no empirical studies or journal articles on either 'I'll go First' or 'Triangle'.

Development of thesis
The work described in this thesis was developed as a response to concern that, despite its early promise, AAC was not always meeting the needs of people with communication difficulties. Funding was obtained to carry out a series of research projects, starting in 1991 with a demographic survey of AAC systems used by people with cerebral palsy in Scotland\(^67\). The results showed that there had been a significant increase in the use of AAC systems in the previous five years but that many of the high-tech AAC devices were only used in formal situations such as therapy or teaching. In 1992 funding was obtained to investigate the obstacles to effective use of AAC systems from the perspectives of 93 AAC users and their communication partners\(^30\). The study suggested that, despite the increase in technology, for many people the potential offered by AAC systems was not fulfilled, which led to frustration and disillusionment not only for AAC users but also for those who worked with and cared for them. The study also showed that whilst the perspectives of the AAC users and their communication partners sometimes converged, there were important instances when their views differed. The importance of gathering the perspectives of all those involved to inform the provision of AAC services was highlighted. In 1996 I received funding to examine the interaction between adult AAC users with cerebral palsy and their peers in a...
residential environment. In order to obtain the views of the participants on the findings from the study data and to check that the researchers' interpretations were credible to them, I devised the Talking Mats framework as an interview tool. This was designed using picture symbols to overcome the difficulty that AAC users had (even those who were competent with their AAC systems) in discussing issues because a) they did not have the relevant vocabulary in their communication aids and b) they had seldom been asked to consider and comment on issues before.68 Following this I carried out a small study involving five adults with motor neurone disease using the Talking Mats framework to explore their views on their quality of life.69 The results of both the 1996 and 1999 studies indicated that the Talking Mats framework was a potentially useful tool and I then investigated its use in other situations in the series of studies presented in this thesis. Full lists of funded research projects and publications are in Appendices 1 and 2.

**Thesis aims**
This thesis reports on the evolution and development of the Talking Mats framework as a communication method with people with a range of communication difficulties. It does so by presenting what amounts to an action research programme comprising six research studies carried out between 1999 and 2008 which address the following questions:

1. How do adults with communication difficulties use AAC, and what is important to them?
2. How feasible is the Talking Mats framework in enabling adults with communication difficulties to express their views?
3. How effective is the Talking Mats framework in enabling adults with communication difficulties to express their views?

Measurement of the effectiveness of interventions to improve communication often relies on analysing features such as word intelligibility, types of syntax or number of words produced. However, as we have seen according to Light, human communication is complex and personal, and depends fundamentally on interaction. Although linguistic counts are not sufficient, purely recounting anecdotes is not rigorous enough to prove communication effectiveness either. I have therefore used both qualitative and quantitative methods in order to attempt to examine the communication effectiveness of the Talking Mats framework.
Question 1 – *How do adults with communication difficulties use AAC, and what is important to them?*
This is addressed in Chapters 2 and 3. These chapters present findings from a three-year qualitative study which examined the views of 15 adults with amyotrophic lateral sclerosis/motor neurone disease and their close communication partners. Motor neurone disease is an acquired progressive illness which can affect the motor skills required for speech but which leaves language skills and cognition mainly intact. Chapter 2 discusses the purpose of communication for the participants in this study and describes the range of communication strategies and techniques used by dyads where one member has motor neurone disease. Chapter 3 describes the perceptions of these dyads of using AAC, both high and low tech. Both theoretical and practical issues relating to AAC are discussed.

Question 2 – *How feasible is the Talking Mats framework in enabling adults with communication difficulties to express their views?*
This is addressed in Chapters 4 and 5. These chapters describe two projects, incorporating both qualitative and quantitative data, which examined the feasibility of the Talking Mats framework with two different adult client groups. Chapter 4 outlines a study involving 12 adults with aphasia after stroke whose communication difficulties included acquired speech, language and in some cases cognitive communication difficulties. The study examined the feasibility of using the Talking Mats framework to allow them to express their views on their quality of life. Chapter 5 focuses on 12 young adults with learning disabilities who had a mixture of congenital communication difficulties affecting speech, language and cognition. They used the Talking Mats framework, at the time of transition from school, to consider and be actively included in discussion about the choices available to them for the future. The Talking Mats framework was modified as a result of the research presented in these papers.

Question 3 – *How effective is the Talking Mats framework in enabling adults with communication difficulties to express their views?*
This is examined in Chapters 6 and 7 which present a further two studies which use both qualitative and quantitative methods to examine the effectiveness of the Talking Mats framework. Chapter 6 presents the findings from a study which involved 48 adults with different degrees of learning disabilities to discuss life planning issues. The study was designed to compare the effectiveness of the
Chapter 7 examines the effectiveness of the Talking Mats framework with people with dementia. It involved 31 people at different stages of dementia whose communication difficulties were acquired and progressive, and included speech, language, cognition, memory and behavioural difficulties. The participants were each interviewed about four aspects of their well-being, comparing the Talking Mats framework with usual communication methods. Finally, in Chapter 8 the main findings from the studies are summarised, strengths and limitations are discussed, and implications for future research and practice are considered.
Introduction

Studies retrieved from literature search:


References

1. Murphy, J. & Boa, S. 2007, Talking Mats and Aphasia, University of Stirling.
Chapter 1


63. Kirkbride, L. "I'll go first", in International Special Education Congress 2000.

64. NSPCC National Training Centre 2001, Two Way Street: Training video and handbook about communicating with disabled children and young people, NSPCC National Training Centre, Leicester.


69. Murphy, J. 1999, "Enabling People with Motor Neurone Disease to Discuss their Quality of Life", Communication Matters, vol. 13, no. 2, pp. 2-6.


Communication strategies of people with ALS/MND and their partners

Based on:
Murphy J
Communication strategies of people with ALS and their partners.

Abstract

There are wider issues relating to the communication difficulties experienced by people with Amyotrophic Lateral Sclerosis (ALS\(^1\)) than simply the physical problems caused by diminished oral control. Existing literature on ALS/MND rarely considers communication to be a joint interaction which depends on the strategies adopted by both communication partners nor does it present communication in real-life settings. This paper presents some of the findings from a three-year qualitative research project which investigated the communication of 15 people with ALS/MND and their partners in their own homes. The participants were visited on seven occasions at six-weekly intervals. The paper discusses the purpose of human communication and, through examination of conversations in people’s own homes, has identified a range of strategies and techniques that families with ALS/MND employ. For some people with ALS/MND, although speech may deteriorate, they are still able to communicate closely and in a way that is more focused on topics that are particularly important to them. The findings from this study will be of interest to those who work with people with ALS/MND.

\(^1\) ALS (Amyotrophic Lateral Sclerosis) is the term used in the USA and MND (motor neurone disease) is the generic term used in Europe. Throughout this paper the combined term ALS/MND is used.
Introduction

One of the most distressing aspects of ALS/MND is the loss of speech. This has at least two essential features. First, there is a gradual deterioration of speech ability. Second, there is a need for both communication partners to adapt to this changing situation by acquiring new communication strategies in order to adapt to the growing speech disability of the person with ALS/MND. The person with ALS/MND may move from communication via speech which becomes gradually less intelligible as the disease progresses to communication using an augmentative communication device or eventually via another person. The preservation of effective communication is very important in allowing people to remain at home and to maintain a good quality of life, and for both psychosocial and physical adaptation to changes that occur as ALS/MND progresses. Early recognition of communication difficulties allows the person with ALS/MND to make decisions before the disease becomes debilitating or life threatening. Most studies of communication and ALS/MND focus on the deficit model and do not suggest how the person with ALS/MND and their communication partner may compensate for their difficulties. Existing literature on ALS/MND rarely recognises that communication depends on the strategies adopted by both communication partners, nor does it consider communication in real-life situations such as a person's own home. Speech is one of many methods of communicating; many other strategies may be employed, particularly when there is a problem in conveying and/or understanding the message.

Four main purposes of human communication have been defined: needs and wants (to regulate the behaviour of another as a means to fulfil needs and wants); information transfer (to share information); social closeness (to establish, maintain and/or develop personal relationships); and social etiquette (to conform to social conventions of politeness).

This paper presents some of the findings from a three-year study carried out with 15 families in Scotland with ALS/MND. The purpose of the project was to examine the communication of these people with ALS/MND and their closest communication partners in their own homes as the disease progressed.

Methods

Ethical approval was obtained from Forth Valley Ethics of Research Committee, Tayside Committee on Medical Research Ethics, Lothian Research Ethics Committee and the University of Stirling Psychology Department Ethics Committee. Data were collected through video recordings, narratives and field
notes. Fifteen families with ALS/MND were visited on seven occasions at home at six-weekly intervals. At each visit, with the exception of the first which was to explain the project and obtain informed consent, a video recording was made of the person with ALS/MND chatting first with their chosen partner and then with the researcher. Occasionally, at the request of the participants, all three people were present at the same time. Data were analysed using a coding grid which included the following main categories: communication modes, purpose of interaction and topics of conversation. It also allowed for the recording of strategies which helped and hindered interaction as well as the perspectives of the participants. To check for reliability, an independent Speech and Language Therapist examined the video data and coded them separately. Following this, the author and the Speech and Language Therapist discussed the findings to reach a consensus. Cognitive mapping was then used to describe interrelations between different issues.

The severity of ALS/MND across the functional modalities of speech, mobility and ability to use upper limbs for activities of daily living was noted using the classification of Riviere et al. which ranged from State 1 (mild); State 2 (moderate), State 3 (severe), to State 4 (terminal).

To obtain a measure of the intelligibility of the participant’s speech at each visit, a one-minute sample was taken from each video recording made. These were then scored by the researcher and another Speech and Language Therapist ranging from Stage 1 (no detectable speech disorder); Stage 2 (obvious speech disorder with intelligible speech); Stage 3 (reduction in speech intelligibility); Stage 4 (natural speech supplemented with augmentative communication) and Stage 5 (no useful speech).

Results

a) Demographic information

Fifteen people with ALS/MND, eight men and seven women all living in their own homes, were involved in this study. Because of the nature of the illness, the researcher was not able to visit all 15 families on all seven visits, but in total 81 visits were made. The following table shows the participants’ details at the first and final visits.

Each participant was asked to choose someone who knew them well to be their communication partner in the study. Ten chose their spouse, two chose a close relative, one chose a friend and two indicated there was no one available to be involved. Thirteen of the 15 participants had predominantly bulbar involvement.
Table 1. Participants’ details at first and final visit

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Partner</th>
<th>Type of ALS/MND</th>
<th>Severity of ALS/MND first</th>
<th>Stage of Dysarthria first</th>
<th>Main Communication Method(s) first</th>
<th>Main Communication Method(s) final</th>
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<td>4</td>
<td>3</td>
<td>Speech and gesture</td>
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<td>Speech and low tech (paper/pen)</td>
</tr>
<tr>
<td>13</td>
<td>59</td>
<td>F</td>
<td>Husband</td>
<td>Bulbar</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>Speech and low tech (alphabet board)</td>
</tr>
<tr>
<td>14</td>
<td>77</td>
<td>F</td>
<td>-</td>
<td>Bulbar</td>
<td>3</td>
<td>-</td>
<td>5</td>
<td>Deceased</td>
</tr>
<tr>
<td>15</td>
<td>65</td>
<td>M</td>
<td>Partner</td>
<td>Bulbar</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>Speech and gesture</td>
</tr>
</tbody>
</table>
Thirteen of the 15 participants had some difficulty with speech at the first visit. For the majority of people there was some deterioration in their speech although the speed and severity of change varied from person to person. Two people died before the second video-recorded visit was made. Figure 1 shows additional symptoms related to speech which were reported by participants and/or observed by the researcher by the final visit.

Figure 1. Symptoms associated with speech at final visit

Fourteen of the 15 participants had some degree of dysarthria. It should be noted that dysarthria affects more than the ability to produce consonants and vowels (articulation). It includes difficulties with respiration, phonation, resonance, articulation and prosody. Four participants had cognitive problems, four complained of problems caused by tenacious saliva (usually described as thick mucous at the back of the throat) and two described excessive watery saliva (usually evident as drooling due to poor control of lips and swallowing). Four participants described some problems with eating and drinking, and seven experienced emotional lability (discussed later).

b) Purpose of communication
In this study it appeared that the most important purpose of communication between participants was not to indicate needs and wants or to transfer
information but rather was for the development and maintenance of social
closeness. Numerous extracts of conversation between couples, even when
largely unintelligible to anyone else, contained many aspects of ‘intimate talking’
such as gossip, personal thoughts, agreement, disagreement, continuers,
confirmation or humour. One extract from the video data showed a couple chatting
when their dog wandered in and made a series of strange noises, which caused
them both to smile at each other and share the joke (non verbally). From observing
the video it was clear that the intimate exchange about the dog was the most
meaningful part of this interaction.

Discussing shared topics is an important factor in developing social closeness.
The topics of conversation were very often shared topics whereby the
communication partners were talking about an activity that they were working on
together. For example, one couple was looking at a mail order catalogue to
discuss the kind of headboard they were going to buy for their bed. They both
already knew the kind of thing they wanted, they both knew more or less what
each other’s views were and they were working together at agreeing on the one
they both wanted.

Another factor relating to the purpose of communication of the people in this study
was that they were rarely talking to strangers and their communication was
primarily with people who were familiar to them. This was often by choice. One
woman described her interaction with neighbours:

Participant: When I am out and people are talking I try not to get involved
cos it’s so tiring – it’s different at home.

Husband: She likes neighbours who just wave and say ‘Hi’ – not long
tiring conversations.

c) Communication strategies

All the participants in this study, both those with ALS/MND and their partners, were
keen to discuss their own strategies and share them with others and many people
said that they felt isolated and unaware of what other people with ALS/MND did to
overcome their difficulties.

Wife of man with ALS/MND: All these wee suggestions help. We don’t
know anybody else who has motor neurone disease.

The following figure summarises the strategies described by the participants in this
study.
Figure 2. Communication strategies used

- Low-tech AAC
  - alphabet chart
  - communication chart
  - pen and paper

- non-verbal strategies
  - positioning
  - gesture
  - facial expression
  - eye contact
i) Speaking strategies:
For those people whose difficulty with speech was in the early stages, simply repeating what had been said or the partner asking them to repeat was usually enough to improve intelligibility. Some people used spelling:

*I speak first – if I’m not understood I stop and think ‘what’s the word that’s causing the problem’ then I spell it if it’s a long word, syllable by syllable.*

For some people emphasising or stressing key words was a help to their partner.

*I try to get her to not repeat the whole sentence – but just repeat one word – just key words – that way you can get the rest of the sentence.*

Two people found that breathing more deeply helped their speech and for some people having a partner who reminded them to relax and to take deep breaths was a helpful cue.

*She has breathing exercises given by the physio – she does it before she speaks.*

In order to conserve energy it was important for some people to pace themselves to take rests. For example, if they knew they were going to be doing a lot of talking or meeting someone later in the day they would take rests earlier on to preserve their energy. One relative said,

*If we’ve been out I wait till we get back into the house and C has calmed down, I make us a cup of tea and then we can talk more easily.*

ii) Conversation strategies
Several people used their partner to interpret for them but emphasised that the partner only interprets if asked or if given permission by the person with ALS/MND. Several partners described using topic cues and making use of the context as a useful strategy. Some communication partners made sure that they confirmed that they were understanding correctly as the interaction progressed rather than waiting until the end and finding that they had gone off on the wrong conversational track.

Where humour was used in order to overcome misunderstandings it was noticeable that couples not only found this provided a satisfying conclusion to a misunderstanding but contributed to the development of social closeness.

Several people talked about how, once they had got over the initial blow of having the diagnosis of ALS/MND, they had developed a much more positive attitude.
It’s a very frustrating illness this – full of ups and downs but I’m determined that my fighting spirit will come back.

iii) Non-verbal strategies
The use of gesture, facial expression and eye contact made a considerable difference in helping with intelligibility of communication and it was particularly important that partners sat in a position where they could make eye contact and notice non-verbal signs.

iv) AAC (Augmentative and Alternative Communication)
In this study 10 participants had been offered high-tech AAC devices but none used a device functionally during the study. Six people were using low-tech AAC methods that included alphabet boards, communication charts, and paper and pen.
Where couples had not developed strategies to compensate for communication difficulties there was anger and frustration. This was particularly noticeable with one couple where there was increased tension with each visit as the spouse became more and more upset at her husband’s unwillingness to compensate for his communication difficulties.

d) Emotional lability
For seven people in this study emotional lability, where they either laughed or cried inappropriately, was a significant problem. One person explained that she cried over apparently trivial events and this distressed her. The researcher observed one participant who giggled inappropriately at all visits when his speech was not understood but at the same time talked about his extreme frustration with his speech – ‘it’s hellish’ – and his feelings of hopelessness. His wife described her annoyance with her husband:
Wife: There’s some nights I’m just beat and I can’t get my head round it (what he’s saying) at all and then he starts laughing and that makes it worse.
The strategies that participants described to overcome this included trying to think positively or change the subject when they felt inappropriate emotion. For one woman it was helpful if her partner simply nudged her or changed the subject to help her get over this feeling. One participant had been prescribed medication by her doctor which had made a noticeable difference:
I am now able to meet my friends and tell them about my illness without crying.

e) Speech and language therapy input
Although 14 of the 15 participants had had some contact with a Speech and Language Therapist only one reported receiving any input directly on their speech. Only four people in this study described problems with eating and/or drinking whereas 14 reported some problems with their speech. However, only one participant mentioned receiving speech and language therapy input on speech. He had been given specific work both to improve his articulation and also to help him think about strategies to alter the way in which he communicated.

Discussion
Although the study involved only 15 people with ALS/MND and their communication partners, the findings have relevance for other people with ALS/MND as the collection of information over a series of visits resulted in a large amount of data. Validity was increased as the video data were analysed by both an independent Speech and Language Therapist and the researcher. The study focused on the way in which everyday conversation actually works between two people. Communication is a collaborative effort and therapy needs to be provided with that in mind, not concentrating solely on the speech of the person with ALS/MND. Any therapy should always consider the person's communication partner or partners.
The main purpose of communication between the participants in this study was for the maintenance of social closeness. It was rare for participants to make requests related to needs or wants. This was mainly because the communication partners in this study were usually aware of needs like drinks and daily care tasks because they knew each other so well. It was also because, for many participants, the effort of communication was so great that they kept verbal communication to the essentials and employed strategies that would reduce fatigue. For the same reasons information transfer and social etiquette were less in evidence than the enjoyment of social closeness.
There were many examples of misunderstandings that were caused primarily by dysarthria. However, the enduring impression with regard to communication in the 15 families in this study was one of closeness, cooperation and understanding. There were very few real communication breakdowns as partners worked together to resolve any misunderstandings. The cooperation and symmetry of
Communication strategies of people with ALS/MND

communication was striking. All the participants with ALS/MND worked with their communication partner and saw communication as a joint undertaking with many relying on their communication partner to interpret.

Although it is the duty of Speech and Language Therapists to provide advice and information to people with communication difficulties it is important that we do not assume that there are only professional answers. People with ALS/MND and their families and friends develop their own strategies and their own solutions to overcome their communication difficulties, and it is very important that those working with people with ALS/MND observe and learn from these strategies and solutions and share them with others. However, it is an important proviso that not all strategies will work for all people. Each person is the expert on their own communication and each family will have their own solutions. Although most of the strategies described in this study may seem fairly obvious, not everybody used them but those who did, found communication much more satisfying, effective and successful.

The difficulty experienced by emotional lability was raised by a number of participants and obviously caused significant distress and embarrassment. It is an area not always addressed by Speech and Language Therapists but one that has a significant impact on communication and warrants further investigation.

Speech and language therapy can make a significant difference to some people with ALS/MND and that there may be critical points when they and their communication partners may benefit from speech and language therapy intervention. These points occur typically when there is a change in the person’s communication situation. However, speech and language therapy is not always targeting the right spots. For some people with ALS, speech and language therapy focuses not on communication but on swallowing difficulties. Despite the amount of useful material available on dysarthria and communication strategies it is dismaying to hear people comment that ‘the Speech and Language Therapist said there was nothing she could do except monitor my swallow’. There should be concern amongst Speech and Language Therapists that helping people to either maintain or improve their communication ability is being overlooked because of the emphasis on dysphagia. This is also reported in relation to dysphasia therapy. In a study carried out across 11 health boards in the UK between 1985 and 1995 the dramatic increase in referrals to speech and language therapy for dysphagia was described and it was noted that the amount of treatment and treatment duration for patients with dysphasia had reduced. This concern, that therapy to help speech...
and language disorders is being overlooked, appears to apply equally, if not more, to people with ALS/MND.

The assumption is invariably made that the communication of people with ALS/MND deteriorates as the illness progresses but the findings of this study show that this does not necessarily have to be the case. Indeed for a number of people, because of the cooperative nature of interaction and because many people with ALS/MND work together with their partners more and more as the disease progresses, they were still able to communicate meaningfully and closely and in a way that focused on topics that were particularly important to them. Finally, the benefits of providing direct input on communication strategies, such as speech, conversation, nonverbal and AAC methods should not be overlooked. It is important that Speech and Language Therapists provide help for people with ALS/MND both on swallowing and communication.
References

‘I prefer contact this close’: perceptions of AAC by people with ALS/MND and their communication partners

Based on:
Murphy J
I prefer contact this close: perceptions of AAC by people with MND and their communication partners.

Abstract
In this paper, findings are presented from a research project in which the communication of 15 people with motor neurone disease (MND) and their closest communication partners was investigated as the disease progressed. Data were collected through video recordings, narratives and field notes. The purpose of communication and the use of augmentative and alternative communication (AAC) according to the perceptions of people with ALS/MND and their partners were examined. For the people in this study, it appeared that AAC was less successful than anticipated. The participants gave a number of reasons for this, which were interpreted by the researcher. The reasons included the need for social closeness that may be prevented by using a device, the complexity of learning to use a high-technology device and inadequate training. Both theoretical and practical issues are raised for professionals who work with and provide services to families with ALS/MND.

1 Motor neurone disease (MND) is the generic term used in Europe. Amyotrophic Lateral Sclerosis (ALS) is the term used in the USA. Throughout this paper the combined term ALS/MND is used.
Chapter 3

Introduction

Motor neurone disease (MND) is the name given to a group of diseases affecting the motor neurones in the brain and spinal cord. Amyotrophic Lateral Sclerosis (ALS), Progressive Muscular Atrophy (PMA), Progressive Bulbar Palsy (PBP), Progressive Lateral Sclerosis (PLS) are all subtypes of MND. MND is the generic term used in Europe and ALS is used more frequently in the USA.\textsuperscript{1,2} ALS/MND is typified by degeneration of the motor neurones that leads to weakness and wasting of muscles. Initially, this degeneration occurs generally in the arms or legs, with some groups of muscles being affected more than others. Some people may develop weakness and wasting in the muscles supplying the face, throat and chest, causing problems with speech (dysarthria) and difficulty chewing and swallowing (dysphagia). ALS/MND does not affect touch, taste, sight, smell, hearing, or bladder, bowel or sexual function directly. In most cases, ALS/MND is steadily progressive with an average course of two to five years. The progression of the disease is variable, however, and a small number of people with ALS/MND have lived for 10 years or more.\textsuperscript{3,4}

The typical development of the disease is one of progressive muscular wasting and weakness leading to an inability to walk, carry out manual tasks, speak and, finally, to swallow and breathe independently. The rapidly progressive nature of the disease requires constant adaptation to increasing and changing levels of disability that, in turn, require increased levels of support. The symptoms experienced by people with ALS/MND are generally classified by site of involvement (i.e. upper versus lower motor neuron) and by whether spinal nerves (those supplying the arms and legs) or bulbar nerves (those supplying the muscles of speech and swallowing) are involved. Initially, either upper motor neuron or lower motor neuron involvement may predominate, but as the illness progresses, both usually become involved. As a result, initial symptoms may involve weakness in one or more extremities or weakness in the speech musculature.\textsuperscript{5,6}

Speech may be affected in various ways in people with ALS/MND. If breathing is affected, the voice may become weak and the person is able to produce only a few words on each breath. If the vocal folds are affected, the voice may sound low pitched and monotonous. Weakness of the soft palate may result in nasality, and weakness of the tongue and lips may affect articulation so that speech becomes slow and indistinct.\textsuperscript{7}

It was previously believed that ALS/MND did not usually give rise to impairment of cognition, but this has been disputed more recently.\textsuperscript{6,8-10} In a review of the literature it was noted that there was evidence that cognition does not necessarily
remain intact. A variety of cognitive and language difficulties experienced by some people with ALS/MND were described, including changes in emotional functioning and personality, and problems with concentration, insight and the ability to change topics. Because of the deterioration in physical abilities, and in some cases cognition, the person with ALS/MND may have to undergo changes such as having to give up work. These changes may dramatically alter their role at home and in the community.

People with ALS/MND and their families need to acquire new communication strategies in order to move with the growing communication disability of the person with ALS/MND. The person with ALS/MND may move from communicating via speech, which becomes gradually less intelligible as the disease progresses, to communication through the use of an AAC device or, eventually, via another person. It has been estimated that four out of five people with ALS/MND will require some sort of assistance with communication some time between receiving the diagnosis and their death.

There has been great enthusiasm for the potential benefits that technology can bring to people with little or no useful speech, and there is a considerable body of literature in which the communication success of people who use AAC devices has been demonstrated. In particular, it would be expected that people with ALS/MND would be ideal candidates for high-tech AAC devices, which include speech generating devices and computers. The potential to benefit from high-tech AAC can be argued from the basis that, for the majority of people, ALS/MND does not result in significant impairments in cognition, language and spelling, or ability to understand nuances of communication. Although it has been suggested that there may be subtle changes in the language of people with ALS/MND, this has not yet been thoroughly assessed clinically as such evaluations have been hampered by the rapid deterioration in motor speech systems as the disease progresses. There is a belief amongst Speech and Language Therapists that AAC can help preserve communication. In addition, the majority of people with ALS/MND remain motivated to communicate.

Technology is not without its problems, however. Robillard described the difficulties he found in using high-tech AAC from a personal perspective. In a study to evaluate AAC intervention for people with ALS/MND in a German rehabilitation clinic, Wendt stated that most of the problems experienced in AAC service delivery were the result of lack of knowledge and information about AAC. In understanding how people with ALS/MND use AAC systems, it may be helpful to consider the purpose of the communication between them and those with whom
they interact. Light defined four main purposes of human communication: (a) to obtain needs and wants, that is, to regulate the behaviour of another as a means to fulfil needs and wants; (b) for information transfer, that is, to share information; (c) for social closeness, that is, to establish, maintain and/or develop personal relationships; and (d) for purposes of social etiquette, that is, to conform to social conventions of politeness. An additional perspective was provided by Locke who argued that communication had two main functions: for propositional speech and intimate talking. He defined propositional speech as the transmission of impersonal facts: that is where partner A has information that is unknown to partner B and wishes to transmit that information to partner B. In contrast to this, he described the purpose of intimate talking as ‘the construction and enjoyment of relationships with others’. Locke further argued that communication is not a mathematical formula of phonemes, morphemes and syntax, but rather includes casual conversation such as gossip and is ‘naturally adorned by affective displays of the voice, the face and the body’. According to Locke, intimate talking reveals personal thoughts and feelings and elicits social reactions to those revelations. He argued that people need to know not just what others tell them, but also what is on their minds; therefore the main feature of intimate talking is this enjoyment and development of relationships with others. This description of intimate talking equates with Light’s notion of social closeness. Typically, in the past, studies of communication have focused mainly on the area of needs, wants and information transfer but, as Locke pointed out, the most important purpose of communication is to develop relationships with others.

This view of communication has implications for Speech and Language Therapists, who traditionally have worked with people in clinical settings, focusing on the propositional type of speaking described by Locke. There may need to be a shift in the way in which clinicians work because, as Locke pointed out, ‘expressive abilities do not develop in clinics’. The preservation of effective communication is very important in allowing people with ALS/MND to remain at home and maintain a good quality of life. As the disease progresses, they may wish to communicate more with their close family and friends than with others and they may be less able to meet with and communicate with others. Carroll-Thomas suggested that effective communication is crucial for both ‘psychosocial and physical adaptation to changes that occur as MND/ALS progresses’.

In 2000, funding was obtained from the Scottish Motor Neurone Disease Association and The Community Fund for a three-year research project at the University of Stirling. One of the aims of the project was to examine the
communication strategies of 15 people with ALS/MND and their communication partners in order to identify factors facilitating or hindering effective communication. A number of issues emerged from the data, including the purpose of communication, the topics of conversation, the strategies that helped and hindered communication, the changing role of communication partners, the communication environment, the use of AAC, and the perceptions of the participants about AAC. The last of these issues is the focus of this paper.

Methods
Qualitative case study methodology was used in the present project. This methodology involved using video recordings of dyads in an open conversation, semi-structured interviews to gain rich and detailed narrative information from a number of sources, and field notes.

Participants
Fifteen people with ALS/MND, eight men and seven women, participated. They were recruited randomly through the Scottish MND Register. All participants were living in their own homes. Each participant was asked to choose someone who knew them well to be his/her communication partner in the study. Ten participants chose a spouse, two chose a close relative, one chose a friend and two indicated there was no one available to be involved. In each of these two cases, the dyad for the video recording was between the participant and the researcher. Thirteen participants had primarily bulbar type MND. The severity of ALS/MND for each participant was determined using a scale developed by Riviere et al.22 This scale provides classification of the severity of ALS/MND across the functional modalities of speech, mobility and the ability to use upper limbs for activities of daily living. The four categories were State 1 (mild), State 2 (moderate), State 3 (severe) and State 4 (terminal). Table 1 shows that between the first and final visit, 13 participants deteriorated, one participant did not change in status and one participant improved.
To obtain a measure of the intelligibility of the participants’ speech at each visit, a one-minute sample was taken from each video recording made. These were scored by the researcher and another Speech and Language Therapist using stages described by Mathy et al.6 The classifications were:
Stage 1. No detectable speech disorder;
Stage 2. Obvious speech disorder with intelligible speech;
Stage 3. Reduction in speech intelligibility;
Stage 4. Natural speech supplemented with AAC; and
Stage 5. No useful speech.

Thirteen participants had some difficulty with speech at the first visit and several patterns of changes in speech emerged. The majority of participants experienced some deterioration in their speech, but the speed and severity of change varied across individuals. Two participants died before the second video-recorded visit was made. Four participants had no useful speech at the last visit and eight had speech that either was supplemented by some other method or had poor intelligibility. Therefore, by the end of the study, the majority of the participants had impaired speech that required some form of AAC. At the time of the final visit, 14 participants were still attempting to use their own speech. Ten participants had been provided with a high-tech device, but none of these was being used at either the first or the final visit. As indicated in Table 1, a number of participants were also using low-tech AAC, which included gesture, paper and pen, and an alphabet board. Further details about participants are provided in Table 1.

Data collection
The plan was to visit each family on seven occasions, including an introductory visit, in their own homes at approximately six-weekly intervals. Not everyone was well enough for all visits, however, and only nine people were visited on all seven occasions. Data were collected using video recordings, narratives and field notes. At each visit, with the exception of the first introductory one, a video recording was made of the person with ALS/MND chatting to his or her chosen partner. They were free to talk about any topic they wished. Video recordings were valuable in capturing the use and interplay of different modes of communication, including speech, non-verbal methods and AAC. Video recording was also the best way to note the different resources for interaction available to the person with ALS/MND and his/her communication partner and to consider the purpose of the interaction. Following the individual video recordings, the participants were invited to talk to the researcher about their perceptions of their communication, including the use of AAC methods. These were also video recorded, thereby providing first-hand and revealing perspectives about the communication of families with ALS/MND. Narratives have become an increasingly valued way of gathering insights and perspectives from people with illnesses and disabilities, and are acknowledged as a valid research method. The current paper is illustrated with comments from the participants and has been written, as much as possible, to reflect the experiences and views of the participants with ALS/MND and their partners.
Table 1. Participants' details at first and final visits

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Partner</th>
<th>Type of ALS/MND</th>
<th>Severity of ALS/MND</th>
<th>Stage of Dysarthria</th>
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According to Patton, ‘Field notes contain the descriptive information that will permit you to return to an observation later during analysis’.\textsuperscript{24} In the present study, field notes were written immediately after each visit. The field notes included any aspect of the visit that was relevant to the study, including the time of the visit, descriptions of the environment (i.e. each participant’s home), the activity in which the participants were engaged, and comments made by participants and their communication partners before and after the video recording.

\textit{Data analysis}

The video data were first analysed using a coding grid that allowed the author to note the following at each visit: (a) control of conversation, (b) communication modes, (c) topics of conversation, (d) strategies that helped communication, and (e) strategies that hindered communication. To check for reliability, an independent Speech and Language Therapist examined the video data and coded them separately. Following this, the author and the Speech and Language Therapist discussed the findings to reach a consensus.

A research assistant transcribed the video data and the transcriptions were examined using cognitive mapping.\textsuperscript{25} This process involved extrapolating comments that related to broad themes, including control of conversation, purpose of interaction and use of AAC. Next, an inductive analysis was conducted to reveal common themes. This process involved drawing a map to represent each participant’s perceptions and the connections between them. The individual maps were combined to compare patterns and to highlight unique reflections. After the initial analysis, the field notes were examined to provide explanation, insights and illustration of the data. AAC was one of the broad themes examined.

\textbf{Findings}

AAC methods can be broadly divided into \textit{high tech} and \textit{low tech}.\textsuperscript{26} In the present study, 10 participants had been offered high-tech devices but analysis of the data indicated that only one of them was using such a device functionally (and that was only occasionally during the night to alert her spouse). Five people were using low-tech AAC. The following figure shows how many participants were offered, and how many used, both high-tech and low-tech AAC.
For most people in the UK with ALS/MND, the high-tech device that is usually supplied, both by Speech and Language Therapists and the MND Associations, is the Lightwriter™, although other devices are available. The participants in this study reported that the Lightwriter™ was the only high-tech device that had been suggested to them. All but one participant in the present study had abandoned, or had never even started to use, their devices. There is no doubt that high-tech AAC devices have the potential to facilitate the communication of people with acquired speech disabilities. Therefore it is important to explore why the participants in this study preferred not to use them. The comments and observations made during this study may help AAC specialists to understand these reasons. The reasons that were revealed through the analysis of the narrative and field note data gathered during the study have been grouped into three categories as illustrated below:
Figure 2. Reason for non use of AAC

AAC vs Dysphagia?

professional input

- vocabulary
- amount
- knowledge
- training
- update
- timing of provision
reasons for non-use of AAC

person

desire to use own speech
communication partners
shared topics of communication
social closeness

device

reliability

speech output

physical access

complexity to learn
Issues relating to the person with ALS/MND:

Desire to use his/her own speech: Video data supported an observation made by the researcher that all participants in this study, even those whose speech was unintelligible, attempted to use their own speech first and many commented that no device could ever replace the human voice.

When first given a communication aid, one participant said: I like it very much. As I said to my Speech and Language Therapist it’s a nice toy but it’s like admitting defeat to not use my own voice. (participant 15)

Another participant said: I try to talk to her cos she’d rather say it rather than write it down or use the Lightwriter™ – with me that is ... as I’ve done for many years. (partner 7).

Shared understanding: Close communication partners are usually aware of needs and wants (e.g. drinks and daily care tasks) because they know each other so well and have a shared understanding of daily life events.

One person described how she and her grandmother talked to each other: We usually speak about what’s happening or what’s going to happen. I usually know what I’m going to say because I’m going to have to say it to someone else. Sometimes it’s a wee bit of luck. We talk a lot – always have – the rest of the family think we’re telepathic! (partner 12)

The following extract illustrates this shared understanding further:

Researcher: What is it that you do that makes it easier for you to understand [i.e. the participant with ALS/MND] than me?

Wife: Probably because we’ve lived together for years and we just know each other’s ways – I mean some time we even think the same and then he’ll be saying something and I’ll say – oh – I was just about to say that. (partner 6).

Participants commented that their communication was primarily with people who were familiar to them. This restriction to familiar communication partners was often by choice. One couple described how the conversation of the husband (who had ALS/MND) with people outside the immediate family was limited to saying ‘Hi’ and communicating by eyes and facial expression.

His wife said that he was now content with – his own four walls and his dogs. (partner 1).
Another woman talked about meeting neighbours:

Participant: *When I am out and people are talking I try not to get involved cos it’s so tiring – it’s different at home.* Partner: *She likes neighbours who just wave and say ‘Hi’ – not long tiring conversations.* (participant and partner 13).

Another participant explained that she rarely used the Lightwriter™ because her family knew her so well and she was never talking to other people without one of them present: *I don’t need to use it much ‘cos there’s four of us in the house – different if I was on my own.* (participant 5)

Shared topics of communication: The decision to collect data in participants’ own homes with their immediate family/carers was made to facilitate observation of communication in the most natural and usual situation for the participants. Expressing needs and wants and transfer of information did not appear to be the main purpose of communication. Topics of conversation were very often shared whereby the communication partners were talking about some activity that they were working on together. One couple, for example, were choosing a new headboard for their bed from a mail-order catalogue to discuss the kind of headboard they were going to buy for their bed. They both knew what they were looking for, were in agreement with what they liked and did not like, and arrived easily at a joint decision concerning what to buy. (participant and partner 13)

Social closeness: Several participants emphasised the importance of close personal interaction and the worry that using a device would remove that closeness, as is illustrated in the following extract.

Partner (husband): *I mean I prefer contact this close (using an alphabet chart) rather than trying to type something with the Lightwriter™ ... to lose that personal contact I think is detrimental really.* (partner 13)

Participant: *A lot of our communication is non-verbal ... it could be important not to let these non-verbal communications stop ... to become oblivious to it.* (participant 2).

In two extracts of video data, there was a stark contrast between the closeness of one pair of participants when trying to resolve a misunderstanding using vocalisations, gesture and eye contact compared with the lack of interaction when another participant was trying to use a high-tech device and her partner was left sitting in silence waiting for the message.

Therefore, for most of the participants in this study, a communication device was not required in most situations because (a) topics were predictable, although
typically not about needs and wants; (b) partners were typically limited to a small number of well-known people; or (c) when communication occurred with less familiar people, it was often limited to social exchanges that could be communicated through non-verbal means.

**Issues relating to AAC devices:**

Speech output: Several participants commented that nothing could replace the ease or speed of natural speech.

One spouse remarked to her husband: *If you’re in a strange place and you want to ask to go somewhere, will people all wait in a queue till you spell it out?* (partner 15).

An additional problem related to whether or not a device had speech output and, if it did, the quality of the speech. Seven participants had been provided with an out-of-date model of the device that either had no voice at all or had poor quality voice. The wife of one man (partner 15) commented that the voice of the device was actually worse and less intelligible than the dysarthric speech of her husband.

Complex learning requirements: Several participants commented on how difficult it was for them to learn how to use a communication device. Some had been given the instruction manuals to learn from but found them to be too technical, complicated and difficult to follow.

One participant commented: *I’ve looked at the manual (grimaces) but I don’t need to use it as comprehensively as that.* (participant 5).

One partner (the wife of a participant) described the help they had been given: *He had a demo one then he got his own. She (the Speech and Language Therapist) sat down with it and sort of took him through it and gave him a book of instructions she had done herself. Just left to puddle along ourselves.* (partner 1)

Another participant said: *Learning something new like this is too hard – but don’t tell my Speech and Language Therapist.* (participant 15)

Physical access: Another difficulty for people in the present study was the decrease in their hand control as the illness progressed. As a result, many participants were unable to use the standard Lightwriter™ that had been provided because they were unable to operate the keys and access the device accurately.

One woman (participant 12) threw her Lightwriter™ off the table when she had difficulty accessing the keys.
Another participant’s wife explained: *He has a Lightwriter™ but he has never used it. I think he finds it is too slow by the time he has typed in his answer. He is not quick by any manner of means and, with his tightening up a bit, he hasn’t got the same movement. With that, I think he feels it is too slow for his reply to come through you know before he can sort of keep going. So I think maybe that’s it. Maybe that’s a good thing in a way that he doesn’t use it because it has maybe made me a wee bit better at trying to listen and to try to pick up what he’s saying.* (partner 6)

Another couple had the following discussion: Wife: *So what do you feel about the Lightwriter™ yourself?*

Participant: *NOT MUCH*

Wife: *It’s no very good because if your fingers are stiff because of the keys I think you feel by the time you’ve punched in an answer to somebody the communication’s gone half a mile down the road.*

(both laugh) Wife: *It’s too small and fiddly for you.*

Participant: *PROBLEM WITH MY HANDS*

Wife: *If it was a bigger keyboard and if it had bigger keys you might manage it better. It’s too small for your hands and when you can’t use your hands any more it’s no good to you anyway.*

Participant: *A BIGGER ONE*

Wife: *A bigger one with bigger keys – that would make it too clumsy for carrying about with you – I don’t think it’s altogether right for you. You haven’t got the patience anyway.*

Participant: *THUMPING IT*

Both [LAUGHTER]. (participant and partner 1)

Only two people in this project had been given information about the possibility of using the Lightwriter™ as a scanning device using a switch but both felt it would be too slow and had not attempted it.

Reliability. Although the reliability of high-tech devices is improving, there were still technical problems that left people frustrated and disenchanted with technology. For one couple, the uncertainty that they already had about using a machine was compounded by the fact that the device had broken down and had been sent off for a repair that was taking several weeks.

Partner: *She’s got a Lightwriter™ but it’s broken just now.* (partner 7)
Issues Relating to Professional Input

Timing of introduction and provision of device: The amount of time that people had to wait for an AAC device, once they had decided to try a form of AAC, varied considerably. One man described how he had to wait for several months to obtain a high-tech device.

Some participants felt that they did not want to try a device while they still had speech, even although it was moderately dysarthric as the following comment illustrates:

Researcher: Has your Speech and Language Therapist suggested any communication aid?
Participant: Aye – but I’m not that bad yet. (participant 15)

Training: It was noticeable that the participants in this study had received very little input in terms of how to use their devices.

Researcher: How much time did the therapist spend going over and explaining it?
Participant: Not much time spent with me. (participant 12)

Another participant said: I tried to use it – going by instructions – nobody helped me very much. (participant 1)

Few participants in the study were seen at home by their Speech and Language Therapists and several reported only being reviewed at three- or four-monthly intervals in a hospital clinic. Only two participants in this project had been given information about the possibility of using the Lightwriter™ as a scanning device. No one in this study had been offered information about any other device apart from the Lightwriter™. Three participants had personal computers in their own home but were using them for searching the internet, writing and sending emails rather than to supplement spoken communication.

Vocabulary: When asked about the amount and type of input the participants had received in relation to their high-tech devices, none of the participants involved in this study had been given advice about specific vocabulary they might need or want to use in the future. One participant had been given a device with six phrases that had been stored for him by his therapist. They included ‘Happy Christmas’ and ‘Good New Year’ but when he was visited in March by the researcher, they had not been changed and he did not know how to change them himself.

Concerns about AAC versus dysphagia: For several of the participants in this study, speech and language therapy intervention was focused on their swallowing rather than their communication, as this extract between the researcher and a participant with moderate dysarthria illustrates:
Chapter 3

Researcher: What does your Speech and Language Therapist do?
Participant: Nothing really – it's more the dietitian – she weighs me – they (Speech and Language Therapists) talk about how you swallow.
Researcher: Is that where the speech and language therapist comes in?
Participant: Yes
Researcher: Is she not doing anything about your speech?
Participant: No – well she knows what I say anyway so … [SHRUG].
(participant 15)
One participant who had moderate dysarthria said: The Speech and Language Therapist says there is nothing she can do except monitor my swallow. (participant 11)

Low-tech AAC:
Many of the above issues applied also to low-tech AAC, but in general low-tech AAC appeared to be seen as more personal and less obtrusive. Five participants in this study were using low-tech communication successfully (i.e. alphabet boards, boards with key words and phrases, paper and pen, or a combination of these modes). One couple, who used an alphabet board with key words and phrases on the reverse side, were keen to point out that they preferred using low tech as the following short conversation between them and the researcher illustrates:

Husband: I much prefer to go through here [POINTING TO ALPHABET BOARD] and it's quicker – it's definitely quicker (than high-tech).
Researcher: You were saying earlier that after one or two letters you usually get the word.
Husband: Yes you do – if you can't pronounce something.
Participant: It all depends what we're talking about.
Husband: Yes it all depends. Yes some letters I can't understand and I've got to guess and it takes a long time obviously but most of the time we get it within seconds. (participant and partner 13)

One participant, who was using writing as his main means of communication, had a number of logistic difficulties that could have been overcome. As an example, he was using a biro pen that was difficult for him to hold and, because it had a thin point, it kept breaking through the paper. He used sheet after sheet of loose paper that became disorganised and jumbled and he had nothing to lean on when writing. No one had suggested that a dry-wipe board or even a firm surface to lean on with a more suitable pen and a pad of paper clipped together might have made
his communication easier. No one in this project reported having been offered any kind of symbol board, picture communication book, memory book or personal communication passport. Personal communication passports are being used increasingly in the UK with people with communication difficulties. They have been suggested to be ‘a practical and person-centred way of supporting people who cannot easily speak for themselves. Passports are a way of pulling complex information together and presenting it in an easy-to-follow format’.27

Discussion

The results of the present study highlighted some of the reasons why AAC is unsuccessful for some people with communication difficulties caused by ALS/MND. The study has implications for Speech and Language Therapists, ALS/MND Clinical Specialists, AAC centres, AAC manufacturers and service providers. Although for some people, AAC, especially high-tech systems, may never be a viable option, for others it may be a lifeline. The results of the present study raise some issues for consideration by those whose job and responsibility it is to advise and support people with ALS/MND and their partners to communicate and interact as well as possible.

First and foremost, the participants expressed a strong desire to use their own speech for as long as possible, even when it was unintelligible to others. Therefore, it can be argued that speech strategies should always be encouraged and supported. People with ALS/MND may find it particularly hard to accept an alternative voice because they have experienced normal speech. This may be true for people with acquired speech difficulties irrespective of the aetiology, as is illustrated by Churchill who lost his speech as a result of a virus that affected his brain. Churchill notes that ‘The human voice can give my words intonation, spontaneity, humour and wit. Machines can’t do that yet’.28 p 134

The researcher considered it vital to explore the communication of people in real-life settings in their own homes communicating with those people closest to them. Most people in Scotland with ALS/MND live at home with their spouse and/or family until the very end of the illness, yet most of the speech and language therapy input had been delivered in a hospital setting. Related to this issue is that AAC specialists need to be aware of the purpose of communication for their clients. In this study the participants’ purpose of communication with their closest communication partners was not to indicate needs and wants or even transfer new information.18 Instead, the purpose was to share thoughts, to engage in small talk and maintain social closeness. It is important that this need for social closeness be
acknowledged with people who may need AAC, that they be supported and reassured that, although their speech may deteriorate, it does not necessarily follow that there will be a decrease in social interaction between them and their partners. It must also be acknowledged that people within a partnership usually know each other well, and may have devised their own successful alternative ways of communicating without the input of a professional who is an outsider to the couple.

At present it seems that no high-tech device truly assists with the intimate talking described by Locke. Researchers at the University of Dundee have developed and evaluated several high-tech devices that incorporate the more interactive and social aspects of communication. However, they still have to make the impact that the simpler, letter-by-letter and word-by-word based systems have made. ‘Attempts have been made, and continue to be made, to develop AAC systems that make use of pre-stored material and employ conversational modelling to increase communication rate and enhance the interactive aspect of the communication. Keeping these systems easy to use and still effective is a challenge. The simpler and easier to use systems at the moment remain the most popular with users and providers.’

The comments of the participants in the present study indicated that a high-tech device may well be a barrier between communication partners and detract from social closeness. Further support for the potential for high-tech devices forming barriers to communication can be found by written comments of people with ALS/MND. Thomson, for example, offered numerous insights from the perspective of a person with ALS/MND who used a speech-generating device effectively. She described the difficulty of preserving her personality via a machine and discussed how each word had to be chosen carefully to express not only meaning but also emotion. She also stressed that communication is a dialogue, not a monologue and that she was in danger of forgetting that ‘I am always a piece in a dynamic jigsaw’. Robillard corroborated this sentiment when he described why he abandoned the several high-tech devices that he was given. The main reasons were that he had to concentrate and work so hard at operating the devices that he could not maintain social closeness with his communication partners.

The information given to people in terms of the possible vocabulary is crucial in introducing an AAC device and time must be taken to discuss the kinds of messages the person might want. The vocabulary needed will depend on many factors, not least the stage of the illness. People with ALS/MND may need vocabulary to help them deal with their grief such as ‘Can I have time alone
I prefer contact this close’;
to explain how they want things done – ‘Put my collar outside, not inside my jumper’;
to express how they feel – ‘I used to feel scared but now I have come to terms with my illness’;
or even to tell short narratives about themselves or to explain events or situations to others. At all stages people may want vocabulary to maintain small talk, to help maintain and nurture their personal relationships, to gossip, to minimise conflict, and to tell and respond to jokes.

It is hard to judge when to suggest that a person with ALS/MND should consider AAC. On the one hand, it is helpful if the device is provided at a time when the person is physically able to learn to use it. The opposing argument is that if an AAC device is suggested before the person is ready, it may cause anxiety and distress by indicating to the person that they will lose their speech. However, when an AAC system is suggested, it is essential that it is available whenever the person requires it, both physically and emotionally. The danger with the kind of delays that were evident in this study is that it may be too late for people to be able to learn to use a device confidently or effectively. Guidelines for the management of MND (1999) state that when a communication aid is needed it is essential that it is provided promptly. When any AAC device is provided, it is essential that it be reliable, have good quality voice output, be available for a sufficient loan period, and have accessible relevant adaptations that can be modified as the client’s needs change. If these basic requirements are not in place, the likelihood of device abandonment is high.

Professionals providing support to people with ALS/MND must have sufficient expertise themselves to be able to introduce, advise, support and update the use of the system sensitively and thoroughly. The results of the present study indicated that one reason for the failure of AAC for people with ALS/MND may be inadequate and insufficient training. Lack of training was noted in a previous study carried out in Scotland in which the obstacles to effective use of AAC systems used by people with cerebral palsy were explored. It was estimated that people with cerebral palsy received only 40 hours of therapy per year. It would appear from the present study that people with acquired communication difficulties receive considerably less input than those with developmental disabilities.

MacDonald attempted to address the problem of limited training. She ran an eight-month group therapy programme designed to help four adults, each using a speech-generating device. She initially observed several of the same problems as those identified in the present study (e.g. lack of knowledge of the operational features of the machines, lack of awareness of social considerations). MacDonald described the contents of the two blocks of group therapy that addressed these
main problems. The first focused on teaching the mechanics of the devices, such as using pre-stored messages, speech exceptions and altering volume control for different situations. The second block was aimed at improving social interaction including awareness of turn taking, appropriate eye contact and non-verbal signals. All clients made observable progress and MacDonald concluded that the amount of support needed to help people use communication devices should not be underestimated.

It is essential that professionals receive adequate training, time and funding if they are to be expected to provide the input and backup that is required for people with ALS/MND and their families to use technology successfully. Many Speech and Language Therapists have a lack of knowledge of the potential of AAC devices because of the pressure of a large general caseload and lack of training. Ironically, one of the limitations of technology is its very sophistication and lack of simplicity. Technology can be used to do so many things that the human beings who are expected to teach and those who are expected to learn to use devices may feel overwhelmed.

There is also a serious concern about the amount of therapy input and the amount of training people are receiving in terms of low-tech AAC. In recent years there has been an increase in attention given to low-tech strategies. Although many people have written about their experiences using high tech, less has been written about the user’s perspective of low tech. The findings in the present study provide support to those of Beukelman & Lasker and Mathy et al. who suggested that people tend to use low-tech or unaided methods in face-to-face communication, particularly when talking to familiar partners.

Only four people in the present study described problems with eating and/or drinking, whereas 14 reported some problems with their speech. Speech and Language Therapists may feel concerned that helping people to either maintain or improve their communication ability is being overlooked because of the emphasis on swallowing.

Limitations of the study

The present study was conducted with 15 people with ALS/MND and their partners in their own homes. People living in their own homes with their most familiar communication partners may have less motivation to learn to use an alternative communication method than those living in a residential facility, such as a nursing home. Therefore the findings cannot be extended beyond the present study. Nonetheless, it is important to recognise that most people in Scotland with
ALS/MND are cared for at home as long as possible and many die in their own homes. By the time someone is admitted to hospital or hospice, s/he may be too unwell to use or learn a new communication method.

The cognitive functioning of the participants in this study had not been assessed formally. Although some of the participants appeared to the researcher to have cognitive difficulties and/or emotional lability, it was not within the scope of this study to discuss the participants’ cognition in relation to their use of AAC.

This aims of this study did not include seeking the views of professionals, and therefore no response was made to some of the participants’ comments on lack of AAC training, timing of provision of AAC and professionals’ lack of knowledge of AAC.

The author acknowledges that as a practising Speech and Language Therapist with this client group, there may have been some bias introduced when interpreting communicative acts but it is generally accepted that in qualitative research a completely value-free inquiry is impossible. This bias is alleviated to some extent by presenting the participants’ own words in the findings. In addition the involvement of an independent rater and multiple visits added to the validity of the study.

**Conclusion**

The findings of the present study indicate that the potential of AAC for people with ALS/MND and their communication partners is not being fully realised. It is important to be aware of the real-life situations of people with ALS/MND and their close communication partners, and to listen to their perceptions of how and why they interact. The purpose of communication as a means to maintain and develop social closeness is particularly pertinent to this group of people who live at home and whose speech may be deteriorating. Because of the intimate nature of communication between the dyads studied and because many people with ALS/MND interact increasingly closely with their communication partners as the disease progresses, communication between partners may grow stronger and social closeness become deeper. Hence, it is important to ensure that people with ALS/MND are provided with the appropriate information and support to achieve and/or maintain the nature of their close communication with familiar partners.
References
17. Wendt, O. 2002, "AAC intervention for ALS patients in a German rehabilitation clinic".
36. MacDonald, A. 1997, "What's the Problem? He can read the manual can't he?", Communication Matters, vol. 11, no. 2, pp. 18-19.
The feasibility of using the Talking Mats framework with people with aphasia to enable them to express their views on their quality of life

Based on:
Murphy, J
Enabling people with aphasia to discuss quality of life.

Abstract
The Talking Mats framework is a low-tech tool to allow people with communication difficulties to express their views. This study examined the feasibility of using the framework to enable people with aphasia to express their views on their quality of life. Twelve people with aphasia as a result of stroke, living in four different residential settings, were interviewed using the Talking Mats framework about six topics relating to quality of life. The interviews were video recorded and analysed using a five-point coding scheme to assess participants’ ability to understand, consider and communicate views on quality of life to others. The completed Mats were analysed using cognitive mapping to identify quality of life issues of importance to them. The findings demonstrate that it is feasible to use the Talking Mats framework as a tool for people with aphasia to express their views in relation to their understanding of topics being discussed, confidence in responding, confirmation of their views in a visual format and satisfaction with the final result. It helped participants to identify the topics and options that were important to them and to indicate how these either improved or hampered their lives. Insightful observations about the use of the Talking Mats framework were obtained from participants and the framework was modified as a result of their involvement.
Introduction
The lifestyle of a person with a stroke undergoes sudden and devastating changes including problems with mobility, activities of daily living, communication and changes in relationships. Damaged communication is one of the most distressing aspects of stroke. Yet, it is at this very time, when the person’s communication may fail, that crucial decisions affecting the person’s future have to be made. In Scotland there are guidelines for the management of patients with stroke during the acute medical phase SIGN 13\(^1\) and during rehabilitation and discharge planning SIGN 24\(^2\) which include patient consultation and involvement in care planning but the detail of *how* they will be consulted is missing. For example, SIGN 24 recognises the importance of aims and objectives being established and agreed by all parties and states ‘*Information should be presented both verbally and in written form to the patient and family or carers*.\(^2\) \(^p\) \(^4\) However, there is no acknowledgement of the difficulties a person with aphasia will have in understanding and/or expressing their views on rehabilitation issues. Once the person returns to the community there are no clear guidelines and many more variable factors that determine the person’s quality of life and the decisions to be made about their life.

Considering people’s own perspectives on quality of life and issues of importance to them is fundamental in enabling them to make decisions and be involved in care planning. One way of doing this is to use an existing quality of life measure such as the Nottingham Health Profile\(^3\) or SF36\(^4\) or even a measure of anxiety and depression such as the Hospital Anxiety and Depression Scale\(^5\) but most were developed for research rather than practice purposes and focus on negative aspects of quality of life such as pain, lack of sleep and social isolation. Moreover they assume verbal or written skills and do not take into account the specific problems people with stroke may have in completing any of these measures such as difficulties with speech, language, fatigue, hand control and literacy.

Few studies have attempted to investigate quality of life amongst people with aphasia. Hinckley sent a questionnaire to 145 adults with aphasia asking them to provide a self-rating on life satisfaction.\(^6\) She noted that the low response rate (21%) was due to the respondents’ difficulty in completing a linguistically loaded, multiple-page questionnaire. Holland reviewed different approaches to functional outcome measures including those that claimed to be specifically designed for people with aphasia.\(^7\) However, none addressed the problems of administering a test to those who have difficulty understanding and/or expressing themselves and Holland states: ‘*No currently available measure examines the effect of communication problems on the quality of life post stroke*.\(^7\) \(^p\) \(^5\) Discussion with a
The feasibility of using Talking Mats with people with aphasia

number of Speech and Language Therapists working with people with stroke across Scotland confirmed this; none knew of any suitable tools being used with patients with stroke either with or without communication difficulties to allow them to express their views of quality of life. There is therefore a pressing need to develop an instrument which could be used as a clinical as well as a research tool that will allow people with communication difficulties to express their views.

As part of a previous research project, the Talking Mats framework was developed to enable people with cerebral palsy and communication difficulties to express their thoughts and views. The framework was first piloted with people with motor neurone disease to discuss their quality of life. The study involved five people at varying stages of the illness who had good understanding but difficulties with motor production of speech. Overall their views of the Talking Mats framework were very positive; all five participants felt it was a useful and innovative way of allowing them to consider topics relating to their quality of life. Following this study the next step was to examine if the Talking Mats framework could be used with people who have more complex communication difficulties such as aphasia.

Aphasia is a communication disability which occurs when the communication centres of the brain are damaged, usually by stroke, but sometimes by head injury or tumours. Aphasia can have a profound effect on the ability of the person to understand, consider decisions and communicate those decisions to others.

The Talking Mats framework is based on three sets of picture symbols which are presented to the person with the communication difficulty. The picture symbols relate to:

a. **topics** which are relevant for quality of life;

b. **options** relating to each topic; and

c. **visual scale** which is a range of emotions to allow participants to indicate their general feeling about each option.

Each Mat has a range of either three or five emotion symbols along the top, depending on the cognitive ability of the participant, and focuses on one topic. The relevant options are presented to the participant who then selects the ones that are important to him/her and places them under the appropriate emotion thus building up a composite picture of his/her views. The interviewer asks the participant to confirm their placement of the symbol either verbally or non-verbally and once the Mat is completed they are asked to indicate how satisfied they are with the final result.

There are a number of distinctive features of the Talking Mats framework which might help people with aphasia. For example:
• it gives information in multiple channels – visual, auditory and tactile;
• it does not require literacy;
• it can be used by people with limited (or no) hand control;
• it breaks information down into small manageable chunks; and
• it reduces memory demands.

The aim of this paper is to examine the feasibility of using the Talking Mats framework with people with aphasia to enable them to express their views on their quality of life. It asks two questions. Firstly, can the framework help people with aphasia to consider and comment on topics relating to their quality of life? Secondly, can the framework help identify topics relating to quality of life that are important to them so that these topics can be included in any subsequent management or treatment plans?

Methods
Participants
The stroke team at Stirling Royal Infirmary helped identify patients to take part in the study based on the following criteria:
1. Participants had a diagnosis of aphasia.
2. Participants were at least four weeks post trauma and neurologically stable to increase the likelihood of being medically fit to take part in the study.
3. After checking for factors 1 and 2, three participants were selected from each of the following four most typical residential situations for people following stroke:
   • living with family;
   • living alone;
   • in-patient in acute ward with discharge imminent; and
   • long-stay nursing home or hospital ward.

The purpose and process of the project was carefully and sensitively explained to the participants both in written form and in person to ensure that the participants and their partners fully understood their involvement and their right to withdraw from the project at any time. All consented to take part and a date for each interview was agreed. Their communication impairments ranged from severe receptive and expressive aphasia to mild expressive aphasia. Table 1 summarises details of the participants.
The feasibility of using Talking Mats with people with aphasia

Table 1. Participant details

<table>
<thead>
<tr>
<th>No.</th>
<th>Gender</th>
<th>Age</th>
<th>Time since stroke</th>
<th>Communication</th>
<th>Residential Situation</th>
<th>Employment</th>
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<tbody>
<tr>
<td>1</td>
<td>Male</td>
<td>53</td>
<td>3yrs. 5mths.</td>
<td>Mild receptive &amp; severe expressive aphasia</td>
<td>Home with family</td>
<td>Retired architect</td>
</tr>
<tr>
<td>2</td>
<td>Male</td>
<td>51</td>
<td>6 mths.</td>
<td>Severe receptive &amp; expressive aphasia</td>
<td>Home with wife</td>
<td>Retired joiner</td>
</tr>
<tr>
<td>3</td>
<td>Male</td>
<td>53</td>
<td>1yr. 2mths.</td>
<td>Severe receptive &amp; expressive aphasia</td>
<td>Home with family</td>
<td>Retired landscape gardener</td>
</tr>
<tr>
<td>4</td>
<td>Female</td>
<td>66</td>
<td>1yr. 3mths.</td>
<td>Mild receptive &amp; severe expressive aphasia</td>
<td>Home alone</td>
<td>Retired home help</td>
</tr>
<tr>
<td>5</td>
<td>Female</td>
<td>65</td>
<td>10mths.</td>
<td>Moderate receptive &amp; severe expressive aphasia</td>
<td>Home alone</td>
<td>Retired Health Service manager</td>
</tr>
<tr>
<td>6</td>
<td>Male</td>
<td>51</td>
<td>7yrs. &amp; 2yrs.</td>
<td>Severe dysarthria &amp; mild aphasia</td>
<td>Home alone</td>
<td>Retired management consultant</td>
</tr>
<tr>
<td>7</td>
<td>Male</td>
<td>72</td>
<td>2mths.</td>
<td>Moderate receptive &amp; expressive aphasia</td>
<td>Acute Ward</td>
<td>Retired farm worker</td>
</tr>
<tr>
<td>8</td>
<td>Male</td>
<td>76</td>
<td>3mths.</td>
<td>Mild expressive aphasia</td>
<td>Acute Ward</td>
<td>Unemployed</td>
</tr>
<tr>
<td>9</td>
<td>Male</td>
<td>67</td>
<td>1mth.</td>
<td>Severe receptive &amp; expressive aphasia</td>
<td>Acute Ward</td>
<td>Retired drainage worker</td>
</tr>
<tr>
<td>10</td>
<td>Male</td>
<td>66</td>
<td>12yrs.</td>
<td>Severe receptive &amp; expressive aphasia</td>
<td>Long-stay Ward / care home</td>
<td>Retired farmer</td>
</tr>
<tr>
<td>11</td>
<td>Female</td>
<td>71</td>
<td>12mths.</td>
<td>Moderate dysarthria &amp; receptive aphasia</td>
<td>Long-stay Ward / care home</td>
<td>Housewife/ homemaker</td>
</tr>
<tr>
<td>12</td>
<td>Female</td>
<td>84</td>
<td>5mths.</td>
<td>Severe receptive &amp; expressive aphasia</td>
<td>Long-stay Ward / care home</td>
<td>Housewife/ homemaker</td>
</tr>
<tr>
<td>Avg</td>
<td>-</td>
<td>64.5</td>
<td>1year 2mths.</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Quality of life topics to be explored

Topics to be explored were identified by examining the literature, selecting existing quality of life topics relevant for people with stroke and discussing them with professional colleagues. The main topics were: people; home; health; work; indoor interests; outdoor interests. The three participants on the long-stay wards, who had the most severe impairments, were presented with two topics only to consider – people and ward – as these were the most concrete and relevant topics for them. Within each topic a variety of different options were displayed. These were converted into pictorial representations using Boardmaker™ software to be used with the Talking Mats framework.

During the project some new symbols were added at the request of the participants, e.g. other residents/patients and tradesmen were added to the people topic and holiday was added to outdoor interests.
**Procedure**

Verbal instructions and a simple explanation of each symbol were given as well as a demonstration of how to use the Mats. For each of the topics in turn, the participants were invited to select the options that they considered affected their quality of life. They then placed each one, depending on how that option helped or hindered their quality of life, under the relevant emotion on a second Mat. Each participant was encouraged to select the symbols in whichever way was most convenient for them, e.g. naming verbally, using electronic communication aid, pointing or head nod with interviewer scanning. Blank squares were always presented in order that the participants could add any other options that were relevant to them. In this way the participants built up a picture of their views on how various options affected their quality of life for each topic. The interviewer then went over each Mat with the participant to allow them to make any changes and confirm that they were satisfied with the final Mat. The video-recorded interviews lasted between 26 minutes and 71 minutes (average 49 minutes 80 seconds) and digital photos were taken of participants’ completed Mats.

**Evaluation methods**

*Can the Talking Mats framework help people with aphasia to consider and comment on topics relating to quality of life?*

To answer the first question the Talking Mats framework needed to demonstrate that participants i) understood the task being presented, ii) could consider and express views confidently on topics relating to quality of life which were relevant to them, iii) confirmed their placement of the symbol, either verbally or non-verbally, and iv) indicated how satisfied they were with the final composite result. A simple coding scheme to include these indicators was developed and was used to analyse the video recordings. It comprised a five-point scale where 5=always, 4=usually, 3=50:50; 2=sometimes and 1=never.none in order to code participants’ responses in relation to each topic. By its nature communication is a complex and consequently subjective interaction and the judgments made also have to be subjective. The videos were coded by the interviewer and an independent observer who was recruited from the Psychology Department at the University of Stirling. In this way a crosscheck was made of the interpretation of results as well as any misunderstandings which may have occurred.

An essential part of research is feedback to the participants. With the exception of one (who had become very ill) all participants were visited a few weeks after their interview and given a copy of the photographs of their completed Mats. They were
also asked to comment on whether they agreed with their previous views or wished to change anything.

Can the Talking Mats framework help identify topics relating to quality of life that are important to people with aphasia so that these topics can be included in any subsequent management or treatment plans?

To answer the second question, the completed Mats were examined by the researcher using cognitive mapping. Northcott describes a cognitive map in the following way:

'A cognitive map is a visual representation of the knowledge base of an individual or individuals. It is cognitive in the sense that it represents the conceptualizations and interpretations of an individual and is set out “thoughtfully” by the transcriber. It is mapped out to allow for all the ideas to be accumulated onto one page, including the connections and interconnections in an ordered and accessible manner.'

In this study the photographs of each topic Mat were examined and the topics and options were manually drawn on one sheet to represent each participant's positive and negative views and any connections between them.

Results

Can the Talking Mats framework help people with aphasia to consider and comment on topics relating to quality of life?

Eight people completed all sections of the interview. One man (participant 9) on the acute ward became tired and appeared to have difficulty understanding the task and the interview was stopped after two topics. He was only just one month post onset and was probably not neurologically stable. When he was followed up after discharge he had improved significantly and when shown his completed Mats, had no recollection of having been interviewed.

Figure 1 shows the scores of all 12 participants on their use of the framework concerning the topic of people as an example. Eleven out of 12 participants (the exception being participant 9) achieved communication scores of 4 or above for understanding, confirmation and satisfaction. They also scored 4 and above for confidence with participant 12 scoring 3. This indicates that the Talking Mats framework is a feasible communication tool for people with aphasia.
Figure 2 shows the mean scores on the four communication indicators across all six topics relating to quality of life. The results demonstrate that when using the Talking Mats framework to consider and express their views the participants’ mean score was 4 and above for each topic – i.e. they either ‘usually’ or ‘always’ understood the task; expressed their views confidently; confirmed their placement of symbols; and indicated satisfaction with the end result. These results reinforce the supposition that the Talking Mats framework is a feasible communication tool for people with aphasia.
At the feedback visit the participants affirmed that their involvement in the research had been enjoyable and interesting. For example, participants commented: ‘It went well’ (participant 4) and ‘Very helpful’, ‘Nice simple idea’ (participant 5). They all indicated that the topics presented to them had covered the main aspects of their lives and no one indicated that they wished to change their Mats. For several participants aspects of their lives were changed as a result.

Can the Talking Mats framework help identify topics relating to quality of life that are important to them so that these topics can be included in any subsequent management or treatment plans?

The use of cognitive mapping allowed the identification of topics that were of concern to individual participants in different circumstances, the relationship between topics and individual experiences of quality of life. Figure 3 illustrates the main topics raised by participant 3 and the connections between them. At the follow-up visit additional unsolicited information was obtained from the participant and his wife about actions that had been taken both by themselves and the Speech and Language Therapist as a result of the Talking Mats’ interview. For example, on his outdoor activity Mat participant 3 had indicated that he missed his dog and getting out in the fresh air. He had also noted uncertainty about his mood and his mobility.
Figure 3. Summary of main issues for participant 3

- wife
- g’children
- daughter
- brother
- son
- cousin
- carer
- minister
- friends
- neighbours

- in touch with colleagues
- boss
- hours
- money
- stress
- travel

- eating
- SLT
- Physio
- garden
- club
- fresh air
- family
- car
positive - unsure - negative

health
- pain
- speech
- hands
- drugs

emotions
- walking
- doctor

outdoor

home
- garden
- cleaning
- phone adaptations
- care
- access
- heat
- meals

indoor
- pets
- TV
- CD
- football

work with SLT to develop communication book

subsequent actions

wife got dog for participant to take for walks

playing music
- reading
- cooking
Figure 4. Summary of main issues for all four groups

family
SLT
in touch with colleagues
access to car
adaptations to house
TV
pets

home with family

speech
use of hands
reading
pain
previous sports
space in house

a way for family to know the person's views

family
ward staff
feeling ill
privacy
reading

acute ward

speech

a way to include patient's views in discharge planning
importance of activities of daily living

comments on quality of service
Following the Talking Mats’ interview his wife had decided to get another dog from the RSPCA. This had had a positive effect on both his mood and his mobility as he had started going out in his wheelchair by himself while taking the dog for a walk. The participant had also shown his completed Mats to his Speech and Language Therapist who had then started working with him on a communication book based on his views. Figure 4 provides a summary of the issues raised for each of the four groups of participants. It also suggests the possible uses of Talking Mats’ data based on what and how they were communicated.

The main issues in relation to quality of life raised by groups in the four different settings are described below and illustrated by photographs of completed Maps for individual participants.

At home with family: those who lived at home with their family rated family members highly in contributing to their quality of life. However, they were also able to express that some family members added more to their life than others, e.g. one man indicated that one daughter added to his quality of life more than the other (who had two young very boisterous children who tired him out). Spouses were present during the interview for all three participants who lived with their family. All were surprised by some of the views expressed. For example, participant 2 indicated that he disliked going out in the fresh air (see Figure 5) whereas his wife said she had assumed that he enjoyed being taken out in his wheelchair. These and similar observations from other participants led to the conclusion that it cannot be assumed that family members always know the views of a person with aphasia and that the Talking Mats framework may be helpful for family members to communicate each other’s views.
At home alone: all three who lived alone indicated that the garden was a source of anxiety as they were no longer able to look after it. Two indicated that some family members upset them and two found shopping stressful. Participant 6, whose map on outdoor activities can be seen in Figure 6, indicated that swimming, shopping and his garden frustrated him. He requested a second car symbol to express how his car hampered his life when it was off the road but greatly improved his quality of life when it was working. For people living alone, without family members to regularly speak for them and possibly with a number of different carers, it is important that they can express their views to others.
**Acute ward:** the main observation from this group was that the Talking Mats framework provided a trigger for the participants to describe their lives and interests which was otherwise lacking. The Mat illustrated in Figure 7 was completed by participant 8, a man who was fairly content despite being in hospital. The Talking Mats framework could also serve as a scaffold for planning discharge as it highlights what people regarded as important in their lives and therefore what help they may need when they leave hospital.

**Figure 7. Participant 8 – Acute ward – Ward**

**Long-stay ward:** All three participants in long-stay wards were unhappy with issues which affected their quality of life. Their main areas of discontent were with the nursing staff and their lack of privacy as is illustrated in Figure 8. This is the Mat of participant 11 who indicated that she was particularly unhappy about the food and lack of privacy on the long-stay ward. The Talking Mats framework could be used to assess quality of service in long-stay facilities.
Discussion
The findings presented suggest that the Talking Mats framework can help people with aphasia to consider and comment on topics relating to their quality of life and can also help identify topics relating to quality of life that are important to people with aphasia. Eleven of the 12 people were able to express their views using the symbols on the topics presented and it appeared to be a meaningful and satisfying activity. As the one participant who was unable to express his views clearly was later found to be neurologically unstable, it is important that the medical status of the person is clear before using the Talking Mats framework. For most it was an opportunity to consider their current lifestyle and possible future changes in a positive and affirming way. For some, it allowed them to express thoughts to their partner that they had not done before while others were able to indicate satisfaction or dissatisfaction with their residential situation. Taken together these findings suggest that the Talking Mats framework could be used to assist with subsequent management or treatment plans.

The Talking Mats framework is innovative. The use of visual clues seems to offer an accessible method of interviewing people who would struggle with a conventional type of interview. The final summary of views is also a visual one enabling participants to return to the completed Mat and share it with others.

The study is inclusive as it endeavours to genuinely involve people with communication difficulties in research. People with aphasia are a challenging group and for this reason are often excluded from research. The study, though small and relevant only to this sample, included people in different locations and presented
topics that were relevant and meaningful for different participants’ situations and contexts. It also attempted to build on and use participants’ views of the research process in adapting the framework. Further strengths of this project are the outcomes for the participants. All but one found using the Talking Mats framework was an enjoyable and rewarding experience and were able to express views which they would not have been able to convey otherwise or so easily. They also appreciated receiving a printed copy of their views and for several participants issues in their lives were improved as a result of the project.

The limitations in this study include the small number of participants and a danger of bias as the interviewer also carried out the analyses. However, the use of video to allow the researcher to confirm that she had interpreted the participants’ views correctly and the involvement of a second person in analysing the data attempted to mitigate any researcher bias. As only people with aphasia were involved it is important to examine the feasibility of the Talking Mats framework with other groups such as people with learning disabilities and people with dementia. This project only studied the feasibility of using the Talking Mats framework. A further study could examine whether the Talking Mats framework improves communication compared to other communicative methods.

From the findings presented in this paper the Talking Mats framework appears to have potential as a tool for clinical practice in relation to understanding the views of people with aphasia on their quality of life. This information is crucial if their involvement in care planning is to become a reality. Clinically it could be used initially to get to know a person and to find out their general views in a relaxed and non-test situation. It also provides the opportunity to gather initial information and then explore issues in more detail. It could also be used to consult with people prior to discharge from hospital and provide information to health service and social work staff working both in acute and community settings. It could be used to involve people with aphasia in setting their own goals for rehabilitation and in subsequently measuring the outcome of their rehabilitation. In relation to service delivery it could be used to allow people to comment on quality of service such as food, privacy, warmth and staff attitudes in hospitals and care homes. Given that measuring quality of life is such a crucial part of much evaluative research and that most research excludes people with communication disabilities, it is possible that the Talking Mats framework might be a useful research tool. However, further testing and evaluation would be necessary.
Conclusion
Although this was a small study, it indicated that the Talking Mats framework is a feasible communication tool to use with people with aphasia in terms of their understanding of topics being discussed, confidence at responding, confirmation of their views in a visual format and satisfaction with the final result. It helped participants to identify the topics and options that were important to them and to indicate how these either improved or worsened their lives. It appeared that this interactive and visual format was more satisfying and successful for the participants than a structured interview or questionnaire. The Talking Mats framework has the potential to be used both clinically and in research with different participants and in different contexts and further research to do this and to refine the functional communication coding scheme is planned.
References
The feasibility of using the Talking Mats framework with young adults with learning disabilities to make choices at a time of transition

Based on:
Cameron, L and Murphy, J
Enabling young adults with a learning disability to make choices at a time of transition

Abstract
Young adults with learning disabilities have particular problems which are compounded if they also have a communication disability at times of transition, such as leaving school or college. This study involved 12 young adults with both learning and communication disabilities and examined the feasibility of using the Talking Mats framework to allow them to express their views on six main topics at times of transition. It also explored their views and considered the skills required to be able to use the Talking Mats framework. The results show that the majority of participants were able to indicate their likes and dislikes and to express views about the choices available to them. The results also suggest that there are five prerequisite skills needed to be able to use the Talking Mats framework successfully.

The study concludes that the Talking Mats framework can help young adults with learning disabilities to consider, and be actively included in discussion and decisions about, the choices available to them at times of transition.
Introduction
It is estimated that there are approximately 120,000 people in Scotland with learning disabilities.\(^1\) In England there are approximately 420,000 people with severe and profound learning disabilities and 1.2 million people with mild/moderate learning disabilities.\(^2\)

It has been suggested that young adults with learning disabilities are at risk of social exclusion and difficult transition on leaving school and during subsequent transitions.\(^3\) For people with learning disabilities choices for the future can often be limited and it can be difficult to ensure their views are included in planning – that their voice is heard. This is particularly true for those young adults with learning disabilities who also have communication impairment. Such an impairment can exist in addition to, or as part of, their learning disability.

Various studies show that young adults with learning disabilities have specific transition needs that ought to be addressed, particularly in relation to self-esteem\(^4\) and lack of leisure\(^5\) and that neglect of transition needs is likely to contribute to some of the difficulties that young adults with learning disabilities experience.\(^6\)

Under current legislation it is obligatory to include the views of children and young adults in review meetings, further needs assessments and decisions affecting them.\(^7\) Given the difficulties entailed, at present the involvement of young adults is no more than ‘lip service’, particularly if the individual also has a communication impairment\(^8\), which is common amongst people with learning disabilities. The Scottish Executive review of services, ‘Same as You’, states that 80% of people with learning disabilities have some communication difficulty and that 50% have a significant communication impairment.\(^9\)

A review of services to young adults by an NHS Trust\(^10\) found that:

- Young adults often do not feel involved and informed in making choices;
- Young adults with severe learning disabilities need planning for what happens when they leave college; and
- Young adults with communication difficulties have no independent voice in transition planning.

There is therefore a need to develop a tool that will allow young adults with learning disabilities to consider, and be actively included in discussion and decisions about, the choices available to them at these crucial times of transition. The Talking Mats framework is a low-tech communication tool which uses graphic symbols to illustrate topics and options which people with communication difficulties can manipulate on a textured Mat in order to consider and express their
views. Previous research projects have involved the use of the Talking Mats framework with people with motor neurone disease\textsuperscript{11} and aphasia.\textsuperscript{12} The aim of this study was to examine the feasibility of using the Talking Mats framework with young adults with learning disabilities by asking the following questions:

1. Can the Talking Mats framework enable young adults with learning disabilities to communicate their views at times of transition?
2. Can the Talking Mats framework help identify the range of issues which are important to young adults with learning disabilities at times of transition?
3. What skills are required in order to be able to use the Talking Mats framework to express views?

Method

Participants

The Speech and Language Therapy Service in Forth Valley identified 17 young adults who were currently on the caseload aged 16–24. This age range was identified as the period of transition from young person to adult.\textsuperscript{3} Three young adults did not wish to participate and two were unwell. Twelve young adults agreed to participate in the study, nine male and three female. The youngest was 18 and the oldest was 23, the mean age being 20 years.

Table 1 shows the aetiology of the participants’ learning disability. In addition, five of the participants had additional mental health problems which included behaviour resulting in harm either to themselves, others or surroundings.

<table>
<thead>
<tr>
<th>Number</th>
<th>Aetiology</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Cerebral Palsy</td>
</tr>
<tr>
<td>2</td>
<td>Down’s Syndrome</td>
</tr>
<tr>
<td>1</td>
<td>Autism</td>
</tr>
<tr>
<td>1</td>
<td>Foetal alcohol syndrome</td>
</tr>
<tr>
<td>1</td>
<td>Hydrocephalus</td>
</tr>
<tr>
<td>2</td>
<td>No known aetiology</td>
</tr>
</tbody>
</table>

Information regarding the participants’ functional communication ability was obtained from the speech and language therapy department prior to the interviews. Two were able to understand only single key words in sentences that were linked to the immediate context. Five could understand sentences that contained two to three key words and five understood sentences with four or more key words but had specific processing and sequencing difficulties.
Table 2 summarises the participants’ expressive communication methods which varied from those who used primarily speech to those who used augmentative systems such as high-tech communication aids, low-tech communication books and Makaton signing. Several participants combined a variety of methods.

Table 2. Expressive communication methods (n=12)

<table>
<thead>
<tr>
<th>Expressive communication method</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 Speech</td>
</tr>
<tr>
<td>5 Low-tech communication aids</td>
</tr>
<tr>
<td>2 High-tech communication aids</td>
</tr>
<tr>
<td>4 Signing</td>
</tr>
</tbody>
</table>

All participants were facing or had recently faced at least one area of transition in their lives in the past nine months, which is illustrated in Table 3.

Table 3. Transition options for participants (n=12)

<table>
<thead>
<tr>
<th>Number</th>
<th>Transition factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Change of accommodation</td>
</tr>
<tr>
<td>4</td>
<td>School to college</td>
</tr>
<tr>
<td>3</td>
<td>School to day centre</td>
</tr>
<tr>
<td>1</td>
<td>College to day centre</td>
</tr>
<tr>
<td>1</td>
<td>College to work</td>
</tr>
<tr>
<td>1</td>
<td>Day centre to undetermined future placement. (This participant’s choices were further limited due to having been excluded from day centre and college.)</td>
</tr>
</tbody>
</table>

**Topics and options**

The main topics and options relating to transition were selected following a search of the relevant literature\(^3,10,13\) in conjunction with discussions with Speech and Language Therapists who work in the field of learning disabilities. Workshops were carried out with staff in a further education college and a day centre to refine the topics and options. In addition the framework was adapted throughout the project in consultation with the participants. The six topics identified were converted into graphic symbols as follows:

*Accommodation*

*Day activity–work/education*

*People*
Choices at time of transition

*Transport*

*Leisure – in*  
(activities carried out primarily in the house)

*Leisure – out*  
(activities where participants usually have to leave the house)

A range of three emotions was presented along the top of each Mat:

- happy
- unsure
- sad

(things you like) (things you are not sure about) (things you don’t like)

Each Mat had the range of emotion symbols along the top and focused on one topic. A wide range of options was prepared to include as many possible choices which might be available to young adults at this time of transition. For example within the topic of *transport*, the following options were presented: *family car, taxi, regular bus, dial-a-journey bus, train, walking/wheelchair, bike, travelling on own.* Care was taken to present options which were realistic and relevant to the participant’s current life. The options were presented to the participants who then selected the ones that were important to them and placed them under the appropriate emotion thus building up a composite picture of their views. Blanks were always presented so that the participant could add any options which the researchers had omitted using speech, gesture or whatever communication method they could manage.

Acquiescence or choosing an option simply because a valued communication partner suggests or expects it is often seen as a particular difficulty when trying to obtain the opinions of people with learning disabilities. The following measures were taken to avoid the danger of the participants acquiescing. The option symbols were presented in random order and it was emphasised that there was no right or wrong and that symbols could be omitted or added if wished. The interviewers were careful not to give any indications of their own views by monitoring their intonation and asking open questions wherever possible.
The framework was piloted and subsequently modified by including a training topic to ascertain that the participants understood the procedure. Food was chosen as the training topic as it is concrete and within everyone’s daily experience. The symbols used in this study were Picture Communication Symbols (PCS) as this was the system with which the participants were most familiar.

Process
Once ethical permission was obtained, the Speech and Language Therapy Department identified 17 possible participants from their caseloads. The GPs and Speech and Language Therapists involved with each participant were informed in order to check if there were any reasons why any participant should not be included.

Care was taken to ensure that participants understood what was being asked of them and they were given both verbal and pictorial information. Witnesses who knew them well were asked to countersign the consent sheet to ascertain that each participant had understood their involvement. The fact that three of the young adults approached chose not to be involved was considered an indicator that the project had been explained well and that those who did not wish to participate were able to say so.

Each participant was visited three times by one of the two researchers, both Speech and Language Therapists. At the first visit the researcher explained again both verbally and visually how the participant would be involved. At the second visit the interview was carried out and the researcher went back over the completed Mat at the end of the interview to obtain confirmation of the participant’s choices. A video recording was made of each interview, a digital photograph was taken of each completed Mat and detailed field notes were taken. At the third visit feedback was provided and each participant was given a copy of the photograph of their completed Mats.

Evaluation methods

Question 1 – Can the Talking Mats framework enable young adults with learning disabilities to communicate their views at times of transition?

The video recordings of each interview were examined and the coding scheme, which was developed in a previous project with people with aphasia, was used to measure four indicators of basic communication – i) participant’s understanding of...
the topic, ii) participant's confidence with manipulating the picture symbols (either manually or visually), iii) participant's confirmation of the researcher's interpretation of their selection and iv) participant's satisfaction with each completed Mat. Each indicator was coded on a five-point scale of 5 (always), 4 (usually), 3 (50:50), 2 (sometimes), 1 (never). Three researchers, one of them independent of the project, examined the video data. The field notes were also studied for additional qualitative information that might explain other findings.

**Question 2** – *Can the Talking Mats framework help identify the range of issues which are important to young adults with learning disabilities at times of transition?*  
The completed Mats were examined and a simple count was made of the positive and negative choices of the participants in order to identify the range of issues which are important to young adults with learning disabilities at the time of transition. The video data were examined for verbal and non-verbal observations. At the follow-up visits the participants were asked to comment if they still agreed with the views expressed on each Mat and any changes were noted.

**Question 3** – *What skills are required in order to be able to use the Talking Mats framework to express views?*  
While coding the video data the researchers noted any factors which they believed affected the ability of the participants to use the Talking Mats framework. These factors together with comments from the field notes were compared between participants who were able to use the Talking Mats framework well and those who were not able to use it.

**Results**

**Question 1** – *Can the Talking Mats framework enable young adults with learning disabilities to communicate their views at times of transition?*  
Ten participants were able to complete Mats on all six topics identified as being important at transition. It became obvious that the two participants with the most severe learning disabilities (participant 1 and participant 8) would be unable to make complex choices such as accommodation. Participant 1 became distracted by objects around her room and participant 8 only responded consistently to concrete symbols such as horse riding. These participants were presented only with the most concrete topics – leisure activities. Nine of the 12 participants either usually or always understood all six topics presented. Participant 11 either usually or always understood four topics, transport, work, leisure – in and leisure – out but only understood people and accommodation 50% of the time (Figure 1).
A similar pattern is evident for the other three communication indicators as is illustrated in Figures 2, 3 and 4.

Figure 1. Participants' understanding of topic

Figure 2. Participants' confidence at manipulating symbols
Choices at time of transition

Figure 3. Participants’ confirmation of researcher’s interpretation

![Bar chart showing confirmation levels for different categories (people, transport, work, accommodation) for participants 1 to 12.]

Figure 4. Participants’ satisfaction with completed Mat

![Bar chart showing satisfaction levels for different categories (people, transport, work, accommodation) for participants 1 to 12.]

All participants were able to use the Talking Mats framework to some extent and the figures indicate that it is feasible to use the Talking Mats framework to help young adults with learning disabilities express their views.
From field notes it was observed that for 10 out of 12 participants there was little difficulty in sustaining their interest in the activity and, given the severity of learning disability of some of the participants, the researchers were surprised at how little they were distracted. Despite the interviews lasting between 45 minutes to 1 hour, and even when interrupted, it was easy to bring participants back to the task. Indeed many became engrossed in making their own decisions and some were keen to carry on for longer. Several expressed how much they enjoyed it. One commented:

*It was alright wasn’t it – putting all in different orders – the sad and happy faces help.* Participant 3.

**Question 2 – Can the Talking Mats framework help identify the range of issues which are important to young adults with learning disabilities at times of transition?** The six main topics identified initially through the literature search remained the same following discussion with staff and from the comments of the participants throughout the study. The more specific options were adjusted through input from the individual young adults, mainly by adding new options, e.g. *plane* was added to *transport* and *photography* was added to *leisure*. On examination of the Mats no one randomly assigned symbols to only one area on the Mat nor did anyone place symbols to produce a pattern or fill spaces on the Mat. None of the participants chose options which were unrealistic or irrelevant.

Figures 5–8 illustrate views of the 10 participants who completed four topics. The results were confirmed not only by the completed Mats but also from observing the participants’ facial expressions and final confirmations on the video. As not all the participants chose every factor, in some cases the results do not add up to 10. Figure 5 shows that the participants expressed positive views about staying in the family home apart from one who clearly did not wish to live at home. Six wanted to live in a group home and four did not. Three wanted to live alone, two were unsure about living on their own, four did not want to live on their own and one did not make a choice.
Figure 5. Views on accommodation (n=10)

Figure 6 shows that nine of the 10 participants wanted to go to college and the other was unsure. Three who were not attending college wished to and one who was due to leave college indicated he wished to stay on. Three indicated they liked attending their day centres, three were unsure and three did not like day centres. Clearly all wanted their day to be structured with meaningful activity and only one participant said she wanted to stay at home during the day.

Figure 6. Views on day activity (n=10)
Figure 7 shows that nine out of 10 identified the importance of their family (although one indicated he did not like his brother) and eight were happy with their carers. Seven liked their new friends since leaving school and six expressed a wish to stay in touch with old school friends. Only one participant indicated that she wanted to spend time alone and 50% had not considered it.

Figure 7. Views on people (n=7)

Figure 8 shows that the family car was seen as a preferred mode of transport and dial-a-journey appeared popular. Four were unhappy about travelling on ordinary buses but only one indicated he did not like trains. The bike was seen as a positive option for five participants and one person specifically indicated that he wanted an electric wheelchair. Another participant expressed his dislike of being encouraged to walk as part of a programme to help him lose weight. It was encouraging to see that he had placed riding a bike on the positive axis until he made it clear on the third visit that he had meant a motorbike! Two people added in that they wanted to fly in an aeroplane, as they had never done this.
Figures 8 and 10 show there was a wide variety of choices for leisure activities – both those done in the house and those done away from the house. The most popular activity in the house was cooking and the most popular activities out of the house were going out for meals and shopping.
Each person’s views are unique but the following general points can be made in relation to transition when leaving school or college for the young adults in this study.

- **Accommodation** – although most participants were happy still living in the family home, several were in the process of thinking about where they might live in the future;
- **Day placement** – access to college was clearly important to the participants and there were mixed feelings about day centres;
- **Leisure** – the participants had definite views about what they wanted to do and what they did not want to do. All of their choices were feasible;
- **People** – the participants expressed clear opinions about the people they wanted to spend time with and maintaining friendships with school friends was important for several; and
- **Transport** – again the participants expressed clear views about using transport which is a particularly relevant topic for young adults trying to gain some independence, but for whom mobility may be an additional problem.

The following photographs illustrate the views of two of the participants: Figure 11 shows the view of a young man who wants to live at home but does not want to live in a group home or have his own flat.
Figure 11. Accommodation

Figure 12 shows that this young woman has chosen six things she likes to do in the house – caring for her budgie, listening to CDs, painting, cooking, using her computer and looking at magazines. She is unsure about playing cards and watching the TV and she does not like housework, snooker or singing.

Figure 12. Leisure – in

The findings show that the Talking Mats framework facilitated the identification of issues important to young adults with learning disabilities at times of transition and allowed the majority of them to express their individual opinions both in general and in detail.
Chapter 5

Question 3 – What skills are required in order to be able to use the Talking Mats framework to express views?

All the young adults in this study, including those with severe learning disabilities, were able to use the Mats at some level but two of them were only able to respond to concrete topics. Observation of the video data, examination of the field notes and discussion among the research team enabled a comparison between participants who were able to use the Talking Mats framework well and those who were not able to use it. Through this process five prerequisites for using the Talking Mats framework were identified:

1. The participant needs to have enough vision to be able to see the picture symbols;
2. The participant needs to be able to recognise the picture symbols;
3. The participant needs to be able to demonstrate understanding of the task;
4. The participant needs to have a reliable pointing method such as finger or eye pointing to select and position the picture symbols; and
5. The participant needs to have a reliable method of confirming views, either verbally or non-verbally.

Discussion

The conclusion of this study is that the Talking Mats framework is a feasible tool for the majority of young adults with learning disabilities to communicate their views at times of transition. The coding scheme was useful in determining how well the participants could communicate their views using the Talking Mats framework and the enthusiasm and engagement of the 12 participants confirmed that they enjoyed using it. The study identified five core skills which are required in order to be able to use the Talking Mats framework to express views.

The six topics initially identified by the researchers were important to the participants involved. The number of options selected by participants as leisure interests raises the question as to why many young adults with learning disabilities are described as being bored and unmotivated. It appears that there are many activities they want to be involved in – none of them unreasonable, excessively costly or impractical. Some raised sensitive topics such as where they wanted to live and who they wished to spend time with and it was considered unlikely that they could or would have done this by using speech alone.

The structured nature of the Talking Mats framework, which chunks the information into smaller more manageable components, and the use of pictures to
reduce memory load, seemed to help people with comprehension difficulties and made the topics easier to respond to than by simply asking verbal questions. In addition, the physical involvement of choosing, moving and placing the pictures all contributed to participants being able to give a negative as well as a positive response.

Distractibility was less of a problem than anticipated. Possible reasons for this are that there is no literacy requirement and using the Talking Mats framework is not perceived as a test but more of a conversation. The researchers observed that the participants visibly relaxed as they realised that the Mats were allowing them to express their views in a meaningful and tangible way where they had ownership of the process, could change their minds and go at their own pace. This study makes a valuable contribution by not only including young adults with learning disabilities in research but also by examining their views on transition when leaving school or college. It provided the young adults with an enjoyable and meaningful task and gave them something tangible at the end of the project as they all received the photos of their completed Mats as a permanent record of their views which in some cases were used to bring about change.

Limitations to this study are acknowledged. As only 12 participants were involved the findings cannot be generalised to all people with learning disabilities. Although the participants all had communication difficulties the study did not compare how the participants would be able to express their views without the Talking Mats framework. The study observed that those participants who were very distractible or who could only understand concrete symbols had difficulty using the Talking Mats framework consistently. However, the study did not investigate the ability of people with different levels of comprehension to use the Talking Mats framework indicating that the prerequisite skills suggested need to be examined more rigorously.

The findings from this study suggest that the Talking Mats framework could be used for young adults with learning disabilities in a number of ways:

- To encourage interaction and conversation;
- To express views in a non-threatening situation;
- To plan daily activities;
- To be used in Person Centred Planning;
- To facilitate the young person to give their views at meetings; and
- To address the challenges of including the views of young adults with learning disabilities in practice and research.
A further study could examine the difference between using the Talking Mats framework and usual methods of communication to obtain the views of people with learning disabilities. Future research could determine who can and cannot use the Talking Mats framework effectively by including a larger cohort of people with different levels of comprehension.

**Conclusion**

The Talking Mats framework has proved to be a useful tool in allowing young adults with learning disabilities to communicate their views. The participants in this study were able to indicate their likes and dislikes and to express views about the choices available to them at the times of transition, which is acknowledged as being particularly difficult for many young adults. There were variations in terms of participants’ ability to use the Mats that appear to be linked to levels of functional comprehension.

This study responds to the challenge described in the literature to develop a tool that will allow young adults with learning disabilities to consider and be actively included in discussion and decisions about the choices available to them at the crucial times of transition. It also moves towards the requirement of government directives to include the views of young adults in reviews, further needs assessments and decisions affecting them.
References

10. Optimum Health Services NHS Trust 1999, *Young Adults Transition Project*.
11. Murphy, J. 1999, "Enabling People with Motor Neurone Disease to Discuss their Quality of Life", *Communication Matters*, vol. 13, no. 2, pp. 2-6.
The effectiveness of the Talking Mats framework for people with learning disabilities

Based on:
Murphy J and Cameron L
The Effectiveness of the Talking Mats Framework for People with Learning Disabilities

Abstract
People with learning disabilities have significant difficulties in ensuring their voice is heard. Talking Mats is a low-tech communication resource which helps understanding and supports expression. This study examined the effectiveness of the resource for people with learning disabilities. A mixed-method quantitative and qualitative study involving 48 people at four levels of comprehension was designed to compare the effectiveness of the Talking Mats framework with the individual's main communication method. Thirty of the 48 participants were identified as using the Talking Mats framework effectively. Effective use of the framework was associated with functional comprehension. The study found that scores on all indicators of communication effectiveness were higher when using the Talking Mats framework compared to main communication methods. This study identified that the Talking Mats framework can be an effective communication resource for many people with learning disabilities and can help them express their views by increasing both the quantity and quality of information communicated.
Introduction
It is recognised that people with learning disabilities should be at the centre of decision making concerning control of their lives, such as accommodation, care and day opportunities and should benefit from ‘person-centred approaches’. Government documents emphasise the importance of ‘person-centred planning’ to help people with learning disabilities realise their own hopes and wishes.\textsuperscript{1,2} However, despite these recommendations, a study funded by the Joseph Rowntree Foundation observed that professionals still tend to seek the views of care-givers rather than allowing people with learning disabilities to make their own decisions about health care.\textsuperscript{3} This study, which examined health care decision-making by adults with learning disabilities, concluded that the boundary between giving support and making decisions for people with learning disabilities is blurred and that relatives and caregivers often overstep into the latter. This is not surprising given the difficulties entailed in obtaining the views of people with learning disabilities, particularly if the individual also has a communication impairment.\textsuperscript{4}

Existing methods for eliciting the views of people with learning disabilities rarely address how people with an additional communication disability can be included in any discussions concerning their Life Planning. Bradshaw identified that the correspondence between the reported understanding level of individuals and the level of staff communication is generally poor. She described how staff were unable to adapt their communication skills to those of people with learning disabilities.\textsuperscript{5} In Bradshaw’s study 45% of communicative acts on the part of staff were outside the understanding skills of the individual with learning disabilities. This situation is particularly worrying as it is estimated that 50% of people with learning disabilities have significant communication problems and up to 80% have some communication problems.\textsuperscript{2} Talking Mats is a dynamic low-tech communication framework that uses picture symbols to help people with a communication difficulty understand and respond more effectively.\textsuperscript{6} The framework is based on three sets of picture symbols that are presented to the person with the communication difficulty – \textbf{Topics} being explored, \textbf{Options} relating to each topic and a \textbf{Visual Scale} to allow participants to indicate their general feeling about each option.

Talking Mats is now used widely with people with learning disabilities and although several papers relating to its use have been published\textsuperscript{7-11}, no studies have yet examined its effectiveness with people with learning disabilities. The aim of this paper is to present an evaluation of the effectiveness of the Talking Mats
The effectiveness of Talking Mats for people with learning disabilities

framework as a communication resource to enable people with learning disabilities to express their views on life planning.

**Materials and Methods**
The research consisted of four stages:

**Stage 1: Selection of an appropriate measure of functional comprehension**
In order to ascertain the most appropriate measure of functional comprehension the researchers carried out a review of existing measures and used this as the basis for a focus group with eight practising Speech and Language Therapists (SLT). The conclusion from the focus group was that no existing measures of functional comprehension were ideal. It was agreed that the most useful framework for describing levels of functional comprehension was the Derbyshire Language Scheme (DLS) which is based on the number of information carrying words (ICW) understood in one sentence. This scheme is widely used but was designed primarily for children. The researchers subsequently developed an adult-appropriate screening test using the same principles. The Stirling Understanding Screening Tool (SUST) identifies four levels of functional comprehension and was piloted with 12 people with learning and communication disabilities. It was also designed to be used by people with motor control problems. The SUST was used with all the participants in the main project to ascertain their comprehension level. The four levels of comprehension are:
Level 1: comprehending at the single ICW level;
Level 2: comprehending at the two ICW level;
Level 3: comprehending at three ICW level; and
Level 4: comprehending at four and more ICW level and with the ability to follow more abstract language.

**Stage 2: Selection of participants**
Information about the study was sent to six SLTs working with adults with learning disabilities, asking them to explain the study to potential participants. Exclusion criteria included those on the caseload purely for dysphagia, those with severe visual impairment and those with profound learning disabilities, i.e. whose responses are primarily at a sensory level. During the recruitment process 91 people were approached and 51 individuals agreed to participate. The SLTs were asked to indicate the comprehension level of each participant according to their own knowledge and also to identify the person’s main
communication method/s (MCM), i.e. the communication methods that the person usually employed such as speech, signing or Makaton. This process was carried out until 12 participants, as required for each comprehension level, were obtained resulting in 48 participants being recruited to the study.

Stage 3: Identification of life planning topics and interviewing participants
A focus group was held with six people with learning disabilities from an advocacy group with the aim of identifying the most relevant life-planning topics for people with learning disabilities. The World Health Organisation domains together with findings from previous AAC Unit research formed the basis of the focus group discussion and led to the identification of the following 13 topics for this project: Communication, Education/Training, Employment, Health, Household Jobs, Housing, Leisure, Mobility, Money, Relationships, Religion, Self Care and Transport. These were converted into symbols using Boardmaker software for use with the Talking Mats framework.

All 48 participants were visited on three occasions.
Visit 1: The purpose and process of the study was explained to participants in written, verbal and pictorial form. Care was taken to adapt the information and consent forms to take account of communication difficulties. Assessment of participants’ level of functional comprehension was completed at this visit using the SUST.

Visit 2: The views of participants on life planning issues were obtained using either a) Talking Mats (TM) or b) MCM (main communication methods) without the use of Talking Mats. Visits were carried out according to a crossover design to ensure that any influences from one type of interview to the other could be identified. Half were interviewed with TM followed by MCM and the other half were interviewed with MCM before TM. Each participant was asked both about general life planning topics and a detailed life planning topic of their choice. A digital photo was taken of each completed Mat as a record of the participant’s view of each topic and both interviews were video recorded.
Visit 3: Participants were visited within two weeks of visit 2 to carry out the second interview.

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1 The Picture Communication Symbols (PCS) are ©1981–2006 Mayer-Johnson Co. and are used with permission – Mayer-Johnson Co., P.O. Box 1579, Solana Beach, CA 92075, USA
Stage 4: Analysis
Four measures were used to examine effectiveness:

i) Effectiveness Framework of Functional Communication
By its nature, judging the effectiveness of an interaction is subjective but through a process of literature review, video observation and peer discussion the following five-point coding framework, which was designed and trialled in previous projects\textsuperscript{16,17} was further refined.

Table 1. Effectiveness Framework of Functional Communication

<table>
<thead>
<tr>
<th>Indicators</th>
<th>4</th>
<th>3</th>
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<td>Participant’s understanding issue for discussion</td>
<td>Always</td>
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<td>Occasion</td>
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<td>Participant’s engagement with person</td>
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<td>Confidence of participant</td>
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<td>Researcher’s understanding of participant’s views</td>
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<tr>
<td>Participant’s satisfaction with end result</td>
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</table>

Definitions and examples from the Effectiveness Framework of Functional Communication:
- Participant’s understanding – based on verbal and non-verbal responses. For example, On Mat A shown in Figure 1 the participant said ‘mouse–not like’ as he placed the pet symbol on the negative side of the Mat.
Engagement – the social closeness that is established in the interaction and maintained through rapport and joint attention. This is also described as ‘intimate talking’, particularly expressed through voice, facial expression and body language, where people convey personal thoughts and feelings and produce reactions in others. For example, when asked about his views on transport, one participant joked with the researcher about driving a car by pretending to turn a steering wheel.

Confidence in articulating views/placing symbols. This confidence was demonstrated by the manner in which the participant responded and the pattern of responses, e.g. low confidence was demonstrated by hesitancy in articulating views or dropping symbols on the Mat rather than placing them. Figure 2 show the different patterns on TM between two participants on detailed Mats on the topic of leisure. The pattern on Mat A reflects deliberate, clear choices, suggesting confidence, in contrast to Mat B where the placing of symbols appeared to be poorly considered resulting in a random pattern, suggesting lack of confidence.
The effectiveness of Talking Mats for people with learning disabilities

Figure 2. Examples of patterns on Mats illustrating confidence

- Interviewer’s understanding of participant’s views – shown by non-verbal and verbal responses of interviewer. For example, the interviewer nodded and pointed to a CD player in response to one participant’s placing of the music symbol on the positive column on the Mat.

- Participant’s satisfaction with their confirmed views – primarily demonstrated non-verbally, e.g. giving thumbs up at the end of the interview or occasionally verbally, e.g. ‘that was great’. In contrast one participant kept looking at his sisters in the kitchen and indicated he wanted to join them rather than complete the interview.

The video recordings of visits 2 and 3 were analysed using this five-point effectiveness coding framework.

The literature describes inherent difficulties when different researchers rate data resulting in inconsistent inter-judge agreement between professionals.20-22 Strategies to improve this were incorporated:

- Avoidance of overly complex judgement tasks;
- Development of clear definitions for making the judgements;
- Providing a consistent setting for rating videos;
- Independent rating of the data followed by negotiation;
- Asking the raters to justify/explain their judgements; and
- Combining the judgements of the raters to achieve a consensus.

Three raters watched the video recording of each topic on both the TM and the MCM interviews and scored each topic on the effectiveness coding framework (Table 1) independently. Where there was not initial agreement the video clips
were re-examined, discussed and negotiated until a consensus was reached. A record was kept of inter-judge agreement as follows:

0 = total agreement on all five indicators
1 = consensus reached with minor shifts – i.e. 1 point difference on, at most, one indicator
2 = consensus reached after some discussion – i.e. 1–2 point differences shifted on one indicator
3 = consensus reached after considerable discussion – i.e. several points shifted on more than one indicator
4 = no consensus reached

ii) The time taken for both interviews was recorded and compared.

iii) The number of topics discussed by each participant was counted and compared.

iv) On-task behaviour was recorded and analysed.

Additional analysis of on-task behaviour was undertaken by a clinical psychology student who was not involved in carrying out the interviews and was not trained in or knowledgeable about TM methodology. Twenty-four of the video recordings (12 TM interviews and 12 MCM interviews) were analysed for on-task behaviour, which involved recording the occurrence of target behaviours at 10-second intervals. The recordings were randomly selected for the student to include six participants from each of the four comprehension levels. The following three target on-task behaviours were identified:

- Purposeful and controlled eye contact towards the interviewer;
- Purposeful and controlled eye contact with objects or visual stimuli connected with the interview; and
- Active engagement – defined as attending to the interview process and being responsive to interview prompts and stimuli.

For all data, homogeneity of variance was assessed, and if there was a significant difference in the variance of the groups, non-parametric analyses were performed. Communication Effectiveness and On-task behaviour were compared between the two interview conditions using the Wilcoxon signed-rank test (Bonferroni-corrected). Time and Number of topics discussed were measured using the paired samples t-test (Bonferroni-corrected).
Results

Demographics

Table 2. Demographic information

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<tr>
<th>Demographic Information</th>
<th>Level 1</th>
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</tr>
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<td>1</td>
<td>-</td>
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<td>High-tech AAC</td>
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<tr>
<td>Non-verbal</td>
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</table>

The mean age of the participants was 25.75 with little variation between the four groups. This was not intentional but merely reflected the age range of participants seen by the SLTs. Comprehension levels obtained from the SUST were compared with information given to the researchers by the participant’s SLT. There was agreement in 41 out of the 48 cases (85.4%). In the remaining seven cases the discrepancy never exceeded one level except for one participant. On discussion with his SLT it was apparent that his behaviour and consequent ability to understand had changed between his therapy input and the time of the data collection.

i) Effectiveness Framework of Functional Communication

The inter-observer agreement between three raters, combining total agreement (0) and consensus reached with minor shifts (1) on the video coding of the TM was 80.4% and on MCM was 66.4%. Where there was not initial agreement the videos were re-examined, discussed and negotiated until a consensus was reached. There were no cases where consensus was not reached.

The median aggregate score for TM was 17.0 compared with 8.0 for MCM for general topics. This difference was statistically significant [Wilcoxon signed-rank test, \( z = 4.64, \ p<0.01 \) (Bonferroni-corrected)]. Figure 3 illustrates that the aggregate scores of effectiveness indicators on both TM and MCM. At level 1 the scores are lower and the range is wider indicating a less stable response than at level 4 where the scores are higher and the range is narrower.
The researchers considered a total score of 15 (75%) or more on the Effectiveness Framework of Functional Communication represented effective communication. Analysis identified 30 participants as being able to use TM effectively – 12 people at level 4, 11 people at level 3, five people at level 2 and two people at level 1. All these participants achieved a score of at least 15 out of a possible 20. The following figures show box plots for the four groups of participants comparing TM and MCM for general topics. Four participants at level 1 were unable to complete interviews on general topics.
Figure 4 illustrates that participant understanding was better for TM than MCM at each level of comprehension. A test for the total group confirms that participant understanding was significantly better for TM compared to MCM [Wilcoxon signed-rank test, z = 4.46, p<0.01 (Bonferroni-corrected)].

Figure 4. Participant understanding of issue
Figure 5 illustrates that engagement was better for TM than MCM at each level of comprehension. A test for the total group confirms that engagement was significantly better for TM compared to MCM [Wilcoxon signed-rank test, $z = 4.14$, $p<0.01$ (Bonferroni-corrected)].

Figure 5. Participant engagement
Figure 6 illustrates that participants’ confidence in responding, both verbally and non-verbally, was better during the TM interviews than during the MCM interviews at each level of comprehension. A test for the total group confirms that participant confidence was significantly better for TM compared to MCM [Wilcoxon signed-rank test, $z = 4.41$, $p<0.01$ (Bonferroni-corrected)].

Figure 6. Participant confidence
Figure 7 illustrates that the researchers’ understanding was better for TM than MCM at each level of comprehension. A test for the total group confirms that researcher understanding was significantly better for TM compared to MCM [Wilcoxon signed-rank test, \( z = 4.85, p<0.01 \) (Bonferroni-corrected)].

Figure 7. Researcher understanding
Figure 8 shows that participants’ satisfaction at the end of the interview was greater when using TM than MCM at each level of comprehension. A test for the total group confirms that participant satisfaction was significantly better for TM compared to MCM [Wilcoxon signed-rank test, $z = 4.65$, $p<0.01$ (Bonferroni-corrected)].

**Figure 8. Participant satisfaction**

![Box plot showing participant satisfaction for TM and MCM at different levels of comprehension.](image)

*ii) Time taken*

Figure 9 shows that, when expressing views on the detailed topic of their choice, at all levels of comprehension, participants interacted for longer. Differences in the aggregate median times (TM 7.21 Minutes, MCM 2.39 minutes) were statistically significant [Wilcoxon signed-rank test, $z = 4.57$, $p<0.001$]

- Level 1 - TM = 7.37, MCM = 2.26 minutes
- Level 2 - TM = 7.09, MCM = 2.25 minutes
- Level 3 - TM = 4.48, MCM = 4.16 minutes
- Level 4 - TM = 8.79, MCM = 3.78 minutes
Chapter 6

Length of time is not necessarily an indication of quality of interaction but the fact that participants interacted for longer means that they have more opportunity to have their views listened to.

Figure 9. Comparison of time taken to complete Talking Mats and MCM on detailed topics

![Box plot showing time taken to complete tasks.]

iii) Number of topics discussed

Figure 10 shows that all participants expressed their views on more topics, both at the general and the detailed level when using TM compared to using their MCM. Overall, TM resulted in significantly more topics than MCM. General topics, [Paired samples t-test, t(42) = 42.2, p<0.01 (Bonferroni-corrected)]. Detailed topics, [Paired samples t-test, t(29) = 8.82, p<0.01 (Bonferroni-corrected)].

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iv) On-task behaviour

Table 3 presents the mean percentages of on-task behaviours in the TM and MCM interviews for each of the four comprehension level groups. Analysis demonstrated more on-task behaviour of participants when using TM as compared to using MCM. The total quantity of on-task behaviour was 94.5% for the TM interviews and 79.4% for the MCM interviews. The largest difference between TM and MCM was found in comprehension level 1, indicating that the use of TM may result in more on-task behaviours for those individuals with lower comprehension levels. A Wilcoxon Signed-Rank Test was carried out to compare the total scores of on-task behaviours between the TM and MCM interviews. This test showed a significant difference in on-task behaviours between TM and MCM (z = 3.060, p = 0.001).

Table 3. Mean percentages of total on-task behaviours between different comprehension levels

<table>
<thead>
<tr>
<th>Comprehension Level</th>
<th>TM</th>
<th>MCM</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>86.8%</td>
<td>52.0%</td>
<td>34.8%</td>
</tr>
<tr>
<td>2</td>
<td>95.3%</td>
<td>83.6%</td>
<td>11.7%</td>
</tr>
<tr>
<td>3</td>
<td>99.1%</td>
<td>94.3%</td>
<td>4.8%</td>
</tr>
<tr>
<td>4</td>
<td>96.7%</td>
<td>87.9%</td>
<td>8.8%</td>
</tr>
<tr>
<td>Aggregate scores</td>
<td>94.5%</td>
<td>79.4%</td>
<td>15.0%</td>
</tr>
</tbody>
</table>
Discussion
This study identified that TM performed uniformly better than MCM in relation to all five measures of communication effectiveness across all four groups of participants suggesting that TM can be a useful resource to assist many people with learning difficulties to express their views.

Participants at level 1
Whilst the TM method was not as effective for most participants who understood only one ICW, there was evidence that the structure provided by TM produced a better performance on all the indicators on the effectiveness framework than when using the participant’s MCM only. Using TM also increased the length of the interview and, whilst time in itself is not a sign of quality of interaction, Porter et al. suggest that where the interaction lasts for longer, there is more possibility of getting to the root of what the person means and of being able to confirm with them that they have been understood. In addition the evidence from the time series ‘on-task’ study suggested that TM reduced distractibility, particularly for participants at level 1. Finding ways of decreasing distractibility, establishing social closeness and maintaining interaction is crucial to this client group and TM appear to do all of these. In addition to TM other methods need to be explored to validate the views of people at level one, such as ‘See what I mean’.

Participants at level 2
Effective use of TM was indicated for 5/12 (42%) of participants who understood two ICWs. Participants at level 2 appeared to be on the threshold of communication effectiveness as their engagement and confidence increased as the interview progressed suggesting that using TM is a skill that could be specifically taught. Further research is required to study ways to improve the ability of this group to use TM effectively.

Participants at level 3 and 4
Participants in these groups were identified as effective users of TM and the findings demonstrate that the views expressed on TM are both richer and clearer than those expressed solely using MCM. Although the participants who were identified as using TM effectively often had verbal language, signing or alternative communication systems, there was an increase in their communication both in terms of quality and quantity when using TMs. There were significantly more topics discussed when using TM than with MCM. This can be explained by the structure
The effectiveness of Talking Mats for people with learning disabilities

of TM which allows a range of topics to be presented via visual symbols in a shared activity which shifts the balance of power towards the participant. When there was limited response during the interviews using the participants’ MCM only, the researchers prompted the participants. Without the structured visual support provided by TM the interaction was weighted towards the interviewer and became increasingly imbalanced. TM provides an alternative structure which reduces this reliance on speech which is at times misplaced.\(^5\)

TM enhances good quality responses in an interview by providing the following essential components as described in qualitative research methodology:\(25\)

- A framework to support open questions;
- Establishment of rapport and neutrality on the part of the interviewer;
- Presentation of information to be considered, in small meaningful chunks;
- A scaffold to help the interviewer listen to, observe and interpret both verbal and non-verbal information;
- Time to provide reflection and review of views;
- A structure to allow participants to focus on their internal thoughts and use their MCM as much or as little as they want; and
- The use of visual symbols to reduce memory demands.

Additional factors

The following factors were observed to influence communication performance in this study and have implications for all people with learning disabilities. For those people identified on the threshold of communication effectiveness eliminating or reducing these factors may improve their ability to use TM.

Distractions such as tannoy systems in day centres and interruptions by others caused significant disturbance for some participants. For some participants, reducing motor demands for the task, such as facilitating eye pointing, assisted those who had difficulty both ‘thinking and doing’. Visual difficulties affected some participants’ responses and by making symbols larger and using black symbols on a yellow background increased the effectiveness of response. Medical factors such as the impact of seizures and drugs affected the communication of several participants.

The effective use of TM may be influenced by the degree of iconicity and concreteness of the topics. For example, options relating to leisure such as swimming or watching TV are more concrete and easier to represent in symbolic form than options relating to health such as diet or mood.
Further investigation of these factors is required.

**Limitations**
One of the limitations of this study is the potential of researcher bias as the researchers carried out the interviews and the analysis. This was addressed to some extent by looking at inter-rater agreement, which was acceptable and by the inclusion of the additional analysis by a researcher who was not part of the research team. No discussion about the project or videos took place and the results followed the same trend as the larger research project. Future research should build in independent rating from the start.

Further work to substantiate the value of the effectiveness framework and the consensus approach to inter-judge rating is being undertaken.

The homogeneity of the age of participants may have biased the results as older adults with learning disabilities may have had a different reaction to using the TM. However, as the age range reflected the participants on the SLTs' caseloads this group would appear to be the most relevant group with whom to examine the effectiveness of TM.

Those who argue for the need for evidence and objective data on communication effectiveness could criticise the methodology of using a coding framework which depends on the raters making ‘subjective’ judgements about communication nuances such as understanding, engagement, confidence and satisfaction. However, communication within a dyad is extremely complex and involves constant shifts in verbal and non-verbal communication signals between the partners. Where there is additional communication impairment, the pace of interaction varies to accommodate delayed responses and misinterpretations. To examine only objective elements of communication such as syntax, vocabulary, initiations and turn taking ignores this continual negotiation and alteration of affect during communication. On the other hand to only measure the effectiveness of communication by inference from observation and ad hoc comments does not provide sufficient rigour. The methods used in this study attempt to combine both the richness of qualitative observations with quantitative attention.

**Conclusion and implications**
This study has demonstrated that, for people whose comprehension is at three or more ICWs, TM has proved to be an effective and reliable communication resource to help them express their views. The quality and quantity of information obtained is significantly greater than when using only their MCM. For those people
The effectiveness of Talking Mats for people with learning disabilities

whose comprehension is at one ICW, TM may not reflect their views reliably but it does improve their attention and interaction. For people whose comprehension is at two ICWs the findings are tentative and this group deserves further research. The study has identified additional factors which influence the quality of interaction.

The TM framework has been developed clinically to allow people to comment on a range of topics including general health, transition, accommodation, healthy eating, mood, activities of daily living, consent to treatment, sexual awareness, friendship, issues of vulnerability, goal setting and service evaluation. The use of the TM framework has increased the number of people with learning disabilities who can meaningfully be involved in decision making and provides a structure for carers and staff to interview, discuss and ascertain opinions. The information from this study has increased confidence in the effectiveness of TM and has determined how TM can and cannot assist people with learning disabilities to express their views.

**Ethical statement**

Ethical permission was granted by Forth Valley Ethics of Research Committee and ethics committee in Psychology Department, University of Stirling.
References

13. Cameron, L. and Murphy, J. (2004) Stirling Understanding Screening Tool - SUST
The effectiveness of the Talking Mats framework in helping people with dementia to express their views on well-being

Murphy J, Gray CM, Cox S, van Achterberg T, Wyke S.

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Abstract
Deteriorating communication is one of the most distressing aspects of dementia and it becomes increasingly difficult to ensure that the person's views are heard. This study involved 31 people at different stages of dementia who were each interviewed about their well-being using Talking Mats, a low-tech communication framework, and usual communication methods. The communication effectiveness of each method was compared. This study found that the Talking Mats framework was associated with higher ability of people at all stages of dementia to communicate compared to usual communication methods. Better communication effectiveness was evident in the participants' understanding, engagement, keeping on track and ability to make their views understood. There was also less repetitive behaviour and less distractibility when participants were using the Talking Mats framework. The findings suggest that the Talking Mats framework can play an important role in improving communication by providing an accessible, low-cost tool which family and staff could use with people with dementia to help them express their views.
Background
There are currently 700,000 people with dementia in the United Kingdom with the forecast that the number will rise to over a million by 2025. All types of dementia are progressive with a gradual decline in the person's ability to remember, understand, reason and communicate. This deterioration is one of the most distressing aspects of the illness. Depending on the type and cause of dementia the communication difficulties may include reduced vocabulary, word-finding difficulty, problems with reasoning, perseveration (repetition of previously used words, phrases or behaviour), lack of coherence, losing track of topic and distractibility. As the illness progresses the person with dementia becomes harder to reach and it is increasingly difficult to ensure that their views are included in planning and that they are involved in decisions about their lives. This deterioration is distressing not only for the person with dementia but also for family, friends and caregivers. It also means that a wide range of staff in different settings such as care homes, day centres, GP surgeries, hospitals, etc. are challenged to improve their communication skills with people with dementia. There is a danger that, if staff or caregivers have difficulty communicating, the person with dementia may be progressively disempowered and their rights may be restricted and choices may be imposed on them by others.

Other studies of AAC and dementia
Resources such as pictures, word cards, memory books and objects have proved helpful mainly for supporting people with dementia to reminisce about their life or to remind them of what they have to do. They may also be useful for stimulating conversation for some people but research into the effectiveness of such interventions with people with dementia has been limited and findings difficult to generalise. Studies of memory aids on the conversational content and social skills of people with dementia and their caregivers showed that use of memory wallets increased the frequency of factual information; decreased the rate of ambiguous, perseverative, erroneous, or unintelligible utterances; increased the conversational responsibility (turn taking) of the person with dementia; and increased the number of on-topic statements during a conversation. Although the use of memory aids may encourage interaction they do not help people with dementia to express their views or be involved in decision making. However, it has been argued that given the right support, individuals with dementia can express opinions about services but that staff need help with identifying and using opportunities for meaningful consultation.
User involvement and participation in shaping and improving services is now a requirement in health and social care throughout the UK. In order to improve service planning and service delivery in care facilities it is important that the views of users are included but because of communication difficulties such as those outlined above, many people with dementia are unable to respond to conventional methods of obtaining their views such as interviews or questionnaires. As a result these are often completed by family or formal caregivers. Whilst there are increasing efforts to gain the views of people with dementia about their quality of life and care even when the condition is fairly advanced, there continues to be reliance on methods such as Dementia Care Mapping, which depends on observation rather than talking directly to the person with dementia. Person-led approaches to involvement are often challenged by time constraints, limited staff support and difficulties in recording and collating views. Despite the debate about the importance of protecting the ‘rights and freedoms’ of people with dementia, there are few studies which have examined the views of people with dementia about their day-to-day care and choices. Moreover, research involving people with dementia invariably excludes participants with communication difficulties. For example in a study by Tyrrell, which investigated freedom of choice and decision making amongst people with dementia, a criterion for inclusion in the study was capability of communicating verbally in an interview situation. It is therefore apparent that the views of people with dementia, especially those with communication difficulties, are seldom sought.

Previous work has emphasised several factors which could improve communication for people with dementia. These included the use of carefully chosen pictures, making use of both verbal and non-verbal communication, giving people opportunities to talk in indirect ways and providing resources to help staff communicate with people with dementia. People with communication difficulties may also take much longer to respond than those whose communication is unimpaired so it is important to give people with dementia enough time to respond. As Killick and Allan suggest, ‘One of the ways in which people with dementia are disempowered in communication is that of being continually outpaced, having others speak, move and act more quickly than they are able to understand or match’.

The Talking Mats framework
Talking Mats is a low-technology communication framework that was developed at the University of Stirling to help people with communication difficulties to express
their views about a number of topics. It is easily accessible, inexpensive, can be used in any setting and meets the criteria for better communication with people with dementia.\textsuperscript{14} The Talking Mats framework uses three sets of picture symbols – topics, options and visual scale:

1. **topics** – whatever participants want to talk about in relation to a specific issue. For example, pictures symbolising *activities, environment, relationships, self care*, etc;
2. **options** relating specifically to each topic. For example, *listening to music, playing card games, visiting friends*, etc; and
3. **visual scale** in order to allow participants to indicate their general feelings about each topic and option. For example, whether they are *happy, unsure, unhappy*.

Once the topic is chosen, e.g. ‘what do you feel about the activities you do?’, the person is given the options one at a time and asked to think about what s/he feels about it. S/he can then place the symbol under the appropriate symbol on the visual scale to indicate what s/he feels. It allows topics to be explored at different levels. The following example shows how an older woman felt about the environment of the care home where she was living. She indicated she was happy with the comfort of the furniture, the food, the area surrounding the care home and the temperature of the building. She was unsure about living in the care home in general and the safety. She was not happy with the noise level.

Figure 1. Example of a Talking Mat used to gather and record the views of an older woman about the environment in which she lived (a residential care home)
The effectiveness of Talking Mats with people with dementia

An important feature of the Talking Mats framework is that, as far as possible, the interviewer asks open questions such as ‘What do you feel about reading?’ rather than ‘Do you have a problem with reading?’ to ensure that they are not influencing the participant. Participants are also encouraged to comment on both positive and negative feelings about the options and to change their minds if they wish to. Participants are given as much time as they need to respond and blank squares are provided for the participant to add any additional options. Participants are also encouraged to look back over their Mats and alter or confirm their views. When they are happy with the final Mat a digital photo is taken as a record of their views. The interviewer can use as many Mats as are appropriate to the person they are talking with and may also want to use a ‘submat’ to explore some issues in more detail such as – what was it about the noise level that this woman was unhappy with?

Previous research has been carried out to examine the feasibility of the Talking Mats framework with different client groups with communication difficulties including people with cerebral palsy, motor neurone disease, aphasia and learning disability. A pilot study was carried out using the Talking Mats framework with 10 frail older people to gain views about quality of life as part of a larger research project. This study included seven people with dementia and found that the Talking Mats framework was ‘an innovative method of gaining views which the person with communication difficulties may not be able to express otherwise’. However, further research on the effectiveness of the framework with people at different stages of dementia was necessary.

In this paper we present the results of a study of the effectiveness of the Talking Mats framework in enabling people with dementia to express their views on aspects of well-being in comparison to other communication methods. We ask two specific research questions:
1) Is the communication effectiveness of people with dementia better with the Talking Mats framework than with a structured conversation and an unstructured conversation?
2) How does the Talking Mats framework affect the communication of people at different stages of dementia?

Research design, methods and analysis
Participants
The study involved 31 participants resident in central Scotland recruited through local dementia services. Inclusion criteria were: to have a confirmed diagnosis of
dementia; to have sufficient vision to see picture symbols; and to be physically well enough to take part. People whose first language was not English were also excluded as it was felt that the picture symbols would give a bias towards the Talking Mats framework.

Although the appropriateness of categorising people in ‘stages of dementia’ is debatable, (progress of the illness varies a lot from person to person and problems can vary from day to day or even hour to hour) it is a common practice. In this study, participants who were eligible and willing to take part (see below) were assigned to one of the three ‘stages of dementia’ on the advice from staff at the relevant dementia service or care home who knew the participant well. We aimed for equal numbers in each. Thus group A included 10 people said by staff to have ‘early stage dementia’, group B included 11 people said by staff to have ‘moderate stage dementia’ and group C included 10 people said to have ‘late stage dementia’.

The participants’ ages ranged from 54 to 90. Seven lived in their own home, two lived in sheltered housing (with warden support) and 22 were in residential care homes.

Consent
As a research group we have considerable experience in working with people with communication difficulties and were sensitive to the ethical considerations of obtaining informed consent. We were aware that the participants in this project were particularly vulnerable as they could have specific difficulties in both understanding the purpose of and their involvement in this study. It was considered of overriding importance that the participants should be treated autonomously, and that every effort should be made to enable them to give informed consent themselves. However, it was also necessary to conform to The Adults with Incapacity (Scotland) Act 41 which specifies that where a person is unable to give informed consent to participate in research, consent must be obtained from a guardian, welfare attorney or from the adult’s nearest relative. Therefore, following the example of Allan 14, a three stage consent process was adopted. First, the families of potential participants were sent information about the project and asked whether they would be happy for their relative to take part. Second, the researcher visited the individual with dementia themselves, explained the study to them and asked them if they would like to participate. Finally, a policy of ongoing consent was followed whereby the researcher made sure at each subsequent visit that the participants were fully aware of what was expected of
them and were happy to proceed. Care was taken to adapt the consent and information forms to take account of cognitive and/or communication difficulties. Where the person was not able to give informed consent a family member/appointee was involved.

*Interviews*

There were three interview conditions:

1. Unstructured (ordinary) conversation – the researcher simply asked the participants to tell her about each topic; particularly about the things/people they liked or did not like.
2. Structured conversation – each topic was subdivided into a number of options that were discussed in turn in random order.
3. Talking Mats – similar to the structured conversation interview, but here the topics and options were converted into visual symbols using Boardmaker™ software¹ and placed under a visual scale.

Four topics central to social well-being, and a range of options within each topic, were identified from a previous study.⁴⁰ The project advisory group, which included people with dementia, met to comment on the project and also advise on the options and the symbols used. These were converted into pictorial representations to use with the Talking Mats framework. Larger symbols on colour contrasting background were available for participants with visual difficulties. The topics with examples of options were: *activities* – reading the paper, going for a walk, listening to music, etc.; *people* – family, shopkeepers, caregivers, etc.; *environment* – safety, comfort, food, etc.; and *self* – clothes, hearing, memory, etc. The topics are illustrated in Figure 2.

![Figure 2. Illustration of main topics](image)

¹ The Picture Communication Symbols (PCS) are ©1981–2008 Mayer-Johnson Co. and are used with permission – Mayer-Johnson Co., PO Box 1579, Solana Beach, CA 92075, USA
Visits

The participants were visited on four occasions:

Visit 1. Once the participants had been identified, the purpose and process of the project was carefully explained to them both in written and pictorial form and they were shown how the Talking Mats framework would be used. At this first visit the researcher also obtained demographic information from the caregiver including an estimate of the stage of dementia of the participant.

Visit 2. The participants were interviewed using the Talking Mats framework about the four well-being topics which were always presented in the same order – ‘Activities’, ‘People’, ‘Environment’ and ‘Self’ from the most concrete and easiest to understand to the most abstract. The options were presented in random order and on completion of each Mat the interviewer went over the symbol choices to confirm that the participant was happy with the views expressed. If a participant indicated they were tired or had had enough the interview was stopped. A digital photo was taken of each completed ‘Mat’ to act as a record of the participant’s views.

Visit 3. The participants were interviewed using their usual communication methods in an unstructured conversation followed by a structured conversation which mirrored the Talking Mats interview, covering exactly the same topics and options, but without the visual support.

Visit 4. Participants were visited to thank them for their involvement and to give them copies of their completed ‘Mats’.

Visits 2 and 3 were carried out according to a crossover design to ensure that any influences from one type of interview to another could be identified. All three interviews were video recorded. The visits took place wherever the participant was most comfortable and, on the advice of care staff or family members, took into account factors which may have affected the participant’s ability to respond such as time of day and administration of medication. It is important that when people with dementia take part in research, they should feel that their contribution has been valued. Accordingly, the researcher made a point of terminating each interview by thanking the participant for their time, and stressing how well they had done and how interesting their views had been.
The effectiveness of Talking Mats with people with dementia

Evaluation methods

Three aspects of communication were considered: effectiveness, perseveration and distractibility. The video recordings were studied by two researchers and a final-year psychology student to examine the effectiveness of communication in the three conditions – Talking Mats, unstructured conversation and structured conversation. The following evaluation methods were used:

a) Effectiveness framework of functional communication

The study piloted and refined a simple coding framework to assess effectiveness of functional communication, which had been developed in previous studies and presented to Speech and Language Therapists both in the UK and overseas to test face validity. The coding framework included the following communication indicators:

- the participant’s understanding of the options presented – based on verbal and non-verbal responses;
- the engagement of the participant with the interviewer and the task. This reflects the social closeness that is established in the interaction and maintained through rapport and joint attention;
- the amount of time during the interview that the content of the participant’s communication was ‘on track’ – ‘on track’ meaning the relevance of the participant’s verbal and non-verbal responses to the topic being discussed; and
- the interviewer’s understanding of the participant’s views – shown by non-verbal and verbal responses of interviewer.

All four communication indicators were measured on a 5-point scale (4 – always; 3 – often; 2 – 50:50; 1 – occasionally and 0 – never/none). The earlier coding frameworks contained an indicator that assessed the confidence of people with intellectual disability when using Talking Mats. This indicator was removed from the coding framework in the current project as people with dementia can often mask their communication difficulties as they try to preserve social skills. Consequently, the perceived confidence of a person with dementia may not accurately reflect their ability to communicate. However, because of the prevalence of problems with topic maintenance in dementia, it was appropriate to add an ‘on-track’ indicator to the effectiveness coding framework.

For the purpose of the analysis the first three options within each of the four topics presented to the participant were studied in all three interview conditions.
A consensus approach was used to analyse the video recordings in all three conditions and the following strategies were employed to improve inter-judge agreement as suggested in the literature.44-46

• All videos were watched in the same room under the same conditions;
• Each participant’s video was watched in one sitting;
• Clear definitions were developed for making judgements;
• The raters watched the video clips and scored the coding framework without knowledge of the others’ scores;
• They then discussed their individual scores for each topic and, where there was discrepancy, the raters were asked to justify and explain their judgements;
• The raters might then adjust their score but only if convinced by another person’s argument. They were not required to reach a complete consensus if, after consideration, their views still differed from each other; and
• A record was kept of inter-judge agreement following any adjustments.

All instances of inter-rater agreement and disagreement were recorded and the percentage of agreement was determined by dividing the number of agreements by the number of agreements plus disagreements and multiplying by 100.11

b) Perseveration
A commonly observed phenomenon in dementia is that people will repeat previously used words, phrases and behaviour that no longer appear relevant to the topic of discussion.4,5,43 Occurrences of perseveration were recorded when examining the video recordings. For example, one participant told the researcher how she liked her ‘own people’ during the unstructured conversation interview, and repeated this sentiment (changing it variously to ‘old people’, ‘old friends’ and ‘Highland people’) on a number of occasions during all four structured conversation topics.

c) On-task behaviour
A fourth-year undergraduate student undertook an additional analysis to determine whether the Talking Mats framework affected the distractibility of participants compared to the unstructured and structured conversations. This analysis focused on the proportion of time each participant spent engaged in ‘on-task’ behaviours during the ‘Activities’ topic. A time series analysis of all three interview conditions was used to record the occurrence of target behaviours at 10-second intervals. For each condition (Talking Mats, structured conversation and unstructured
conversation) the overall percentage of time spent on-task was calculated. For each participant, the number of time intervals where a participant was recorded as being on-task was divided by the total number of intervals used in observation. This resulted in a ratio showing the total percentage of time spent on-task. The judgement of ‘on-task’ behaviours was based on:

- Making purposeful eye contact towards the interviewer;
- Making purposeful eye contact with the visual stimuli connected with the interview; and
- Showing active engagement, i.e. attending to the interview process and being responsive to interview prompts and stimuli.

**d) Time**

The time taken for each of the three interview conditions was recorded and compared as it is important to know if the Talking Mats framework is practical in terms of staff time.

Data were analysed using SPSS. Because data related to communication effectiveness, perseveration and on-task behaviour were ordinal and not normally distributed, results across interview conditions were compared using the Wilcoxon signed-rank test (Bonferroni-corrected). Time was compared using the paired samples t-test (Bonferroni-corrected).

**Results**

**Response rate**

Sixty families were asked if they would be willing for their relative to be involved in the project (Consent Stage 1). Thirty-six (60%) responded. When the participants themselves were approached (in Consent Stage 2) two were not happy to take part, two were unable to see even large symbols and one did not have English as his first language. The remaining 31 people were eligible and willing to take part (52% of original sample and 86% of those whose relatives responded).

**Consensus approach to inter-rater reliability**

The average inter-rater agreement before consultation was 54% of the scoring decisions produced. The average inter-rater agreement after consultation was 92% (range 77.4–100%). This figure is well above 70%, the common lower bound for an acceptable level of agreement.47
Comparison of communication effectiveness between the Talking Mats framework, structured conversation and unstructured conversation.

a) Communication Effectiveness

Table 1 demonstrates that the Talking Mats framework was associated with significantly better performance than both structured conversation and unstructured conversation for all four indicators of communication effectiveness.

Table 1. Median scores for each communication indicator across all participants by interview condition and asymptotic z-scores and associated p-values (2-tailed)

<table>
<thead>
<tr>
<th></th>
<th>TM</th>
<th>SC</th>
<th>UC</th>
<th>Statistical test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>TM vs. SC</td>
<td>TM vs. UC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant Understanding</td>
<td>3.79</td>
<td>3.38</td>
<td>3.25</td>
<td>z = 3.84, p &lt; 0.001  z = 3.61, p &lt; 0.001</td>
</tr>
<tr>
<td>Engagement</td>
<td>3.88</td>
<td>3.46</td>
<td>3.50</td>
<td>z = 3.72, p &lt; 0.001  z = 3.02, p &lt; 0.005</td>
</tr>
<tr>
<td>On Track</td>
<td>3.63</td>
<td>2.50</td>
<td>2.25</td>
<td>z = 4.43, p &lt; 0.001  z = 4.00, p &lt; 0.001</td>
</tr>
<tr>
<td>Researcher Understanding</td>
<td>3.71</td>
<td>3.00</td>
<td>2.17</td>
<td>z = 4.18, p &lt; 0.001  z = 4.28, p &lt; 0.001</td>
</tr>
</tbody>
</table>

TM=Talking Mats; SC=Structured conversation; UC=Unstructured conversation

Comparison of the Talking Mats framework with structured and unstructured conversations between people at different stages of dementia.

Table 2 shows the median total effectiveness scores across all four topics for all stages and for each stage in turn. It suggests that the Talking Mats framework is associated with improved communication for all stages compared to either structured or unstructured conversation. Following Murphy et al.48, a total score of 12 (75%) or more across the four communication indicators was considered to represent effective communication. However, scores of between 10 and 12 can be considered to represent communication interactions which are borderline effective.

At early-stage dementia, people communicated effectively regardless of whether they were using Talking Mats, structured conversation or unstructured conversation. There was a significant difference in total communication effectiveness between Talking Mats and structured conversation but not between Talking Mats and unstructured conversation.

At moderate-stage dementia, effective communication was only achieved when Talking Mats was used. Moreover, Talking Mats scored significantly higher than either structured conversation or unstructured conversation.

At late-stage dementia, communication remained below the effectiveness level for all three interview conditions. However, Talking Mats scored significantly higher than structured conversation and unstructured conversation. Several people with late-stage dementia produced Talking Mats effectiveness scores of 10 or more.
which is considered to be borderline effective. Nevertheless, there was a high degree of variability in this participant group and, with three participants scoring less than 7, it is clear that not all people with late-stage dementia can use the Talking Mats framework effectively.

Table 2. Median communication effectiveness scores at each stage of dementia by interview condition and asymptotic z-scores and associated p-values (2-tailed)

<table>
<thead>
<tr>
<th></th>
<th>TM (IQ range)</th>
<th>SC (IQ range)</th>
<th>USC (IQ range)</th>
<th>Statistical test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>TM vs. SC</td>
</tr>
<tr>
<td>All stages</td>
<td>14.92 (13.17–15.88)</td>
<td>12.33 (7.96–14.96)</td>
<td>11.25 (5.33–15.58)</td>
<td>z = 4.47, p&lt;0.001</td>
</tr>
<tr>
<td>Early</td>
<td>15.98 (15.76–16.0)</td>
<td>15.42 (14.90–15.81)</td>
<td>15.88 (15.40–15.97)</td>
<td>z = 2.51, p&lt;0.01</td>
</tr>
<tr>
<td>Moderate</td>
<td>14.50 (13.42–15.54)</td>
<td>11.55 (11.08–12.92)</td>
<td>11.25 (7.75–13.58)</td>
<td>z = 2.93, p&lt;0.01</td>
</tr>
<tr>
<td>Late</td>
<td>11.19 (6.56–13.46)</td>
<td>6.23 (3.16–10.05)</td>
<td>4.56 (2.91–10.19)</td>
<td>z = 2.40, p&lt;0.05</td>
</tr>
</tbody>
</table>

TM=Talking Mats; SC=Structured conversation; USC=Unstructured conversation

b) Perseveration

Table 3 shows that participants at all stages exhibited significantly less perseverative behaviour when being interviewed using the Talking Mats framework than structured conversation or unstructured conversation. At early-stage dementia, there was very little perseverative behaviour whether people were using Talking Mats, structured conversation or unstructured conversation, although the difference between Talking Mats and structured conversation was significant. At moderate-stage and late-stage dementia, there was significantly less perseverative behaviour when using Talking Mats compared to structured conversation or unstructured conversation.

Table 3. Median scores for perseveration at each stage of dementia by interview condition and asymptotic z-scores and associated p-values (2-tailed)

<table>
<thead>
<tr>
<th></th>
<th>TM (IQ range)</th>
<th>SC (IQ range)</th>
<th>USC (IQ range)</th>
<th>Statistical test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>TM vs. SC</td>
</tr>
<tr>
<td>All stages</td>
<td>0.63 (0.00–1.67)</td>
<td>1.56 (0.13–2.67)</td>
<td>1.33 (0.13–2.92)</td>
<td>z = 3.54, p&lt;0.001</td>
</tr>
<tr>
<td>Early</td>
<td>0.00 (0.00–0.03)</td>
<td>0.10 (0.00–0.22)</td>
<td>0.00 (0.00–0.22)</td>
<td>z = 2.21, p&lt;0.05</td>
</tr>
<tr>
<td>Moderate</td>
<td>0.86 (0.21–1.42)</td>
<td>2.08 (1.25–2.67)</td>
<td>1.67 (1.00–2.92)</td>
<td>z = 2.40, p&lt;0.05</td>
</tr>
<tr>
<td>Late</td>
<td>1.90 (1.25–2.35)</td>
<td>2.69 (1.73–3.00)</td>
<td>2.33 (1.42–3.94)</td>
<td>z = 1.99, p&lt;0.05</td>
</tr>
</tbody>
</table>

TM=Talking Mats; SC=Structured conversation; USC=Unstructured conversation
c) On-task behaviour
Table 4 shows that participants at all three stages exhibited more on-task behaviours when being interviewed using the Talking Mats framework than when being interviewed using structured conversation or unstructured conversation. At early-stage dementia, participants remained on-task whether they were using Talking Mats, structured conversation or unstructured conversation and there was no statistical difference between the three conditions. At moderate-stage dementia, there was more on-task behaviour when using Talking Mats compared to structured conversation and the difference was significant. There was no statistical significance between Talking Mats and unstructured conversation. At late-stage dementia Talking Mats scored significantly higher than either structured conversation or unstructured conversation for on-task behaviour.

Table 4. Median scores for on-task behaviour at each stage of dementia by interview condition and asymptotic z-scores and associated p-values (2-tailed)

<table>
<thead>
<tr>
<th>Stage</th>
<th>TM (IQ range)</th>
<th>SC (IQ range)</th>
<th>USC (IQ range)</th>
<th>Statistical test</th>
</tr>
</thead>
<tbody>
<tr>
<td>All stages</td>
<td>0.87</td>
<td>0.68</td>
<td>0.66</td>
<td>z = 3.38, p&lt;0.01</td>
</tr>
<tr>
<td></td>
<td>(0.65-0.95)</td>
<td>(0.47-0.93)</td>
<td>(0.18-1.00)</td>
<td>z = 2.40, p&lt;0.05</td>
</tr>
<tr>
<td>Early</td>
<td>0.98</td>
<td>0.94</td>
<td>1.00</td>
<td>z = 1.37, n.s.</td>
</tr>
<tr>
<td></td>
<td>(0.90-1.00)</td>
<td>(0.75-0.99)</td>
<td>(1.00-1.00)</td>
<td>z = 0.67, n.s.</td>
</tr>
<tr>
<td>Moderate</td>
<td>0.81</td>
<td>0.63</td>
<td>0.66</td>
<td>z = 2.19, p&lt;0.05</td>
</tr>
<tr>
<td></td>
<td>(0.59-0.93)</td>
<td>(0.49-0.73)</td>
<td>(0.30-1.00)</td>
<td>z = 1.07, n.s.</td>
</tr>
<tr>
<td>Late</td>
<td>0.75</td>
<td>0.39</td>
<td>0.10</td>
<td>z = 2.30, p&lt;0.05</td>
</tr>
<tr>
<td></td>
<td>(0.39-0.86)</td>
<td>(0.11-0.57)</td>
<td>(0.00-0.45)</td>
<td>z = 2.50, p&lt;0.05</td>
</tr>
</tbody>
</table>

TM=Talking Mats; SC=Structured conversation; USC=Unstructured conversation

d) Time
Across all stages, the Talking Mats conversation did not last significantly longer compared to the structured conversation but it did last significantly longer than the unstructured conversation. At early- and moderate-stage dementia there was no significant difference in the time taken to complete Talking Mats compared with the structured conversation but compared to the unstructured conversation Talking Mats lasted significantly longer. At late-stage dementia the Talking Mats conversation lasted significantly longer than both structured and unstructured conversations.

However, when the Talking Mats’ confirmation phase (where the researcher went over the completed Mat with the participant to ensure that s/he was happy with the views expressed) was included, the average time for each Talking Mats’ topic across all stages, and for each stage in turn, was significantly greater than that for...
The effectiveness of Talking Mats with people with dementia

each structured conversation topic. The brevity of the unstructured conversation interviews was due to the fact that many participants were unable to provide much information about the topic being discussed. This lack of elaboration persisted even when the participants were prompted to talk about the things (or people) that they liked or did not like.

Table 5. Mean time (in minutes) taken to discuss each topic at each stage of dementia by interview condition using the paired samples t-test (2-tailed)

<table>
<thead>
<tr>
<th></th>
<th>TM</th>
<th>SC</th>
<th>USC</th>
<th>Statistical test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>TM vs. SC</td>
<td>TM vs. USC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All stages</td>
<td>9.22</td>
<td>8.47</td>
<td>1.27</td>
<td>t(30) = 1.90, n.s.</td>
</tr>
<tr>
<td>Early</td>
<td>7.91</td>
<td>7.83</td>
<td>1.26</td>
<td>t(9) = 0.10, n.s</td>
</tr>
<tr>
<td>Moderate</td>
<td>10.23</td>
<td>9.49</td>
<td>1.43</td>
<td>t(10) = 0.98, n.s</td>
</tr>
<tr>
<td>Late</td>
<td>9.42</td>
<td>7.98</td>
<td>1.12</td>
<td>t(9) = 4.12, p&lt;0.01</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>TM+C vs. SC</th>
<th>TM+C vs. USC</th>
</tr>
</thead>
<tbody>
<tr>
<td>All stages</td>
<td>11.10</td>
<td>8.47</td>
</tr>
<tr>
<td>Early</td>
<td>9.59</td>
<td>7.83</td>
</tr>
<tr>
<td>Moderate</td>
<td>12.43</td>
<td>9.49</td>
</tr>
<tr>
<td>Late</td>
<td>11.15</td>
<td>7.98</td>
</tr>
</tbody>
</table>

TM=Talking Mats; TM+C=Talking Mats+Confirmation; SC=Structured conversation; UC=Unstructured conversation

Discussion
These results suggest that the Talking Mats framework may be more effective than both structured and unstructured conversations in helping people with dementia communicate their views. In addition the Talking Mats framework may help to reduce instances of perseverative behaviour and distractibility. Talking Mats conversations appear to last longer than structured and unstructured conversations. Significantly, the largest differences between Talking Mats and both unstructured conversation and structured conversation are evident in people with moderate- and late-stage dementia.

Consent
The consent procedure appeared to work well overall. The numbers recruited at the consent stage suggest that the families did not feel under any pressure to cooperate with the research. The fact that relatively few people with dementia withheld consent is likely to be a reflection of the fact that several of the care homes selected only those residents they felt would be happy to participate. Where this initial screening did not occur, the approach to the families may have
resulted in permission only being given for the researcher to visit those people with dementia who would be likely to want to become involved.

**Consensus approach to coding communication effectiveness**

When using any new intervention in research or clinical settings, it is important to be able to assess whether that intervention is effective. However, because communication effectiveness is predominantly a subjective judgement, any two people viewing the same interview may reach different conclusions, thus raising the problem of poor inter-rater reliability and bias. The figures obtained in this study by using the consensus approach are well above 70%, which is generally considered an acceptable level of agreement.\(^47\) Interestingly, inter-rater agreement was lower for the late-stage group (average 87.8%) compared to the early-stage group (average 91.3%). This finding reflects the fact that the interviews of late-stage participants were harder to score and created most discussion between the raters. The findings in this study suggest that the consensus approach can be useful in improving the consistency (and therefore the reliability) of subjective ratings.

**Communication effectiveness**

Several key aspects of both verbal and non-verbal communication which affect people with dementia have been examined in this study. The positive indicators on the Effectiveness Framework of Functional Communication (participant understanding, engagement, staying verbally on track and researcher understanding) in conjunction with the negative factors (perseveration and distractibility) appear to be relevant and helpful in judging the effectiveness of the communication of people with dementia.

**Stages of dementia**

As people with early-stage dementia can communicate effectively regardless of the medium used, they may benefit most from using the Talking Mats framework when they face difficult decisions (e.g. giving up driving or accepting care). In these situations, the Talking Mats framework may allow people in the early stages of dementia to organise their thoughts, and to weigh up the benefits and drawbacks of a particular course of action more easily. Significantly, the largest differences between Talking Mats and ordinary conversations are evident in people with moderate- and late-stage dementia although many people with late-stage dementia did not reach the threshold of effectiveness on our coding
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framework when using the Talking Mats framework. However, it could be argued that the 75% threshold on the Effectiveness Framework of Functional Communication is overly rigorous and if a lower threshold of 60% were accepted some participants with late-stage dementia would achieve ‘effective’ communication. Therefore, the Talking Mats framework may help people with dementia to continue taking an active role in shaping and controlling decisions about their lives for longer than usual.

Distractibility
The findings that participants in all three groups exhibited fewer perseverative behaviours and remained on task more when being interviewed using Talking Mats than when being interviewed using structured conversation and unstructured conversation suggest that people with dementia may be able to focus their attention to a greater extent and become more involved in an interaction when they are using the Talking Mats framework. The fact that they can see what they have said appears to help the problem of not remembering what they have said. The Talking Mats framework gives both parties in the discussion an alternative focus that deflects their attention from the normal conventions of conversation, such as turn taking.

Time
Conversations with Talking Mats usually last longer than either simple or more structured conversations. Therefore participants should be offered breaks to ensure that they do not tire. However, this issue of time has important practical implications. People with dementia often end up with ‘nothing to do but sit with vacant time and empty thoughts’. Using the Talking Mats framework allows paid carers and relatives to spend more time with a person with dementia and, crucially for person-centred care, the person with dementia is engaged in an activity that is highly personally significant to them. For example, one participant later informed a dementia service manager that she had appreciated the opportunity to do something that seemed really meaningful. Therefore, in addition to helping people to express their views, the Talking Mats framework may simply be enjoyed as an activity allowing people with dementia to occupy their time meaningfully.

Implications
The main finding of the project – that many people with dementia can use Talking Mats to communicate effectively – means that the framework may be helpful in
allowing people with dementia in a variety of situations to express their views about a wide range of topics more easily. For example, the Talking Mats framework could be used to:

- allow people with dementia to choose what they want to do on a day-to-day basis;
- help people with dementia remember what they have said through the photographic record;
- provide a structure for people to express their views and thus facilitate conversation between a person with dementia and their family/friends during social visits;
- provide a record of people’s views to put in their notes or show to their families; and
- be enjoyed as an activity allowing people with dementia to occupy their time meaningfully.

The findings also have clear implications for practitioners, commissioners and policy-makers. Recent government guidance, from both the Department of Health and the Scottish Executive, recommends that all older service users (including people with dementia) should be involved in decision making about care, treatment options and key life transitions. Health and social care staff must therefore be able to identify the specific needs and preferences of older people. The demonstration that the Talking Mats framework can allow people with dementia to communicate their opinions suggests that the use of the framework can help staff to consult people with dementia. It has the potential to help people express their views on various topics including: what they want recorded in their personal care plans; health and social issues such as accepting care or moving to different accommodation; what they think about services on offer; and where they would like to see improvements made. An additional implication is that with increasing numbers of care home staff now being recruited from overseas, and with increasing numbers of older people with dementia for whom English is not a first language who may revert back to their first language as their condition progresses, the Talking Mats framework may also prove extremely useful in overcoming language differences because of the use of picture symbols.
Limitations
The numbers in the study are small but it would not have been practical to involve larger cohorts due to the amount of video data generated, the time constraints and the funding available. Furthermore, due to the large amount of video data generated, it was not possible to incorporate analysis of every interview from start to finish. Therefore only the first three options for each topic were considered when scoring the Talking Mats and structured conversation interviews for effectiveness. However, as the options had been presented in random order, the options that were scored differed from one condition to the next and from one participant to the next. The unstructured conversations were generally much shorter than the other two conditions and the researchers watched these interviews in their entirety.

Conclusion
The project found that the Talking Mats framework could be used by many people with dementia and that it was associated with an improvement in their ability to communicate compared with structured and unstructured conversations. The Talking Mats framework is likely to be capable of providing family and staff with an effective tool to allow many people with dementia to communicate their thoughts and preferences more easily than through usual conversation. Furthermore, photographs of the completed Mats can readily provide a permanent record of the views of a person with dementia as in Figure 3.
This record can subsequently be used to inform care planning, and the development of services and support systems, as well as to ensure that the person with dementia remains in control of their own day-to-day living arrangements for as long as possible.

The study raises questions for further research including – i) how effective the Talking Mats framework would be in helping people at the early stages of dementia, and their families, make key decisions such as accepting care, and ii) would becoming familiar with the Talking Mats framework in earlier stages of dementia make the framework easier to use in the later stages of the condition?
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References
18. Department of Health, 2003 What does Valuing People say?
19. Disability Rights Commission 2006, Fair for All- achieving fair access, DRC.


32. Murphy, J. 1999, "Enabling People with Motor Neurone Disease to Discuss their Quality of Life", Communication Matters, vol. 13, no. 2, pp. 2-6.


Discussion
Discussion

Introduction
This chapter summarises the findings from the previous six chapters in relation to the aims of the thesis. Methodological issues, including strengths and limitations of the studies are then discussed. Research into the effectiveness of other AAC systems is summarised, the implications for future research and clinical practice are then considered and finally, conclusions are drawn.

The research has included different methods and has involved a range of people with different communication difficulties associated with different conditions. Communication, as stated in previous chapters, is a fundamental aspect of all human relationships and problems with communication can have a major negative impact on a person’s quality of life. As a practising Speech and Language Therapist working in the field of Augmentative and Alternative Communication (AAC), my main role is to help people communicate as effectively as possible, taking into account their physical and emotional abilities as well as their home situation. I believe in the same rationale for carrying out my research, i.e. that it should result in an improvement in communication practices and should add to knowledge and evidence in relation to supporting communication in those with communication difficulties. I am also aware of the need to strive for objectivity and transparency in research.

This thesis has described the development and initial evaluation of the Talking Mats framework, a low-tech communication tool designed to help people with communication difficulties consider and express their views about specific topics. The thesis has presented a selection of research projects carried out since 1999, starting with a study which examined the perceptions of people with communication difficulties and their communication partners. It then progressed to an investigation of the feasibility of the Talking Mats framework with different client groups and culminated in two projects which studied the effectiveness of the Talking Mats framework.

Aims
The thesis aimed to answer the following three questions:

1. How do adults with communication difficulties use AAC, and what is important to them?
2. How feasible is the Talking Mats framework with adults with communication difficulties?
3. How effective is the Talking Mats framework with adults with communication difficulties?
Main findings

1. How do adults with communication difficulties use AAC, and what is important to them? (Chapters 2 and 3)

This question was addressed in a three-year qualitative study which investigated the communication of 15 people with motor neurone disease (MND), also known as amyotrophic lateral sclerosis (ALS), and their partners in their own homes. This group of people were particularly discerning as almost all had intact cognition and good insight into their communication situation.

The first finding reported in Chapter 2 was that the key purpose of communication between participants was to develop and maintain social closeness, rather than to indicate needs and wants or to transfer information. This is particularly significant as the review presented in Chapter 1 showed that many AAC devices focus on the latter and overlook the importance of social closeness. Secondly, it was evident that discussing shared topics rather than completely new topics was an important factor in developing social closeness. A third finding was the amount of cooperation and symmetry of communication between the couples in this study which was remarkable considering the severity of the communication difficulties involved. This related to the importance of considering the activities and participation in the daily life of the person rather than concentrating on their impairment. Despite deteriorating speech, many participants were still able to communicate meaningfully and intimately and in a way that focused on topics that were particularly important to them. This was because the participants worked together more and more on the cooperative nature of interaction as the disease progressed.

Chapter 3 highlighted some of the reasons why AAC is unsuccessful for some people with communication difficulties. The participants with ALS/MND expressed a strong desire to use their own speech for as long as possible, even when it was unintelligible to others, rather than using a high-tech voice output device. Again the importance of sharing thoughts, engaging in small talk and maintaining social closeness was paramount. The participants in this study suggested that a high-tech device might well be a barrier between them and could detract from social closeness. The communication issues identified in the above study, namely the importance of social closeness, shared topics, cooperation, symmetry, the desire to use their own speech for as long as possible and the need for simplicity in AAC tools, were all critical to the ongoing development of the Talking Mats framework which was already being used clinically at the time of this study.
Discussion

The next step was to investigate the use of the Talking Mats framework with participants who had more complex communication difficulties with language as well as speech impairments.

2. How feasible is the Talking Mats framework with adults with communication difficulties? (Chapters 4 and 5)

Chapter 4 examined the feasibility of the Talking Mats framework with 12 adults with aphasia after stroke. The participants had a range of acquired speech and language difficulties and were living in a variety of situations. Eleven of the 12 people were able to use the Talking Mats framework to express their views on the topics presented and it appeared to be a meaningful and satisfying activity. The findings indicated that the Talking Mats framework provided participants with the opportunity to consider their quality of life and to express views that they had not been able to express previously. The use of visual clues appeared to offer an accessible method of interviewing people who would struggle with a conventional type of interview. The study identified topics that were relevant and meaningful for different participants' situations and contexts.

To demonstrate if communication was effective a simple coding scheme, containing basic elements of communication effectiveness, was developed during this study and was used to analyse the video recordings. It comprised a five-point scale in order to code participants' responses in relation to each topic.

Chapter 5 focused on 12 young adults with learning disabilities who had a mixture of congenital communication difficulties affecting speech, language and cognition. They used the Talking Mats framework to consider, and be actively included in discussion about, the choices available to them at the time of transition after school.

This study found that the Talking Mats framework was a feasible tool for young adults with learning disabilities to communicate their views at times of transition. The coding scheme, developed for the previous study, was further refined and was used to determine how well the participants could communicate their views using the Talking Mats framework. The enthusiasm and engagement of the 12 participants confirmed that they enjoyed using it. The study identified five core skills which are required in order to be able to use the Talking Mats framework to express views, namely:

1. sufficient vision to be able to see the picture symbols;
2. the ability to recognise the picture symbols;
3. the ability to demonstrate understanding of the task;
4. a reliable pointing method; and
5. a reliable method of confirming views.

Both these small studies indicated that the Talking Mats framework was a feasible communication tool to use with adults with complex communication difficulties and resulted in improvements to the design and use of the Talking Mats framework. However, only 12 participants were involved in each study and it did not compare how the participants would be able to express their views using their usual communication methods without the Talking Mats framework. There was a need for further studies with larger groups to investigate the effectiveness of the Talking Mats framework with people with different levels of comprehension in comparison to usual communication methods.

3. How effective is the Talking Mats framework with adults with communication difficulties? (Chapters 6 and 7)

Chapter 6 presented the findings from a study which involved 48 adults with different degrees of learning disabilities discussing life planning issues. It was designed to compare the effectiveness of the Talking Mats framework with the individuals' main communication methods. The study demonstrated that, for people whose comprehension was at three or more information-carrying words, the Talking Mats framework was an effective communication resource to help them express their views. The quality and quantity of information obtained was significantly greater than when using their usual communication methods. For those people whose comprehension was at one information-carrying word, the Talking Mats framework was less effective but nevertheless their attention and interaction was better than for main communication methods. For people whose comprehension was at two information-carrying words the findings were equivocal and this group deserves further research. The study also identified additional issues which influenced the quality of interaction for the participants, namely distractions, motor control, visual difficulties and medical factors. The findings from this study increased confidence in the Talking Mats framework and indicated how it can and cannot assist people with learning disabilities to express their views.

Chapter 7 examined the effectiveness of the Talking Mats framework for people with dementia. It involved 31 people at different stages of dementia whose communication difficulties were acquired and progressive, and included speech, language, cognition, memory and behavioural problems. The participants were
each interviewed about four aspects of their well-being, comparing the Talking Mats framework with usual communication methods. This study demonstrated that the Talking Mats framework can help people with dementia express their views. People in the early and moderate stages of the illness were able to communicate effectively using the Talking Mats framework. People with late-stage dementia were also capable of using the framework. Importantly, the Talking Mats framework allowed people with moderate- and late-stage dementia to communicate their views about their well-being more effectively than either unstructured or structured conversation. This study showed that conversations with the Talking Mats framework lasted longer than either structured or unstructured conversations. Also, participants in all three groups were distracted less when using the Talking Mats framework as they exhibited fewer perseverative behaviours and remained on task more when being interviewed using Talking Mats than when being interviewed using usual communication methods.

This précis of the previous six chapters has described the progression of the studies into the development of the Talking Mats framework. The next section of this chapter discusses the methodological issues which have arisen from these studies.

**Methodological issues**

**Strengths**

There are a number of distinctive features of this thesis. As I am both a researcher and a practising clinician the studies are all grounded in clinical practice and come from the real needs of real people. The basic premise for the Talking Mats framework originated from the requests from people with communication difficulties to be able to express themselves more easily and have their views heard. The papers presented in this thesis illustrate what, for me, was an evolving process of research and practice over a number of years. It progressed from the identification of user views to the investigation of feasibility of the Talking Mats framework and finally, to the examination of effectiveness of the Talking Mats framework. It developed from purely qualitative methods to a combination of qualitative and quantitative methods. The research presented is also distinctive as it involved groups of people who are often excluded from research because they are generally unable to complete written questionnaires or to participate in qualitative interviews. Obtaining consent to participate in research presents particular ethical challenges to researchers in the field of communication difficulties. A significant tension exists between ensuring that participants understand the nature and implications of their
involvement in research and at the same time avoiding any coercion. There is a concern that researchers either exclude people with communication difficulties from research or include them without their consent. There is a need to ‘protect potential vulnerable participant groups, while ensuring that demands placed on researchers are not so restrictive as to preclude valuable research’.1  p 49

All of the studies in this thesis have received ethical permission both from the University of Stirling and from the relevant medical and social ethical committees. Particular care was taken to use accessible methods of communication and adapt information and consent forms to ensure that, wherever possible, participants were able to give informed consent. Adaptations included involving people who knew participants well in the initial approach to become involved; using pictorial explanations; giving participants more time and repeated explanations when explaining the nature of their involvement in the study; getting ongoing consent at each part of the project; and giving visual feedback about the results. A paper summarising these conclusions and discussing consent issues arising from Chapter 6 has been published.2

The Talking Mats framework originated from the desire to demonstrate that research findings and researchers’ interpretations were credible to the participants.3 Respondent validation, or ‘member checking’, includes techniques in which the researchers’ account is compared with those of the participants’ to establish the level of correspondence between the two. Participants' reactions are then incorporated into the study findings.4 Some researchers view this as the strongest available check on the credibility of a research project.5 Throughout all the studies in this thesis the participants’ views about the Talking Mats framework have been sought to confirm and validate their completed Talking Mats. Participants have been overwhelmingly positive about the use of the Talking Mats framework and very few negative reactions have been expressed.

The development and refinement of the Effectiveness Coding Framework of Functional Communication, and the use of multiple raters combined with the consensus approach in analysing communication effectiveness, are significant features of the research presented in this thesis. These methods evolved in successive chapters and had not previously been used in the field of augmentative communication.

All the studies were carried out in the participants’ own environment which increased ecological validity as the settings and the focus of the conversations approximated real-life situations.6
Discussion

Limitations

The first limitation is that the numbers in the studies in Chapters 2 to 5 are small and one must be cautious in generalising to other groups. However, in the ALS/MND study presented in Chapter 2, by the time the tenth participant was involved, there were no new insights being produced and saturation of perception was reached. In all the studies it would not have been practical to involve larger numbers due to the amount of video data generated, the time constraints and the funding available. However, the use of multiple interviews is a strength of the studies in this thesis.

There could be a criticism of selection bias in the studies as the only practical sampling strategy was a convenience sample for all of the studies and, in order to fulfil ethical requirements, only those and/or their carers who were motivated to consent were involved. However, there was no deliberate selection of participants by the investigator as, in each study, participants were recruited through the relevant professionals who gave information to all potential participants known to them and who fulfilled the inclusion criteria. The participants in Chapters 2 and 3 were recruited through the Scottish Motor Neurone Disease Register, those in Chapter 4 were approached by members of the Stroke Team in Stirling Royal Infirmary, those in Chapters 5 and 6 were recruited via the Speech and Language Therapy Department in NHS Forth Valley and those in Chapter 7 were recruited through local Dementia Services in Central Scotland. At this initial approach, the potential participants were invited to get in touch with the researchers if they wished further information and, only then, the researchers made contact to explain the project in more detail and obtain informed consent. All those who consented were recruited systematically until the required number for each study, as accepted by the funding body, was reached. A further mitigation of selection bias is that the thesis as a whole includes studies on a range of conditions and abilities within these conditions. The studies also include people with different ages, abilities and home situations.

A methodological criticism in Chapters 6 and 7 could be the use of a coding framework which depends on the raters making ‘subjective’ judgements about communication features such as understanding, engagement, confidence and satisfaction. These studies dealt with the complex interaction between dyads which is further complicated by communication impairment. I have attempted to avoid traditional detailed ‘speech’ analyses but rather to recognise the communicative act as a ‘whole’ and combine both the richness of qualitative
observations with quantitative attention. Given the complexity and amount of
information involved in communication, judgements of interactions are likely to be
predominantly intuitive. Hamm suggests that, to shift judgement from being
intuitive to being analytical, helpful building blocks are:

• Peer-aided judgements: more than one person contributes to the judgement;
and

• System-aided judgement: a judgement that follows a defined process.7

In using a consensus approach as described in Chapters 6 and 7 these two
strategies were employed to minimise shared subjectivity. The shift in inter-rater
agreement from 54% before consultation to 92% after consultation (Chapter 7)
indicates that this approach to coding communication effectiveness can be useful
in improving the consistency (and therefore the reliability) of subjective ratings.
The Effectiveness Framework of Functional Communication is currently being
further examined for validity and reliability using the consensus approach with 15
Speech and Language Therapists.

A methodological limitation associated with the use of observational procedures is
the concept of reactivity, in which the behaviour of participants is thought to be
affected by the process of being observed or taped. The primary concern with
reactivity is the possible threat it poses to the external validity of study findings.8
Therefore, a consideration in this thesis is whether the presence of the video
camera and the process of being recorded affected the participants' behaviour.
Participants in all the studies were interviewed and recorded in familiar
environments (either at their home or day facility), which helped reduce the
intrusion of the video recording since participants were likely to feel more
comfortable in a familiar environment. In addition, once the interviews began the
participants showed little awareness of the video recording, possibly because they
were focused on the interview task.

Another limitation is the potential of researcher bias. The same researcher had
developed the initial Talking Mats' tool, was the principal investigator in the studies
and was involved in the analysis of data. Despite professional diligence, there is a
danger that the desire to see positive results might influence the findings.9 This
was less likely in the later studies where other staff who were not part of the
research team were involved in the analysis of data. In addition, data was
collected in a structured way and standardised tools were developed to prevent
subjectivity. Participants were invited to give feedback to validate the findings and
other researchers viewed and critiqued the analyses and reporting of results.
Ideally the studies should be repeated by other researchers. In Sweden a research team is currently using the design and methods described in Chapter 6 in a study of the effectiveness of the Talking Mats framework compared to usual communication in a group of people with Huntingdon’s Disease. When effectiveness is positively evaluated in this study, this will be a more independent demonstration of effectiveness as none of the researchers was involved in the development of the Talking Mats framework.

Other AAC methods
A search of the literature, described in Chapter 1, identified that the purpose of other AAC methods such as low-tech boards or books and high-tech voice output devices is primarily for expressing needs and wants or, less often, for the transfer of information. Papers retrieved described some of the positive outcomes of AAC systems. Studies involving children describe the acquisition of the commenting function by children using VOCAs which enabled them to have a longer conversation and positive attitudes from children were noted when they felt that their AAC system improved their self image. Students in another study preferred a VOCA over the low-tech aid offered and VOCAs were found to be most effective when used to fulfil the main goals and roles of an activity. Studies involving adults suggested that PECS was a viable method for three out of five adults with severe learning disabilities in order to express needs and wants. Another study found that there was general acceptance of AAC by adults with traumatic brain injury but that the type of device used varied with the changing needs of the participants. Adults in an intensive care setting initiated communication interactions more often when VOCAs were used than when communicating by non-vocal methods.

However, the research evidence into the effectiveness of other AAC systems is clearly limited. In 2000 Schlosser observed that most AAC studies providing quantitative outcome measures were single case studies. In 2004 a review of AAC systems for people with aphasia indicated that there was very little research to support efficacy of AAC teaching despite a great deal of clinical knowledge. In 2006 a study evaluating the long-term outcomes of AAC intervention with seven young adult AAC users noted that prior to their study there were no data on the long-term outcomes of AAC interventions. However, as the participants all used different AAC systems the study found that the outcomes for the group were diverse, with individual variations across all measures. Pennington, in 2007, and
Johnson, in 2008, both commented that AAC studies were difficult to evaluate as they did not always specify the participants, approaches and strategies used.\textsuperscript{21,22}

**Uniqueness of the Talking Mats framework**

The Talking Mats framework is different from other AAC methods as its purpose is to allow people to organise their thoughts and express their views on a specific topic at a specific time. It is not a tool to be used for daily communication, requires very little prior training and does not need to be generalised from therapy to home or other everyday situations. There are a number of distinctive features of the Talking Mats framework which seem to help people with communication difficulties, several of which reflect the original issues raised by the participants in the ALS/MND study in Chapters 2 and 3. It appears to facilitate engagement between people as they are occupied in a joint task with a sharing of topic and symmetry of interaction which is so often absent where one person has communication difficulties. It provides an alternative focus that deflects attention from the normal conventions of conversation and allows the person with communication difficulties to have more control. It may help people who still want to use their own voice as it provides topics of conversation and gives the communication partner visual cues which the person with communication difficulties can elaborate on. It overcomes the physical effort often involved in operating high-tech devices as it can be used by people with limited (or no) hand control. It is simple to use and removes the need for participant training. The structured nature of the Talking Mats framework can help people with language and cognitive difficulties by chunking the information into smaller more manageable components. The use of pictures may overcome literacy problems as well as reducing memory load and making the topic easier to respond to than by only asking verbal questions. It allows the participant to consider each point of discussion in relation to all the others. In addition, the physical involvement of choosing, moving and placing the pictures all contribute to people being able to give negative as well as positive responses and having a more equal control of the conversation. Using the Talking Mats framework can be enjoyable, personally meaningful and fulfilling for both partners in the conversation. Finally, unlike a high-tech device it is inexpensive and it never breaks down.

**Weaknesses of the Talking Mats framework and possible improvements**

The Talking Mats framework is not a panacea for all people with communication difficulties. Firstly, not everyone can use the Talking Mats framework and it must...
be acknowledged that people with profound cognitive difficulties will not be able to use it. Secondly, the selection of the topic and the options to be discussed must be carefully prepared to ensure that the discussion is both relevant and comprehensible to the user.\(^{23}\) The interviewer should be aware of the relative iconicity of symbols, e.g. leisure options may be easier to portray than health options. The interviewer must make time to plan and prepare the symbols and to record and store the results. In order to help with the selection of topics the nine domains from the Activities and Participation section of the World Health Organisation International Classification of Functioning Disability and Health (WHO-ICF)\(^{24}\) have been converted into symbols to make them more easily understood and to allow them to be used in conjunction with the Talking Mats framework.\(^{25}\) These domains or ‘topics’ act as a good starting point to help people consider issues in their lives and, as a further expansion, subsets of ‘option’ symbols relating to each topic have been developed.

Another weakness is how the user’s views, as expressed on the Mats, are interpreted. The interviewer must be vigilant when inferring what the user intends, especially where the user has no other useful means of communication. Several researchers who have used the Talking Mats framework as a research tool have noted this problem of validation.\(^{9,23,26-28}\) One has gone on to make suggestions for improvement, e.g. the Talking Mats framework could be used as an ongoing process where a series of Mats are produced to validate views.\(^{23}\) Others suggest that the same interviews could be repeated by different interviewers.\(^{9,23}\) A further suggestion is to compare the views of the user, staff and carers thus triangulating the results.\(^{28,29}\)

The choice of visual scale symbols and the corresponding wording of the related question are crucial. If the wording is confused or inconsistent the user will be unclear as to what view to express and if the interviewer resorts to closed questions this can be leading and controlling.

The use of the Talking Mats framework may open up difficult or sensitive issues for the user and/or caregivers. It is important that these are acknowledged and dealt with sympathetically.

To address some of these problems a range of training courses has been developed to try to ensure that the Talking Mats framework is used correctly. Details of these are on the Talking Mats website (www.talkingmats.com). However, the Talking Mats framework should be seen as an AAC method still under development and future research projects to examine some of these issues are being considered.
Implications for future research

The papers presented in this thesis have suggested a number of areas for further research:

1. Although the effectiveness of the Talking Mats framework has been demonstrated in Chapters 6 and 7 in relation to communication effectiveness, this has not been done according to gold-standard design. A randomised controlled trial comparing use of the Talking Mats framework with usual or main communication methods would be ideal.

2. A further use of the Talking Mats framework is its potential to improve participation in decision making. This might involve the person with communication difficulties and their caregiver in using the Talking Mats framework as a joint activity. Two studies, one with people with dementia and one with people with aphasia, are current. There is also potential for a randomised controlled trial comparing the Talking Mats framework with main communication methods in relation to involvement in decision making. An application to develop an outcome measure suitable to use with people with communication problems is currently being developed.

3. To date there has been only limited research into the use of the Talking Mats framework with people on the autistic spectrum and with children. Further investigation is needed into its use with other client groups.

4. The use of the Talking Mats framework is currently being extended through training courses, seminars and packages. Further research is required into the best models for providing training to different staff groups. A small study into this is current.

5. The study described in Chapter 6 indicated that people whose understanding is less than two information-carrying words could not use the Talking Mats framework effectively. Further research into the effectiveness of training people with very limited understanding to use the Talking Mats framework would be valuable. Alternatively, other low-tech tools for this group could be explored.

6. The use of the Talking Mats framework as a focus group tool with six people with communication difficulties was explored in Chapter 6 to identify the most relevant life planning topics for people with learning disabilities. Firstly, each member of the group completed their own Mat with a researcher, then each person was given the chance to show and explain their Mat to the rest of the group. Common themes were discussed and the participants then completed a group Mat in order to identify the issues that are important in helping people
with learning disabilities to plan their lives. During the ensuing discussion, the visual scale was altered to: a small asterisk (not so important), a middle-sized asterisk (fairly important) and a large asterisk (very important). The Talking Mats framework was thus used to assist the group in making individual decisions about the importance of the topics identified and then reaching a consensus amongst themselves. This method could be explored more thoroughly in future research.

7. During the studies presented in this thesis it was clear that some topics such as ‘activities’ were more concrete and easier for participants to respond to than others such as ‘self’. Further research into the relative transparency of different topics is required.

8. The Talking Mats framework can be considered not only as a communication tool but also as a cognitive organiser. Further research into the mechanisms through which the Talking Mats framework works is required.

Further funding has been received to carry out another three research projects:

- Adapting to Aphasia – Gillespie A & Murphy J – Funding from the Economic and Social Research Council (ESRC) to use the Talking Mats framework to investigate how people with aphasia and their partners adapt to the life changes caused by stroke. (Related package to follow)
- Talking Mats Training Project – Murphy J & Macer J – Funding from Joseph Rowntree Foundation to investigate how best to provide Talking Mats training to care home staff. (Related package to follow)
- Decision making with people with dementia – Murphy J, Oliver T & Cox S – Funding from Joseph Rowntree Foundation to investigate if the Talking Mats framework can be used by people with early-stage dementia and their family to make decisions together about care needs.

The Talking Mats framework is now recognised by others as a research tool to include people with communication difficulties and there is a growing body of research using the Talking Mats framework to obtain participants’ views on issues such as self concept, AAC devices, learning software, social networks and inclusion, out-of-school activities, sexual knowledge and to obtain informed consent.
Implications for clinical practice
The research findings have relevance for staff in a variety of settings including health, social services, education and the voluntary sector. The demonstration that the Talking Mats framework can help people with communication difficulties to express their views suggests that it can be used by staff to consult with people on a variety of topics.

The following are some examples of its clinical use:
• as a goal-setting tool in therapy and rehabilitation;
• to include people with learning disabilities in life planning;
• as an advocacy tool both with people with learning disabilities and people with dementia;
• as an interview tool to obtain the views of people with stroke in acute hospital surveys;
• to determine the capacity of individuals to understand and make health decisions;
• to provide evidence that people with dementia have been consulted about their care; and
• to consult with groups of people to arrive at a consensus of decision.

An important outcome from each research project has been the development of a practical package for those working with people with communication difficulties. These packages are now used worldwide and have been translated into other languages. In addition, a range of training courses, including accredited training courses, are available both throughout the UK and abroad (www.talkingmats.com).

Conclusion
The papers in this thesis have addressed the following questions:

1. How do adults with communication difficulties use AAC, and what is important to them?
Examination of the communication and perceptions of people with ALS/MND and their communication partners identified their desire for AAC to attend to i) the development and maintenance of social closeness; ii) discussion of shared topics of conversation that are relevant; and iii) the desire for cooperation and symmetry in communication. Despite the advances in augmentative and alternative communication technology in the past 20 years, high-tech AAC is still unsuccessful
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for some people and there is a need for simplicity not only for people with communication difficulties but also for those who care for and work with them. These issues were critical to the ongoing development of the Talking Mats framework.

2. **How feasible is the Talking Mats framework with adults with communication difficulties?**

   The findings from two studies, one with adults with aphasia and the other with young adults with learning difficulties found that the Talking Mats framework enabled the majority of the participants to consider aspects of their life and to express views that they had not been able to express previously. These studies ascertained that the Talking Mats framework is a feasible communication tool for many people with communication difficulties but did not investigate the ability of people with different levels of comprehension to use the Talking Mats framework in comparison to usual communication methods.

3. **How effective is the Talking Mats framework with adults with communication difficulties?**

   Two further studies, one with adults with different levels of learning difficulty and the other with adults with different levels of dementia, found that, in comparison to usual communication methods, the Talking Mats framework enabled the majority of participants to express their views more effectively. It also improved attention and interaction, and the quality and quantity of information gathered was significantly greater than when using usual communication methods.

   The field of AAC is a relatively new one and the evidence base for the effectiveness of AAC methods needs to be developed with more rigour. This thesis contributes to AAC knowledge by identifying important issues for people with communication difficulties and demonstrating that the Talking Mats framework is a communication method which offers a unique contribution to the field of AAC. It has also established that the Talking Mats framework is both feasible and effective for certain client groups but that further research into its use, both as a clinical and a research tool is needed.
References


2. Cameron, L. & Murphy, J. 2006, "Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities", British Journal of Learning Disability, vol. 35, pp. 113-120.


10. Sahlin, A. & Sundin, L. 2008, Utvärdering av samtalsmattor som kommunikationsstöd för personer med Huntington sjukdom. Talking Mats for persons with Huntington’s disease., Institute of Neuroscience and Physiology, Department of Clinical Neuroscience and Rehabilitation/ Speech and Language Pathology, Sahlgrenska Academy, University of Gothenburg, Göteborg, Sweden.


38. Bell, D. M. & Cameron, L. 2008, "From Dare I say? to I dare say: a case example illustrating the extension of the use of Talking Mats to people with learning disabilities who are able to speak well but unwilling to do so", British Journal of Learning Disabilities, vol. 36, no. 2, pp. 122-127.
Summary
Introduction and research questions
Communication includes speech, language, reading, writing and social skills. It is one of the most complicated abilities humans learn and is a fundamental aspect of all human relationships. While effective communication can improve a person’s quality of life, problems with communication can have a major negative impact. The person may lose confidence and self-esteem which can affect their personal and social relationships. Their disability can reduce their opportunities in education and employment and it may prevent them from receiving health and social services. It may also result in a sudden or gradual restriction in their social networks. Consequently they may be unable to fulfil their roles as partner, parent, family member, colleague and/or friend.

Augmentative and Alternative Communication (AAC) is the term used to describe methods of communication which can be added to the more usual methods of speech and writing when these are impaired. AAC can help someone understand as well as express themselves and includes unaided systems, such as signing and gesture, and aided techniques, ranging from pen and paper to the most sophisticated computer technology currently available. Most people who use AAC employ a combination of unaided and aided methods. The Talking Mats framework is an innovative aided low-tech AAC tool which I designed to help people with communication difficulties both to consider topics of relevance to them and to express their views in a way that others can understand.

In this thesis I present an action research programme comprising six research studies which address the following three questions:

1. How do adults with communication difficulties use AAC, and what is important to them?
2. How feasible is the Talking Mats framework with adults with communication difficulties?
3. How effective is the Talking Mats framework with adults with communication difficulties?

In Chapter 1 I describe the importance of communication and the impact of communication disability on quality of life. I explain what is meant by Augmentative and Alternative Communication (AAC) and summarise the history of AAC. I then outline the evolution of this thesis in relation to both my clinical and research experience over 20 years and explain the background to the Talking Mats framework with examples of its use.
In Chapter 2 I present some of the findings from a three-year qualitative research project in which I investigated the communication of 15 people with Amyotrophic Lateral Sclerosis/Motor Neurone Disease (ALS/MND) and their partners in their own homes. The study examined the communication of people with deteriorating speech and their partners, and their perceptions of their communication difficulties. There are wider issues relating to the communication difficulties experienced by people with ALS/MND than simply the physical problems caused by diminished oral control. In addition, existing literature on ALS/MND rarely considers communication to be a joint interaction which depends on the strategies adopted by both communication partners nor does it present communication in real-life settings. The participants were visited on seven occasions at six-weekly intervals. I discuss the purpose of human communication and, through examination of conversations in people's own homes, identify a range of strategies and techniques that families with ALS/MND employ. For some people with ALS/MND, although speech may deteriorate, they are still able to communicate closely and in a way that is more focused on topics that are particularly important to them.

In Chapter 3 I examine the use of Augmentative and Alternative Communication (AAC) in the light of the perceptions of people with ALS/MND and their partners. For the people in this study, it appeared that AAC was less successful than anticipated. The participants gave a number of reasons for this, which were interpreted as: the need for social closeness that may be prevented by using a device; the complexity of learning to use a high-technology device; and inadequate training. Both theoretical and practical issues are raised for professionals who work with and provide services to families with ALS/MND.

In Chapter 4 I introduce the Talking Mats framework as a low-tech AAC tool to allow people with communication difficulties to express their views. This chapter examines the feasibility of using the framework to enable people with aphasia to express their views on their quality of life. Twelve people with aphasia as a result of stroke, living in four different residential settings, were interviewed using the Talking Mats framework about six topics relating to quality of life. The interviews were video recorded and analysed using a five-point coding scheme to assess participants' ability to understand, consider and communicate views on quality of life to others. The completed Mats were analysed using cognitive mapping to

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1 ALS (Amyotrophic Lateral Sclerosis) is the term used in the USA and MND (Motor neurone disease) is the generic term used in Europe.
identify quality of life issues of importance to them. The findings demonstrate that it is feasible to use the Talking Mats framework as a tool for people with aphasia to express their views in relation to their understanding of topics being discussed, confidence in responding, confirmation of their views in a visual format and satisfaction with the final result. It helped participants to identify the topics and options that were important to them and to indicate how these either improved or hampered their lives. Insightful observations about the use of the Talking Mats framework were obtained from participants and the framework was modified as a result of their involvement.

Young adults with learning disabilities have particular problems at times of transition, such as leaving school or college, which are compounded if they also have a communication disability.

In Chapter 5 I describe a study which involved 12 young adults with both learning and communication disabilities and examined the feasibility of using the Talking Mats framework to allow them to express their views on six main topics at times of transition. It also explored their views and considered the skills required to be able to use the Talking Mats framework. The results show that the majority of participants were able to indicate their likes and dislikes and to express views about the choices available to them and suggest that there are five prerequisite skills needed to be able to use the Talking Mats framework successfully. The study concludes that the Talking Mats framework can help young adults with learning disabilities to consider and be actively included in discussion and decisions about the choices available to them at times of transition.

In Chapter 6 I describe a study which examined the effectiveness of the Talking Mats framework for people with learning disabilities in relation to being able to express their views on life planning. A mixed method quantitative and qualitative study was designed to compare the effectiveness of the Talking Mats framework with the individual’s main communication method. It involved 48 people at four levels of comprehension. Thirty of the 48 participants were identified as using the Talking Mats framework effectively. Effective use of the framework was associated with functional comprehension. The study found that scores on all indicators of communication effectiveness were higher when using the Talking Mats framework compared to main communication methods. This study identified that the Talking Mats framework can be an effective communication resource for many people with
learning disabilities and can help them express their views by increasing both the quantity and quality of information communicated.

Deteriorating communication is one of the most distressing aspects of dementia and it becomes increasingly difficult to ensure that the person’s views are heard.

The study described in Chapter 7 involved 31 people at different stages of dementia who were each interviewed about their well-being using the Talking Mats framework and usual communication methods. The communication effectiveness of each method was compared. This study found that the Talking Mats framework was associated with higher ability of people at all stages of dementia to communicate compared to usual communication methods. Better communication effectiveness was evident in the participants’ understanding, engagement, keeping on track and ability to make their views understood. Using the Talking Mats framework also came with less repetitive behaviour and distractibility. The findings suggest that the Talking Mats framework can play an important role in improving communication by providing an accessible, low-cost tool which family and staff could use with people with dementia to help them express their views.

In Chapter 8 I summarise the findings from the previous six chapters in relation to the aims of the thesis. Methodological issues, including strengths and limitations of the studies are then discussed. Research into the effectiveness of other AAC systems is summarised, the implications for future research and clinical practice are then considered and finally, conclusions are drawn. The main conclusions in answer to the research questions are:

1. How do adults with communication difficulties use AAC, and what is important to them?

Examination of the communication and perceptions of people with ALS/MND and their communication partners identified their desire for AAC to attend to i) the development and maintenance of social closeness; ii) discussion of shared topics of conversation that are relevant; and iii) the desire for cooperation and symmetry in communication. Despite the advances in augmentative and alternative communication technology in the past 20 years, high-tech AAC is still unsuccessful for some people and there is a need for simplicity not only for people with communication difficulties but also for those who care for and work with them. These issues were critical to the ongoing development of the Talking Mats framework.
Summary

2. How feasible is the Talking Mats framework with adults with communication difficulties?

The findings from two studies, one with adults with aphasia and the other with young adults with learning difficulties, found that the Talking Mats framework enabled the majority of the participants to consider aspects of their life and to express views that they had not been able to express previously. These studies ascertained that the Talking Mats framework is a feasible communication tool for many people with communication difficulties but did not investigate whether it is more effective than usual communication methods for people with different levels of comprehension.

3. How effective is the Talking Mats framework with adults with communication difficulties?

Two further studies, one with adults with different levels of learning difficulty and the other with adults with different levels of dementia, found that, in comparison to usual communication methods, the Talking Mats framework was associated with the majority of participants being able to express their views more effectively. It was also associated with better attention and interaction and greater quality and quantity of information compared to usual communication methods.

The studies in this thesis have identified important issues for adults with communication difficulties and have shown that the Talking Mats framework is both feasible and effective for certain client groups. Suggestions for future research involving the Talking Mats framework include a randomised control trial with a larger number of participants to compare the use of the Talking Mats framework with usual communication methods; examination of the Talking Mats framework in self management and decision making; research into the use of the Talking Mats framework with other client groups; examination of models of training; and research into the mechanisms through which the Talking Mats framework works.

There are also implications for clinical practice, many of which are already happening. The most significant of these is the use of the Talking Mats framework for consulting with people with communication difficulties within a number of contexts including health, social services, education and the voluntary sector.
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Introductie en onderzoeksvragen


Ondersteunde Communicatie (OC, in het Engels: Augmentative and Alternative Communication) is een term die gebruikt wordt om communicatiemethoden te beschrijven die toegevoegd kunnen worden aan de meer gebruikelijke spraak- en schrijfmethoden, wanneer deze beperkt zijn. OC kan iemand helpen bij zowel het begrijpen als het zich uitdrukken en omvat systemen zonder hulpmiddelen, zoals het gebruik van gebarentaal, alsook technieken met hulpmiddelen, variërend van pen en papier tot de meest verfijnde computertechnologie die momenteel verkrijgbaar is. De meeste mensen die OC gebruiken doen dat met een combinatie van methodes met en zonder hulpmiddelen. De Sprekende Matstructuur is een door mij ontworpen innovatief hulpmiddel, een technisch laagwaardig OC instrument om mensen met communicatieproblemen te helpen om voor hen relevante onderwerpen in beschouwing te nemen, alsook om hun ideeën duidelijk te maken op een manier die anderen kunnen begrijpen.

In dit proefschrift introduceer ik een actieonderzoeksprogramma dat bestaat uit zes onderzoeksstudies die de volgende drie vragen behandelen:

1. Hoe gebruiken volwassenen met communicatieproblemen OC, en wat is daarbij voor hen belangrijk?
2. Hoe geschikt is de Sprekende Matstructuur voor volwassenen met communicatieproblemen?
3. Hoe effectief is de Sprekende Matstructuur bij volwassenen met communicatieproblemen?

In Hoofdstuk 1 beschrijf ik het belang van communicatie en de impact van belemmeringen bij het communiceren op de kwaliteit van leven. Ik leg uit wat bedoeld wordt met Ondersteunde Communicatie (OC) en vat de geschiedenis van
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OC samen. Daarna schets ik de evolutie van dit proefschrift in relatie tot zowel mijn klinische ervaring als mijn onderzoekseervaring van de afgelopen 20 jaar en leg de achtergrond van de Sprekende Matstructuur uit aan de hand van voorbeelden van het gebruik ervan.

In Hoofdstuk 2 introduceer ik enkele van de bevindingen van een drie jaar durend kwalitatief onderzoeksproject, waarin ik de communicatie van 15 mensen met Amyotrofische Laterale Sclerose/Motor Neurone Disease (ALS/MND\(^1\)) en hun partners in hun eigen woonomgeving onderzocht. In de studie werd de communicatie van mensen met een achteruitgang in spraak en hun partners onderzocht, alsook hun percepties van de daarbij optredende communicatieproblemen. De kwesties betreffende de communicatieproblemen die mensen met ALS/MND ervaren omvatten meer dan alleen de fysieke problemen, veroorzaakt door een verminderde orale controle. Daarbij komt dat in de bestaande literatuur over ALS/MND, communicatie zelden beschouwd wordt als een gezamenlijke interactie die afhankelijk is van de strategie die door beide communicatiepartners toegepast wordt. Evenmin wordt communicatie gepresenteerd in een realistische omgeving. De deelnemers werden zeven keer bezocht, met daartussen steeds een periode van 6 weken. Ik bespreek het doel van menselijke communicatie en door onderzoek te doen naar de gesprekken van de mensen in hun huis identificeer ik een reeks van strategieën en technieken die gebruikt worden door families met ALS/MND. Ondanks dat hun spraak verslechterd is, zijn sommige mensen met ALS/MND toch in staat om beknopt te communiceren en op een manier die vooral gericht is op onderwerpen die met name voor hen belangrijk zijn.

In Hoofdstuk 3 onderzoek ik het gebruik van Ondersteunde Communicatie (OC) in het licht van de percepties van mensen met ALS/MND en hun partners. Het bleek dat OC voor de mensen in deze studie minder succesvol was dan werd aangenomen. De deelnemers gaven daarvoor een aantal redenen, die als volgt werden geïnterpreteerd: de behoefte aan sociale nabijheid die mogelijk verhinderd werd door het gebruik van een hulpmiddel; de complexiteit van het leren gebruiken van een hoogtechnologisch apparaat; inadequate training. Zowel theoretische als praktische kwesties worden naar voren gebracht voor de professionals die werken met en diensten verlenen aan families met ALS/MND.

\(^1\) ALS (Amyotrofische Laterale Sclerose) is de term die gebruikt wordt in de Verenigde Staten en MND (Motor neurone disease) is de generieke term die gebruikt wordt in Europa.
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In hoofdstuk 4 introduceer ik de Sprekende Matstructuur als een laagtechnologisch OC instrument, dat mensen met communicatieproblemen in staat stelt om hun ideeën duidelijk te maken. Dit hoofdstuk onderzoekt de geschiktheid van het gebruik van de structuur om mensen met afasie in staat te stellen hun ideeën over de kwaliteit van hun leven uit te drukken. Twaalf personen met afasie als gevolg van een beroerte, die in vier verschillende woonomgevingen leven, werden geïnterviewd met behulp van de Sprekende Matstructuur over zes onderwerpen gerelateerd aan de kwaliteit van leven. De interviews werden op video opgenomen en geanalyseerd met behulp van een schema met codes bestaande uit vijf punten, waarmee het vermogen van de deelnemers om hun ideeën over de kwaliteit van leven te begrijpen, te beschouwen en te communiceren naar anderen getoetst werd. De ingevulde Matten werden geanalyseerd door ze cognitief in kaart te brengen, om zo de voor deze mensen belangrijke kwesties met betrekking tot de kwaliteit van leven te kunnen identificeren. De bevindingen laten zien dat de Sprekende Matstructuur inderdaad geschikt is om gebruikt te worden als een instrument voor mensen met afasie, om zo hun ideeën duidelijk te maken met betrekking tot hun begrip van de besproken onderwerpen, hun vertrouwen in het reageren daarop, het bevestigen van hun ideeën in een visuele stijl en hun voldoening met het uiteindelijke resultaat. Het hielp de deelnemers om de onderwerpen en de opties die belangrijk voor hen zijn te identificeren en om aan te geven hoe die hun leven verbeterden of hinderden. We verkregen inzichtelijke observaties over het gebruik van de Sprekende Matstructuur van de deelnemers, en als gevolg van hun betrokkenheid werd de structuur gewijzigd.

Jongvolwassenen met leerproblemen worstelen met specifieke problemen in overgangsperiodes, bijvoorbeeld na de middelbare school of na het beroepsonderwijs. Deze problemen verergeren als zij ook nog eens een handicap hebben in het communiceren.

In hoofdstuk 5 beschrijf ik een studie waarbij 12 jongvolwassenen met zowel leer- als communicatiehandicaps betrokken waren. Ik onderzocht hoe geschikt het gebruik van de Sprekende Matstructuur is om de jongeren in staat te stellen hun ideeën duidelijk te maken over zes hoofdonderwerpen tijdens overgangsperiodes. Ook werden hun ideeën bestudeerd en werden de vaardigheden in beschouwing genomen die nodig zijn om de Sprekende Matstructuur te gebruiken. De resultaten laten zien dat de meerderheid van de deelnemers in staat was om hun sympathieën en antipathieën aan te geven en hun ideeën duidelijk te maken over...
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de keuzes die beschikbaar voor hen zijn. De resultaten suggereren ook dat er vijf noodzakelijke vaardigheden zijn om de Sprekende Matstructuur succesvol te gebruiken. In de studie kom ik tot de conclusie dat de Sprekende Matstructuur jongvolwassenen met leerproblemen kan helpen om discussies en besluiten omtrent de keuzes die beschikbaar voor hen zijn in overgangsperiodes, in beschouwing te nemen en er actief bij betrokken te worden.

In hoofdstuk 6 beschrijf ik een studie waarin de effectiviteit van de Sprekende Matstructuur voor mensen met leerhandicaps onderzocht wordt in relatie tot het in staat zijn om ideeën duidelijk te maken omtrent het plannen van hun leven. Er werd een gemengde methode van een kwantitatieve en een kwalitatieve studie ontworpen om de effectiviteit van de Sprekende Matstructuur te vergelijken met de belangrijkste communicatiemethode van de betreffende persoon. 48 personen, ingedeeld in vier niveaus van bevatingsvermogen, werden daarin betrokken. Van de 48 deelnemers waren er 30 die de Sprekende Matstructuur op een effectieve manier gebruikten. Een effectief gebruik van de structuur werd in verband gebracht met een functioneel bevatingsvermogen. Uit de studie bleek verder dat, in vergelijking met de voornaamste communicatiemethoden, de uitslagen van alle indicatoren van effectieve communicatie hoger waren wanneer de Sprekende Matstructuur gebruikt werd. Deze studie liet zien dat de Sprekende Matstructuur een effectief communicatiemiddel kan zijn voor veel mensen met een leerhandicap, en dat het hen kan helpen in het duidelijk maken van hun ideeën, doordat zowel de kwantiteit als de kwaliteit van de informatie die gecommuniceerd wordt toeneemt.

Verslechterende communicatie is een aspect van dementie dat veel leed veroorzaakt, en het wordt in toenemende mate moeilijker om er voor te zorgen dat de ideeën van de persoon zeker opgemerkt worden.

De studie die beschreven wordt in hoofdstuk 7 betrof 31 personen in verschillende stadia van dementie, die elk geïnterviewd werden over hun welzijn met behulp van zowel de Sprekende Matstructuur als de gebruikelijke communicatiemethoden. De effectiviteit van de communicatie van elke methode werd vergeleken. Uit deze studie bleek dat de Sprekende Matstructuur geassocieerd wordt met een grotere bekwaamheid van mensen in allerlei stadia van dementie om te communiceren, vergeleken met meer gebruikelijke communicatiemethoden. Die grotere effectiviteit in communicatie was duidelijk merkbaar bij de deelnemers in hun mate van begrip en betrokkenheid, hun
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bekwaamheid om het spoor niet bijster te raken en om hun ideeën duidelijk te maken. Door het gebruik van de Sprekende Matstructuur was er ook minder sprake van zich herhalend gedrag en het afgeleid zijn. Deze bevindingen suggereren dat de Sprekende Matstructuur een belangrijke rol kan spelen in het verbeteren van de communicatie door een toegankelijk, goedkoop instrument te leveren dat familieleden en personeel kunnen gebruiken om mensen met dementie te helpen in het duidelijk maken van hun ideeën.

In hoofdstuk 8 vat ik de bevindingen samen van de voorgaande zes hoofdstukken met betrekking tot de doelstellingen van het proefschrift. Vervolgens behandel ik methodologische kwesties, inclusief de sterke punten en de beperkingen. Ik vat het onderzoek naar de effectiviteit van andere OC systemen samen, beschouw de implicaties voor toekomstig onderzoek en de klinische praktijk en trek ten slotte mijn conclusies. De belangrijkste conclusies in antwoord op de onderzoeksvragen zijn:

1. **Hoe gebruiken volwassenen met communicatieproblemen OC, en wat is daarbij voor hen belangrijk?**
   Het onderzoek naar de communicatie en de percepties van mensen met ALS/MND en hun communicatiepartners laat hun behoefte aan OC zien om te zorgen voor i) de ontwikkeling en het in stand houden van sociale nabijheid; ii) discussie over gezamenlijke, relevante gespreksonderwerpen; en iii) de behoefte aan samenwerking en symmetrie in de communicatie. Ondanks de vooruitgang in de afgelopen 20 jaar in de ondersteunde communicatie-technologie is een hoogtechnologische OC nog steeds niet succesvol voor sommige mensen, en er is duidelijk behoefte aan eenvoud; niet alleen voor mensen met communicatieproblemen, maar ook voor de mensen die voor hen zorgen en met hen werken. Deze kwesties waren cruciaal in de verdere ontwikkeling van de Sprekende Matstructuur.

2. **Hoe geschikt is de Sprekende Matstructuur voor volwassenen met communicatieproblemen?**
   Uit de bevindingen van twee studies, een met volwassenen met afasie en een andere met jongvolwassenen met leerproblemen, blijkt dat de Sprekende Matstructuur het merendeel van de deelnemers in staat stelt om aspecten van hun leven in beschouwing te nemen en om hun ideeën duidelijk te maken; iets wat ze daarvoor niet konden. Uit deze studies blijkt dat voor veel mensen met
communicatieproblemen de Sprekende Matstructuur een geschikt communicatiemiddel is. De studies onderzochten echter niet of het effectiever is dan de gebruikelijke communicatiemethoden voor mensen met verschillende begripsniveaus.

3. **Hoe effectief is de Sprekende Matstructuur bij volwassenen met communicatieproblemen?**

Twee verdere studies, een bij volwassenen met verschillende niveaus in leerproblemen en een bij volwassenen met verschillende niveaus van dementie, laten zien dat in vergelijking met de gebruikelijke communicatiemethoden, de Sprekende Matstructuur geassocieerd wordt met het zich effectiever kunnen uitdrukken door het merendeel van de deelnemers. Het werd ook in verband gebracht met een grotere mate van aandacht en interactie en een betere kwaliteit en kwantiteit van de informatie, vergeleken met de gebruikelijke communicatiemethoden. In de studies in dit proefschrift zijn belangrijke kwesties voor volwassenen met communicatieproblemen geïdentificeerd. Ook hebben deze studies laten zien dat de Sprekende Matstructuur zowel geschikt als effectief is voor bepaalde cliëntgroepen. Suggesties voor vervolgonderzoek met de Sprekende Matstructuur zijn een ‘randomised controlled trial’ met een groter aantal deelnemers, om zodoende het gebruik van de Sprekende Matstructuur te vergelijken met de gebruikelijke communicatiemethoden; onderzoek van de Sprekende Matstructuur bij zelfmanagement en besluitvorming; onderzoek naar het gebruik van de Sprekende Matstructuur met andere cliëntgroepen; onderzoek van trainingsmodellen; en onderzoek naar de mechanismes waardoor de Sprekende Matstructuur werkt.

Er zijn ook implicaties voor de klinische praktijk, waarvan er al veel op dit moment voorkomen. De meest belangrijke daarvan is het gebruik van de Sprekende Matstructuur voor gesprekken met mensen met communicatieproblemen binnen een aantal contexten, inclusief de gezondheidszorg, sociale voorzieningen, het onderwijs en de vrijwilligersector.
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Finally, love and thanks to my family who have helped me keep it all in perspective, especially Danny, who has had to put up with all variety of moods from elation to anguish. He is my rock and my main source of support throughout the journey.
Curriculum Vitae
Joan Murphy was born on April 14th 1951 in Edinburgh, Scotland.

After graduating from the Glasgow School of Speech Therapy in 1972 she studied for her Masters Degree in Linguistics at the University of Reading. She worked in Reading in the Royal Berkshire Hospital for one year then worked in Malaysia for two years under the auspices of VSO where she set up a speech therapy service for children with cerebral palsy. It was at this time that she developed an interest in Augmentative and Alternative Communication (AAC). On her return to Scotland she worked in Glasgow and then moved to Stirling in Central Scotland in 1978 where she was Specialist Speech and Language Therapist in AAC in the main Speech and Language Therapy Department before becoming the Senior Specialist Speech and Language Therapist with the Area Rehabilitation Team in Forth Valley in 1997.

In 1989 Joan carried out a demographic study of Augmentative and Alternative Communication in Scotland under the supervision of Professor Ivana Markova. Since then she has been lead researcher on 21 research projects focusing on communication disability. These projects have been carried out with grants from a range of funding organisations including – Capability Scotland, Economic and Social Research Council, Scottish Executive Chief Scientist Office, Viscount Nuffield Auxiliary Fund, Gannochy Trust, NHS Forth Valley, Scottish Motor Neurone Disease Association, the National Lottery and the Joseph Rowntree Foundation.

In 2005 Joan was appointed as Senior Clinical Research Fellow with the Alliance for Self Care Research at the University of Stirling. Joan’s research involves people with different disabilities, both congenital and acquired, and she regards communication as a collaborative effort between communication partners. Her work focuses on finding ways of helping people with speech disability and their communication partners to communicate in the most effective way. There is a great deal of emphasis placed on the links between research and clinical practice and on producing practical outcomes from the research.

As an outcome of a project funded by the Gannochy Trust in 1998 Joan developed an innovative low-tech communication tool called Talking Mats, which is a visual framework that uses picture symbols to help people with a communication difficulty understand and respond more effectively. Since then she has carried out a
number of related and interlinked projects using the Talking Mats framework with different client groups and for different purposes. The findings from these projects have been published widely and the Talking Mats framework is now used increasingly by other researchers. Joan and her colleagues have also produced a series of training packages with accompanying videos which have now been marketed worldwide. Talking Mats is now used by a range of professionals both clinically and in research and Joan is regularly invited as keynote speaker at both national and international conferences. In addition the AAC Unit runs practical training workshops for people with communication disabilities, carers and professionals locally, nationally and internationally.

Up until October 2009 Joan worked part time as a researcher and part time as a clinician with the NHS in Scotland. She is now the Research Manager at the Talking Mats Research and Development Centre at the University of Stirling.
Appendices
Appendices

Talking Mats training project

Decision making with people with dementia

Adapting to aphasia
Gillespie A & Murphy J (2008) Funded by ESRC

Effectiveness of Talking Mats with people with dementia
Related package

Evaluating the ability of children with social emotional behavioural (SEB) and communication difficulties to express their views using Talking Mats
Coakes L & Murphy J (2005) Funded by Forth Valley NHS

The acute hospital experience for adults with a lifelong communication disability

Consultation between GPs and people with a communication disability
Murphy J (2004) Funded by the Scottish Executive

Exploring perceptions of quality of life of frail older people during and after transition to institutional care
Related Package

Evaluating the effectiveness of Talking Mats as a communication resource to enable people with a learning disability to express their views on life planning
Murphy J, Cameron L, Markova I & Watson J (2004) Funded by the Scottish Executive
Related package

Talking together: communication strategies of people with motor neurone disease and their partners
Murphy J (2003) Funded by the National Lottery Charities Board and the Scottish Motor Neurone Disease Association
Related package

Multidisciplinary training with Talking Mats
Murphy J & Cameron L (2001) Funded by Forth Valley Primary Care NHS Trust

Making choices at the time of transition for young people with learning disability
Cameron L & Murphy J (2000) Funded by the Viscount Nuffield Auxiliary Fund
Related package

Enabling people with a communication difficulty, as a result of stroke, to discuss quality of life issues
Murphy J (2000) Funded by the Scottish Office Department of Health
Related package
Appendices

Don't hang up: a training package to help people with communication difficulties use the telephone more effectively
Related package

Enabling people with MND to have control of their lives: the development of a communication tool
Related package

Telephone use by people with severe communication difficulties
Murphy J (1999) Funded by the Scottish Office Home and Health Department
Related package

The development of a training package to facilitate more effective use of AAC systems
Murphy J & Scott J (1999) Funded by the Viscount Nuffield Auxiliary Fund
Related package

Interaction between AAC users and their peers in a residential environment
Murphy J & Lester-Cribb M (1998). Funded by the Gannochy Trust
Related package

The development of an introductory training video in AAC
Murphy J & Scott J (1998) Funded by the Viscount Nuffield Auxiliary Fund
Related package

Good practice in the provision of AAC services: processes of training and communication support networks
Collins S, Lester-Cribb M, Markova I, McCall F, Moodie E & Murphy J (1997) Funded by The Scottish Office Home and Health Department

The role of communication support networks in the training and use of AAC systems by people with cerebral palsy
Murphy J & Scott J (1994) Funded by Capability Scotland and Liberator Ltd.

The interactive strategies of users of AAC systems and of their partners
Markova I, Murphy J, Collins S, Scott J & Boa S (1994) Funded by The Scottish Office Home and Health Department
Related package

Augmentative and alternative communication systems used by people with cerebral palsy in Scotland: a demographic survey
Appendices


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Dementia: International Journal of Social Research and Practice

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Cameron L, Murphy J. (2006). Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. British Journal of Learning Disability, 35, 113–120.


