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Research feature

More than pictures: developing an accessible resource

Lois Cameron and Rhona Matthews

Abstract

Purpose – The purpose of this paper is to describe the process of developing an accessible communication resource which enables people with a learning disability to reflect on their lives and raise issues of concern. **Design/methodology/approach** – The process of making the resource and the facets that contribute to making it accessible are explored, e.g. design specification, the relationship between pictures and meaning, the order in which concepts are presented. The paper goes on to describe how the resource is put into practice using the format of a "Talking Mat". Talking Mats is a communication framework which has a strong evidence base that shows it improves the quality and quantity of information a person with a learning disability gives in a conversation. It provides practitioners with a consistent framework to support implementation. The impact of using the resource is explored through feedback from practitioners trained to use it and the stories that resulted. **Findings** – A well-constructed resource can support people with a learning disability to express their views on what matters to them at a specific time and raise concerns they may have. The individual views that have emerged from people are varied. This resource enabled them to be genuinely included in planning the steps required to bring about positive change in their lives.

Originality/value – There is much emphasis on the development of accessible resources in the field of learning disability but little on the actual development process and the context of how resources are introduced. This paper aims to contribute to this knowledge base.

Keywords Learning disabilities, Implementation, Intellectual disability, Safeguarding, Abuse, Accessible information

Paper type Technical paper

Lois Cameron and Rhona Matthews are both based at Talking Mats Limited, Stirling, UK.

Introduction

It is widely recognised that people with a learning disability are at increased risk of all forms of exploitation and abuse. An example is the scandal of Winterbourne View (Care, 2012), highlighted by the Mazars (2015) report. People with learning disabilities living in the community are not immune from exploitation. McCormack *et al.* (2005) identified the most common location of abuse as being the family home, followed by day services and public places. Reiter *et al.* (2007) found most physical abuse was reported as occurring in the local neighbourhood. In the Gravell (2012) study "Cruelty and Loneliness", of the 67 people interviewed, 62 had experienced some form of harassment, abuse and related crime. In addition, there is a strong correlation between abuse and poor communication skills because people may not have the language and communication skills to report issues of concern.

The initial driver for the current project came from Survivor Scotland, a Scottish organisation that supports people who have experienced abuse. They recognised that as a mainstream organisation they had little contact with people with learning disabilities even though they knew that in this population there would be many survivors. They wanted to find a way forward and one solution was to develop a visual communication resource that would enable people with learning

With grateful thanks to the Scottish Government for funding the projects. Thanks also to the Comic Artist Adam Murphy. The Symbols are designed and © to Adam Murphy 2015 and assigned to Talking Mats Ltd in perpetuity. Symbols ©2013-2016 Adam Murphy (www.adammurphy.com). They may not be reproduced without permission.

disabilities to reflect on their lives and raise any issues or concerns. It was quickly recognised that people cannot be expected to disclose the big issues of their lives, if they have not been encouraged to reflect and share the small ones. Both big and small issues can have an impact on well-being. The resource was therefore designed to support a holistic reflection of how an individual is feeling about many aspects of his/her life.

We know, of course, that there are many threats to the well-being of people with learning disabilities. They die, on average, 20 years earlier than the general population (Matheson, 2013) and generally suffer poorer physical and mental health than the rest of the population. Health is determined by a variety of complex factors, e.g. genetics, the way we live, and our broader social and environmental conditions. Emerson and Hatton (2014) argue that people with learning disabilities are disadvantaged at all these levels. It is therefore critical that practitioners take a holistic approach to addressing health inequalities.

Social connectedness is an important factor in well-being. Recent research from the Royal Society of Arts (2015) suggests that social connectedness correlates more strongly with well-being than social or economic characteristics such as long-term illness or unemployment. Yet it is known that the social networks of people with learning disabilities are often limited. For example, Robertson et al. found that, for people living in residential settings, the median size of their social networks (excluding staff) was two people.

In the field of learning disabilities there has been much emphasis on the development of accessible resources including several guidelines produced – for example, the Mencap (2002) guidelines on making myself clear. However, there is little written (though see Olsen and Carter, 2016) about the process of developing accessible information in terms of: how understanding is supported, particularly when the issues involved are complex and/or sensitive; how images aid or hinder meaning; the influence of the order of information; and the varying language demands of different topics. As well as considering the development of resources, a focus on implementation is key to ascertain the impact that accessible resources have in terms of enabling positive change in the lives of people with a learning disability.

Development of a visual resource

Survivor Scotland, a charity which supports survivors of abuse and Talking Mats, a social enterprise that supports people with communication difficulties, recognised that a resource was needed that would enable people with learning disabilities to raise and disclose concerns. Funding for the projects was provided by the Scottish Government. The development of the Keeping Safe resource has been an iterative process that has seen it change and develop over a period of six years from a trial in one health board, to being tested out with people with learning disabilities throughout Scotland.

Talking Mats®

The resource was based on the Talking Mats framework originally developed at the University of Stirling, to help people with communication impairment understand and reflect on an issue and express views. Feasibility research (Cameron and Murphy, 2002) and the subsequent effectiveness research (Murphy and Cameron, 2008) indicate that using Talking Mats improves both the quality and quantity of communication in people with learning disabilities; people say more, and the quality of what they say is enhanced, compared to using only their usual methods of communication:

In any Talking Mats conversation there is a "thinker" (the person expressing the view), and a "listener" (the person facilitating discussion). Talking Mats supports the thinking and expression of the thinker by:

- providing a structure where information is presented in small chunks supported by symbols;
- giving people time and space to think about information;
- saying what they feel in a visual way that can be easily recorded; and
- building a thinker's confidence by starting with easy topics and moving to more abstract ones.

Talking Mats encourages the listener to:

- be non-judgemental, non-leading and accepting in their approach;
- pay particular attention to additional non-verbal and verbal comments;
- think how they can personalise the options for the thinker to support their understanding particularly for more abstract concepts, for example, by using examples relevant to their lives; and
- be creative and if required, draw further options that are particularly pertinent to that individual.

Collaboration and iteration

We are grateful for the input of our various partner organisations: NHS Fife, Survivor Scotland and Kingdom Abuse Survivors Project. Working with people from a range of perspectives adds a depth to thinking and allows different approaches to be included. The initial resource was based on the work of 6D Cards (Neufeind and Hannah, 2012). The development of this Talking Mats resource involved:

- Structured seminars (one at the outset and one midway) with the key partner organisations to establish the framework. Three topics were agreed: well-being, relationships, and thoughts and feelings.
- 2. People with learning disabilities used the resource to reflect on their lives and give their feedback on it. It was felt that this approach of using the resource in practice would enable more people with learning disabilities to be involved and ensure a broad range of feedback on the resource across a group of people with diverse communication and cognitive challenges. Examples of changes made were:
 - the move away from black and white line drawings;
 - the need to reduce unnecessary visual details in the symbol and focus on key meaning; and
 - changing the language of the top scale from the original "fine" vs "problem" to "going well" vs "not going well".
- 3. Staff who worked throughout Scotland with adults with learning disabilities also contributed to the resource by reflecting on their practice and experience of using the resource. All of these staff attended a training course and received a copy of the resource to use in their work settings. Example of changes made from their feedback included:
 - the language used;
 - suggesting further options;
 - the structure and sequence of the resource; and
 - reducing the number of difficult feelings in the thoughts and feelings topic and adding more positive concepts, e.g. "resilience, like a laugh".

Developing a resource is an iterative process between all the parties and in this case involved a triangulation of the organisations involved, people with learning disabilities and staff. Their opinions were taken on board by ourselves and the artist. A feedback loop of trial-change-retrial was established, thinking about design of the pictures, structure and order of delivery, language used and user experience.

A clear design specification

In order for the resource to support communication it was imperative that the visuals supported understanding and thinking and were not a distraction from the meaning. Therefore, the development of a cohesive design specification was critical. This specification was developed in conjunction with the comic artist as it was key that we shared a common understanding of purpose. It was important that the images developed were:

Attractive and engaging. An earlier resource was black and white and the feedback from people with learning disabilities was that this was not liked and colour was viewed as important. There is very little empirical research about the optimal symbol size and colour for different client groups. However several leading graphic and cartoon designers use yellow as this is easily recognisable and attractive, e.g. Simpsons, Lego.

- Focussed on the meaning of the concept to be communicated, so that the image is a scaffold to understanding but does not overload or complicate.
- As neutral as possible, to facilitate placement in either the negative or positive category. It is important that the image cannot be construed as leading.
- In some instances the image is only a starting point to explain the concept. This was particularly true where the concepts were abstract, e.g. coping with loss or mood and where appropriate we encourage the listener to personalise those concepts to help increase the thinker's ability to understand the process.

Through the course of the project we had feedback on the heterosexual nature of the images, particularly on the cards depicting hugs and kisses and sex. Several options were considered, including having cards that reflected the range of heterosexual or gay relationships. However, we were aware that sex was the card that many people (both thinkers and listeners) were reluctant to discuss, so we did not want to add further barriers. Our solution was to make those more intimate options as androgynous as possible. This may not be a long-term solution as it would be hoped that as thinkers and listeners are more able to have open conversations about sexuality then further more varied images could be developed.

A clear structure

Talking Mats supports cognition, so ensuring the resource follows a logical sequence to support thinking is critical. The structure of the resource is based around having conversation on three major aspects of life; well-being, relationships, thoughts and feelings. It allows adults with learning disabilities to take time to stop and think about their lives, and express a view on "How is it going for me?" For each option the thinker reflects and places the option on a scale which ranges from "going well" to "not going well" for the first two topics, and "this is me" to "this is not me" for the last topic (thoughts and feelings). The overall structure was agreed early on and remained the same from the outset, but different options within the topics have been moved, deleted or altered to improve the flow of the conversation. It was always recognised that the "thoughts and feelings" section is abstract in nature, and therefore will only be accessible to people with mild learning disabilities. The order in which options are presented to the thinker is important and starting with the more concrete options is helpful. We do provide guidance to the listeners by having a small signifier mark on the abstract cards to indicate that these are more difficult and may require more explanation and/or examples.

Relationship between image and understanding

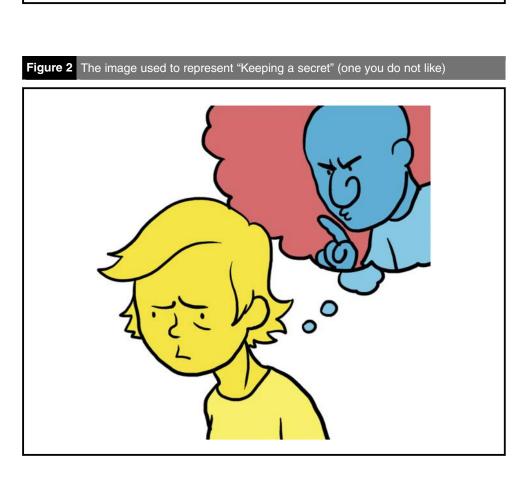
Resilience is a good example of a word that is abstract and can be difficult for people to understand, so the wording chosen for this concept was "strong inside". This decoding of language also helps the artist to depict the meaning (representing the concept by a little person in a power pose inside a body) (Figure 1).

The meaning of more complex concepts is aided by the combination of both the words and imagery. Sometimes the imagery adds to the particular connotation of the concept, e.g. keeping a secret includes a rather sinister looking person saying "sh", so it aids the understanding that this is a secret you do not like (the listeners are encouraged to explain this verbally to the thinkers) (Figure 2).

Disseminating the resource

The resource was disseminated through a training programme offered to staff working in health and social care settings throughout Scotland. It is critical that staff are confident with the key principles of Talking Mats to help maintain the integrity and effectiveness of the approach. The training included a session from a specialist team - Kingdom Abuse Survivors Project. The length of training varied and was either two days or one day depending on the Talking Mats experience of the staff.

Figure 1 The image used to represent the concept of strong inside (resilience)



As at April 2016, 113 people were trained over nine courses held in Borders, Fife, Glasgow, Ayrshire, Stirling and Inverness attended by learning disability nurses, social workers, allied health professionals, advocates and psychologists.

To support the long-term sustainability of the resource a Train the Trainers Keeping Safe course was developed and delivered. A detailed training manual was developed for the trainers.

There are currently 15 Keeping Safe trainers in eight of the 14 Health Board areas in Scotland and they provide continued training in their local area.

In total, we have distributed 234 Keeping Safe resources through our training and the accredited trainers' courses. Further funding has been received from the Scottish Government so this is ongoing.

The feedback from the courses was very positive and included comments such as:

Relief to have a relatively easy and effective communication tool.

Like the fact the resources have been made and consideration given to using symbols to aid people to have a clear voice about things which are difficult to talk about.

Impact of the resource

The key question is whether this resource has a positive effect on the lives of people with learning disabilities. As part of the evaluation process 113 staff who attended the training were asked to submit a report of an example of their use of Talking Mats. In total, 83 examples were submitted. These were from staff working in a variety of settings including: day services, residential, forensic, inpatient and advocacy. Those who did not submit stories were followed up and a variety of reasons given for not submitting, e.g. change of jobs, not able to use it yet, no time. This may mean there is an inherent bias in the results as staff are more likely to report when the outcome is positive.

Talking Mats was seen as a helpful way to discover new information (89 per cent), discuss and resolve fears (84 per cent) and help thinking (89 per cent).

Quality of information

Staff frequently commented on the quality of information gained:

This mat was so helpful for person B. It gave so much information which we did not expect. It will assist in Adult Support and Protection feedback. It gave him his own say in things (53H2).

As Q has auditory processing difficulties this is a very effective method of chatting to Q about any worries she may have. It also helps with memory and attention as she has something visual to keep her focused (6R4).

The information gained reflected the person's view and not the views of those around them:

There are concerns about A being influenced by others' opinions and I feel that when we use Talking Mats she is able to say what she really thinks (108T1).

The resource enabled staff to have a conversation about more sensitive and or difficult issues:

Usually when she expresses her feelings she can get either upset or angry. She did not get upset or angry at any point through doing the Talking Mats, although the subject and things she was saying were at times difficult issues (18H2).

The striking thing in this feedback is the extent to which this resource is helpful to people with learning disability who are verbal, this finding reflects previous research findings (Murphy and Cameron, 2008) and challenges a misperception that can be found in learning disability services that a conversation with visual support is only for the non-verbal or those with limited verbal skills.

Therapeutic impact

At times the mats appeared to have therapeutic impact:

Talking Mats are a nice way to break down situations for her and help her to gather her thoughts. K always seems relaxed and calm after having a discussion and this is a very good way to guide that conversation (6R2).

Feedback on the resource from people with learning disabilities

There was a lot of positive feedback on using the resource from people with learning disabilities:

I adore this. The mats really helped me speak about my feelings (18H2).

Later, when she was getting a lift back home, she said the mats really helped her speak about her feelings. She said it was overall really good and she would like to do Talking Mats more in the future (28t2).

Range of topics explored and examples of Mats

Through the resource people with a learning disability reflected on their lives and the issues that they raised were wide ranging, e.g. bereavement, breakdown of relationships, fear of health appointments, loneliness, level of exercise, diet, drugs. The following are two examples of the Mats.

Mat 1 well-being

A man with cerebral palsy placed exercise on the "not going well" section of the mat and commented that (Figure 3):

[...] exercise wasn't going well but he would like to try using the new parallel bars in the centre to help improve his strength (62H1).

This reflects a good example of someone recognising how he could own some of the solutions to his health (Figure 3).

Mat 2 relationships

For one man there was a particular girl who he was close to at his day centre but he placed partner on the not going well part of the Mat and commented that "he has a girlfriend but they rarely have the opportunity to meet out with the local day centre. He would like to move this relationship on but is unsure how to" (92R1) (Figure 4).

Figure 3 An example of a Talking Mat exploring well-being



Figure 4 An example of a Talking Mat exploring relationships



Conclusion

Developing the Keeping Safe resource has been a process involving several projects, with trials in a variety of settings. It has been a framework shaped over time by all the people involved.

Creating a visual resource that is meaningful is much more than just adding pictures. There needs to be a design process that maximises both the impact of the visual image but also its link to the concept or concepts it is trying to support. In addition, consideration needs to be given to the order of the potential conversation both in terms of the complexity of issues discussed but also the natural flow of dialogue so that there are minimal topic shifts. The aim should be to keep the cognitive load for individuals as low as possible.

The use of the existing Talking Mats framework has been critical as it gives the listener guidance and a structure to facilitate the discussion. The Talking Mats principles remind the listeners to think about the impact of their interaction and be an "open listener" and not try to fix the first problem that arises. It is important to consider the different facets of a person's life and build an overall picture. Use of the resource involves two people so inevitably personal factors and different styles of interaction come into play. More effective communication is achieved when a resource is structured as a framework that addresses the complexity and individuality of communication such as in the Keeping Safe Talking Mats Resource. There is, however, a significant question still to be addressed about the long-term sustainability of the resource including the extent to which it will be used once the project has come to an end. Plus the long term impact of using the Keeping Safe Talking Mats resource with people with a learning disability. These aspects require future evaluation.

Despite the considerable focus on accessible information there is still a limited evidence base into what are the most effective ways to present visual information, what are the most

helpful images and how to support more abstract and challenging concepts. Developing a specification using a broad evidence-base combined with the iterative process of feedback from specialist organisations, front line staff and people with a learning disability has been helpful.

The views that have emerged from using the Keeping Safe Talking Mats are powerful and varied, and illustrate that a visual resource can help people to reflect and express what is important to them at a specific time. It mitigates against the danger of making assumptions and habituating to the familiar. This process of listening can contribute to safeguarding and allows people with a learning disability to take more control of their lives and identify changes that can improve their health and well-being. As one member of staff involved in the training and using the resource said, this resource has the "potential for making important changes to the lives of the most vulnerable people in our society".

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