The development of a screening tool for obese adults with learning disabilities

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2005

EXECUTIVE SUMMARY

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Background
Adults with learning disabilities (LD) have an increased risk of obesity (Emerson, 2004; Lennox et al, 2003). In addition, they have a high incidence of communication difficulties which can prevent meaningful involvement in their care plan (Melville et al, 2005). Existing resources do not address these needs (search on Medline, Ovid and Google, plus discussions with other health professionals across the UK).

Aims
- To adapt the screening tool developed by the author and make it accessible for adults with LD.
- To determine whether the 'Talking Mat' framework involves people with LD in the decision-making process regarding the treatment of obesity.

Method
Following discussion with various disciplines from the community learning disability teams, a draft 'Talking Mat: Important things to losing weight' was compiled, using Board Maker picture communication symbols. The 'Talking Mat' was then used with twelve adults taken from the dietetic waiting list, to determine the suitability of the questions and chosen symbols. The semi-structured, individual interviews were video recorded. These recordings and the resultant 'Talking Mats' provided qualitative data, which was analysed using cognitive mapping (Jones, 1985). The raters used each client's verbal and non-verbal information to judge and reach a consensus regarding the most important factors to weight loss.

Key results
- All clients, whether mild or borderline LD, benefit from using the 'Talking Mat' to consider weight management.
- The placement of the symbol should not be taken in isolation from the discussion around its placement on the Mat.
- Compared to general communication methods used in weight management, the 'Talking Mat' provided a greater quality of interaction and information gained.
- Clients took greater ownership of weight management and the resulting 'Talking Mat' gave a clear focus for person centred planning.
- The process enabled onward referral to appropriate health and social care professionals.

Conclusion
Resources which are designed to enable clients to both understand and express themselves, improve the quality of information and allow their issues to be incorporated into care planning programmes.

What does this study add to the field?
A resource that:
a) involves adults with LD in the decision-making process regarding the treatment of obesity
b) identifies areas where the client is motivated to make change
c) encourages a multi-disciplinary approach to weight management.

Implications for Practice and Policy
The need to address health inequalities and encourage a client-centred approach is recognised by NHS Health Scotland (2004) and the Scottish Executive (2000a, 2000b, 2003). The 'Talking Mat: Important things to losing weight' provides a means of overcoming these issues. In addition, the Mat encourages a more efficient and effective use of clinicians' time, as the resource identifies areas where the client is most motivated to make lifestyle changes.

ACKNOWLEDGEMENTS

Our thanks are due to Forth Valley Primary Care Operating Division for funding the project; to Morag MacKellar for allowing time to undertake the research and to Mary Turnbull and Mary Fraser for their support.

Special thanks go to the 12 participants whose involvement was invaluable. We would also like to thank Janie Faulkner for helping with the qualitative analysis and Joan Murphy and Linda Tierney, from the AAC Unit, for sharing their resources.

Thanks are also due to members of the Integrated Learning Disability Teams for their constructive comments – in particular Lorraine Cunningham, Carol Davie, Lorna Dougans, Edith Matheson, Claire McBeath, Rita McIlwaine, Sheila Wason and Karen Whitehead.

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BACKGROUND

The incidence of obesity is more common in adults with learning disabilities (LD) than in the general population (NHS Health Scotland, 2004; Emerson, 2004; Lennox et al, 2003; Lea, 1999) and higher still for women with Down Syndrome (Melville et al, 2005). The increasing trend for obesity in the UK is also noticeable in this client group. 64% of participants in a study by Marshall, McConkey and Moore (2003) had weight problems (36% obese and 28% overweight) compared with 52% of obese and overweight adults highlighted in a similar study carried out by Barr et al six years previously.

Adults with LD tend to lack an awareness of the cause and complications of obesity, as the majority of available health promotion material does not account for their cognitive and communicative abilities (Melville et al, 2005; Large & Jenkins, 1999). Clinicians inexperienced in dealing with people with LD are also recognised as a barrier to effective healthcare – predominantly through not relating to, or communicating properly with, this client group (NHS Health Scotland, 2004; Lennox et al, 2003; McConkey & Truedale, 2000; Beange et al, 1995). In addition, people with LD tend to have a greater number of health needs that can result in weight gain, for example, poor mobility and side-effects of prescribed medication (Espie & Brown, 1998). This combination of factors increases the risk of developing complications from obesity such as coronary heart disease and cancer, which can contribute to premature death (Scottish Office, 1999).

The need to address such health inequalities is recognised by NHS Health Scotland (2004) and the Scottish Executive (2000a, 2003) along with a client-centred approach (2000b). The Clinical Standards Board of Scotland (2002) also recommends that clients be 'involved in decisions about their own care through effective 2-way communication and information sharing' (p31). Yet, research by McConkey, Morris & Purcell (1999) highlighted that people with LD rarely get the chance to talk with their carers as 'equal partners'. To overcome some of the barriers McConkey et al recommend the use of simple language along with non-verbal signals. This aids verbal comprehension, slows down delivery and gives the client more time to formulate a response or initiate a question. 'Talking Mats' (Murphy & Cameron, 2002) is an augmentative form of communication that takes these factors into account.

This project, therefore, focused on developing a tool that would allow obese adults with LD to be actively included in the discussion and decisions around the issue of their weight. A previous project by the author on 'Barriers to weight loss in obese adults with LD' (unpublished) identified learning difficulties, psychological issues, medical conditions and inadequate resource provision as factors that may prevent weight loss in this client group. A screening tool was developed from this study for use by clinicians in determining the most appropriate care pathway. However, with adaptation it may meet the needs of the clients' cognitive and communicative abilities and enable them to be more actively involved in the decision-making process.

AIMS

The project has 2 aims:

- To adapt the screening tool developed by the author and make it accessible for adults with LD.
- To determine whether the 'Talking Mat' framework involves people with LD in the decision making process regarding the treatment of their obesity.

METHOD

Medline, Ovid and Google were searched for information on 'pictorial obesity screening tools'. No appropriate reference was found.

The next stage was to meet with various disciplines from the community learning disability teams to determine symbolised representation of the individual headings from the written screening tool (appendix 1). Peer review was essential to ensure the following:

- the meaning of the chosen symbol was consistently obvious
- simplifying text with symbols did not alter the original message.

Certain text from the original checklist was either difficult to translate into symbol form or contained information outwith the client's knowledge base, e.g. can the client make an informed choice or does prescribed medication have a side-effect of weight gain? An additional information sheet was therefore compiled (appendix 2) with the view to being completed with the client and their carer on the initial visit. Where possible this information was shared with the client at interview e.g. 'your medicine may make you put on weight. What do you think about that?'

Following these discussions a draft 'Talking Mat' was produced using Board Maker picture communication symbols - a resource designed by Mayer-Johnson, USA. These symbols are used in educational, social and health establishments across Forth Valley, and are therefore familiar to many of the clients.

This mat was used with half a dozen colleagues to determine the appropriateness of the content, prior to piloting the tool. Slight changes were made to the symbols on genetics and decision making, and additional symbols were added i.e. eating out and shopping list. The final tool consisted of 27 symbol options associated with the topic: important things to losing weight.

Ethical permission was provided by the Ethics of Research Committee of Forth Valley Health Board. A total of 12 participants was considered sufficient as the project involved piloting the designed 'Talking Mat'. Participants were only accepted if the following criteria applied:

- Over 16 years of age
- Were obese
- Had a learning disability, but could comprehend a sentence with at least three information carrying words. (This level of comprehension was

necessary in order for the participants to understand their involvement in the project and be able to give consent to participate).

All participants were taken from the dietetic waiting list. Discussions with relevant colleagues excluded people already known to the LD team who did not meet the above criteria. 30 symbolised information leaflets outlining the project were forwarded to the remaining clients. The leaflets included tear-off slips, to be returned if the individual was willing to take part in the project. 16 people declined, their reasons being inappropriate timing as changing tenancy; not wanting to be video recorded; no longer obese, and insufficient cognitive and communicative ability.

The remaining 14 received a personal visit where the project was explained in more detail and their level of obesity and comprehension ascertained. Heights, weights and body mass indices were used to determine the former (WHO, 1997) and the Stirling University SUST tool (unpublished) to assess the latter. 2 people were excluded from the study at this stage, as they could only understand 1-2 information carrying words and were therefore unable to give informed consent. The remainder signed the symbolised consent form, completed the additional information sheet with their carers, and agreed to their GP being forwarded a letter outlining the project.

The return appointment involved semi-structured and individual interviews – with or without a carer present, at the client's request. The interviews used the designed Risk Reinforcer (appendix 3) and Talking Mat (appendix 4). Participants were reminded that they could stop the project at any time without having to give a reason. Records of events included a video recording of each interview, a digital photograph taken of the completed 'mats' and detailed field notes.

Risk reinforcer

Participants were reminded of the original referral to the dietitian to lose weight, then symbols were used to try and explain the complications of obesity.

Talking Mat

A sample 'Talking Mat' on 'animals' was then undertaken to familiarise the participant, and where necessary teach the process, prior to completing the 'Talking Mat' designed for this project. For information on the framework of a Talking Mat see appendix 5.

Analysis

The video recordings were analysed by the two main researchers, plus an associate researcher to reduce subjective bias. The coding framework (appendix 6), had a rating scale and included the following questions:

- Participant's understanding of the issue for discussion
- Participant's engagement with interviewer
- Confidence of participant in articulating views/placing symbols
- Interviewer's understanding of client's views
- Participant's satisfaction with their confirmed views.

All significant verbal and non-verbal responses were recorded on a cognitive map (Jones, 1986), (appendix 7). The raters then judged and reached a consensus regarding the most significant factors to weight loss. The consensus was reached through the non-verbal and verbal information given from the clients.

PARTICIPANTS

Of the twelve people who took part in the study the following information is available:

Table 1 **GENERAL INFORMATION**	
Gender	**Number**
Female	6
Male	6
Age	**Number**
20-29 years	3
30-39 years	2
40-49 years	1
50-59 years	5
60-69 years	1
Comprehension level	**Number**
3 information carrying words	5
4/4+ information carrying words	7

Table 2 **HEALTH INFORMATION**	
Level of obesity (Body Mass Index)	**Number**
30-39kg/m^2	6
40-49kg/m^2	5
50-59kg/m^2	1
Possible factors contributing to obesity	**Number**
Hypothyroidism	2
Polycystic ovarian disease	1
Poor mobility	3
Side-effect of medication	5
Mental health issues	**Number**
Bi-polar	1
Depression	4
Schizophrenia	2

Table 2, continued HEALTH INFORMATION	
Medical problems possibly exacerbated by obesity	**Number**
Ankle oedema	2
Asthma	1
Chest pain	1
Hypercholesterolaemia	2
Hernia, requiring surgery	1
Raised blood pressure	4
Raised sugar levels	1
Sleep apnoea	1

Table 2 represents 7 participants whose medical problems were possibly exacerbated by their weight. 3 clients had a combination of physical and mental health problems. Only one participant had no diagnosed mental or physical problem at the time of the study, but experienced breathlessness on exertion.

RESULTS

All participants completed the Risk Reinforcer and Talking Mat on 'Important things to losing weight'. The researchers compared results from photographs of the Talking Mats with participants' verbal content and facial expressions, captured in the video recordings and recorded on cognitive maps. 100% consensus was obtained in using the coding framework by the 3 raters. The judgement reached on significant factors to weight loss is listed below.

Table 3 **RESULTS FROM THE TALKING MAT**	
Topic	**Percentage of participants who felt the topic was an issue**
Health	83%
Food	67%
Activities	58%
Information	50%
Decisions	50%
About you	33%
Relationships	25%
Money	8%

*See appendix 7 for further categories as outlined in the cognitive map

It was essential to compare verbal/non-verbal communication with actions, as a symbol could be placed under the 'agree' 'unsure' or 'disagree' columns by different participants and still indicate that the topic was an issue for that person. Examples of responses to the interview questions (appendix 8) are outlined overleaf and demonstrate the importance of listening to the discussion around the placement of the symbol. (The number in the bracket refers to the participant number).

Health

Agree	Unsure	Disagree
"I'm getting a lot heavier" (8)	"I could be in better condition for a start, like" (10)	"Got to slim down." (2)

Food

- Shopping list

Participant 4 placed the shopping list symbol in the 'disagree' column as he was not involved in compiling the list. However, when asked if he would like to help putting the shopping list together he moved the symbol to the 'agree' section.

- Packet food

Agree	Unsure	Disagree
"I heat up leftovers (from previous home-made meal)" (12)	"not sure what to cook in microwave" (10)	"don't get much in them" (8).

Activities

Agree	Disagree
"That's what I'm doing, sitting not moving. If my Mum's reading I sit in a chair and fall asleep – it's automatic. I like swimming, but I've got nobody to go with." (3)	"I say no to that (sitting activities), 'cause who wants to sit in the house all the time?" (8)

Information

Agree	Unsure
"Yes, but letters must be big and neat." (12)	"Good to have picture by written word. If you don't have the pictures you might not remember" (8)

The Talking Mat and resulting discussions also identified anomalies in an individual's answers. For example, participant (7) cooked at the centre, but did not generalise his skills into the home setting. Levels of mobility also affected activities undertaken: participant (4) goes swimming, but just sits in the pool, while participant (5) "watches others dancing" as "I can't get around".

Decisions

For many participants the section on decisions was not expressed as an issue. The raters, however, judged it to be a significant factor as the locus of food control did not appear to rest with the participants – see overleaf for examples.

- "I know how to cook, but Mum does the cooking" (3)
- "Would sometimes like to do more cooking" and get involved in shopping (4)
- "Biggest problem I've got – not being able to do a shopping list (for the people who shop for him)" (8)
- Portion sizes are "too little … or sometimes far too much" (10)
- "Mum buys fatty food. Mum no lets me get food that I like. I like apples and bananas" (11)
- "I'm putting less on a plate, or my co-worker puts less on a plate. They just do it, but I'm happy about this." (12)
- "Some people say "You shouldn't have that, but if I shouldn't have it why is it put on my plate?" " (13)

The section on decisions appeared to cause some confusion generally with many of the clients placing the symbols 'making decisions' and 'keeping to decisions' in the 'unsure' section. The concept of decision making was the most abstract topic and one participant who had a comprehension level of 4 information carrying words sought clarification, suggesting that some of the others may not have fully understood these questions.

<u>About you</u>

There was also some discrepancy around how people saw themselves and viewed their health. Participant 12 when asked about the risk to her health said she "definitely didn't want to be fat", yet saw herself as "having a good figure". Participant 7 had a similar response: "I don't like being fat", but when asked how he looked replied "OK". Participant 4 was happy with how he looked, but felt his mood was not good as he "gets lots of rows from his sister about his weight".

<u>Relationships</u>

The relationship people have with family, friends and carers can affect not only their moods, but their support system and their self-esteem. Replies to the questions on relationships included:

"I'm stuck here. All my friends are in Stirling" with little contact from Mum & Dad (1)

"Friends come to visit me at Mums" (2) – suggesting they are family friends who do not visit him in his own home

"Like having relationships with them (carers). If I need help I get help from them" (5)

"I was abused so I don't have a relationship with the family. These carers I've got have been fantastic to me – better than the previous place. I like my carers 'cause they listen to me" (8)

"I like carers that can handle me, listen to me" (10)

"Had a friend who moved away – no others. Had a boyfriend – he moved away" (12)

"Listened to at the centre and sometimes at home" (14)

Time taken to complete mat

The participants generally gave much consideration to their answers, with the longest response taking 13 seconds between the question finishing and the answer being vocalised.

DISCUSSION

Fully understanding the issues for discussion can be a barrier to obtaining opinions from people with learning disabilities (NHS Health Scotland, 2004; Clinical Standards Board of Scotland, 2002). Talking Mats helped overcome this problem by its inherently structured approach; breaking information down into manageable pieces; using symbols to support the written and spoken word, and giving the client control to place the symbols on the mat (Murphy & Cameron, 2002; McConkey, Morris & Purcell, 1999). The use of Talking Mats held clients' attentions for 30 - 45 minutes and the process generated responses of 'I enjoyed that' (11) and 'that was interesting' (13).

The use of the Mats gives a visual focus and allows people to take as long as they wish to consider and respond without losing the flow of the conversation. The researcher herself commented in field notes about the need for her to keep quiet and not ask further prompt questions which can disturb the train of thought and reduce the quality of response.

Topic placement

As mentioned previously, a topic could be an issue for the participant whether the symbol was placed in the 'agree', 'unsure' or 'disagree' column. It was the discussion and non-verbal communication around the placement of the symbol that determined the results outlined in table 3.

Health

The section on 'health' related to participants' perception of their present health as well as their thoughts on how being fat affects long term health. Although this category appeared top of the list, the result is possibly biased as just prior to undertaking the Talking Mat on 'Important things to losing weight' the Risk Reinforcer (appendix 3) was carried out.

As mentioned previously, the Risk Reinforcer involved explaining the complications of obesity using symbols. Anecdotal evidence has shown that this is an area adults with learning disabilities know little about and the interviewer was hoping that such knowledge may motivate clients to make lifestyle changes. Although the proximity of carrying out the Risk Reinforcer to the Talking Mat was small and would help with memory recall, it does not diminish participants' concern on hearing this information.

Food

67% of participants raised 'food' as an issue. Such a high figure was expected as participants were taken from the dietetic waiting list and had therefore already agreed to a referral for dietary advice. The section on food covered choice (type and quantity of food as well as venue), purchasing and

preparation. For many of the participants, issues around decision making, self-esteem and relationships impacted on their control over what they bought, prepared and ate. Dealing with these other issues (which may involve disciplines other than dietitians) could indirectly improve someone's dietary intake.

Activities

'Activities' was another topic to score highly and prompted the following after the Talking Mat interview:

- three participants agreeing to a physiotherapy referral for suitable exercise regimes
- 7 people charting any gentle exercise undertaken
- 1 participant purchasing a pedometer
- Another arranging swimming sessions with a relative
- A further participant considering purchasing sports equipment – following physiotherapy approval.

Discussion around the topic of 'activities', highlighted that adults with learning disabilities may be motivated to exercise but rely on others for transport and safety issues – this reflects findings from Beart et al (2001) and Messent et al (1999). A classic example is given by participant 3, "I like swimming but I have no one to go with". While participant 14 only goes swimming when on holidays. Alternatively poor mobility can interfere with exercise, as highlighted by participant 5's comment "I just go and watch them dancing".

Consideration has to be given to ensuring activities are tailored to the individual's need and if necessary additional support, such as 'befrienders', provided. Advice from physiotherapists and social workers may therefore have to be sought, and once energy expenditure from activities starts to exceed energy input from food, weight loss will be experienced.

Information

For half the participants the means by which information is presented was an issue. This concurs with work by Melville et al (2005), Lennox et al (2003) and McConkey, Morris and Purcell (1999).

There was some discrepancy over the word 'pictures' as this could be interpreted as childish. However, everyone was happy with the use of 'symbols'. The general consensus was that information should be presented in large text and supported by symbols and the spoken word. Interestingly this view was raised irrespective of the participants' comprehension level and supports the use of the Talking Mat, which involves both verbal and visual signifiers.

Decisions

For Talking Mats to be effective, consideration must be given to the phrasing and order of questions. This project identified a problem with the section on

'decisions'. Although placement of these symbols on the Mat indicated that seven of the twelve participants had no problems in 'making and keeping to decisions, general discussion (as mentioned earlier) identified various difficulties.

The question on making decisions was too complex and the overall subject rather abstract. In retrospect, it would be better if the sections on 'decisions' and 'health' move to the end of the interview. More concrete topics would then be first to allow participants to build their confidence before moving to the more abstract issues.

About you – body image

The 'about you' category included questions on how participants felt about their appearance; themselves as a person; being listened to; mobility, and mood. These issues were fairly low priority for participants. Three-quarters were happy with the way they looked despite having moderate to morbid obesity. This reflects anecdotal evidence that suggests adults with a learning disability have a poor body image. It also reinforces the author's belief that appearance does not motivate weight loss in this client group.

Listened to

All participants placed the 'listened to' symbol in the 'agree' column. However, there may have been some ambiguity over the question as people felt it was important to be listened to, even though it did not always happen. These results do highlight the need to talk to people with learning disabilities as 'equal partners' as recommended by McConkey, Morris and Purcell (1999).

Mobility

People responded appropriately to the 'mobility' question. It would be more appropriate, however, to split the symbol into three i.e. 'walking', using a 'frame' or a 'wheelchair', and giving the participant the symbol that best reflects their form of mobility. This would avoid people interpreting the symbol as 'requiring walking aids in the future'.

Mood

Despite over half of the participants having a mental illness (a figure that reflects the increased incidence of mental health problems in this client group (O'Brien, 2002; O'Hara, 2000)) the majority of participants were happy with their mood. This possibly reflects the effect of prescribed medication as quite a few participants said they were "happy" while others gave examples of appropriate responses to unpleasant situations.

Relationships

Only a quarter of participants felt relationships were an issue in losing weight. However, it is likely that this criterion is under-valued as some relatives/carers were present during the interview (at the participant's request) which may have tempered the person's responses. In addition, answers to other areas in the interview, such as activities and food, highlighted the control other people have over adults with learning disabilities (see 'decision' heading under results section).

Other problems mentioned included:

- family members making condescending remarks about the participant's weight (11 & 13)
- little or no contact with parents (1 & 3)
- close friends/boyfriends not living locally, making it difficult to meet up or keep in contact (1 & 12).

Therefore, although the question on relationships seemed to be an issue for only a few of the participants, examination of the whole Talking Mat interview showed this to be more extensive. The implications are far reaching, as friendships help us confirm our identity; raise our self-esteem, and possibly protect against depression (Brackenridge & McKenzie, 2005)

Money

The lowest scoring criterion was 'money'. This issue was raised by only one participant, but was a valid response as he was the most independent person interviewed and took sole responsibility in purchasing and preparing food.

The section on 'money' has the potential to prompt referrals to income support maximisation officers, social workers and local area co-ordinators regarding budget. Other referrals from the project included physiotherapy for mobility issues and occupational therapy regarding kitchen skills and cooking abilities. Discussions also took place with care managers to ensure additional support staff helped participants to meet targets set on completion of the Talking Mat.

Prescribed medication

A possible oversight was the researcher not contacting GPs/psychiatrists if prescribed medication had the potential to cause weight gain – assuming that this had already been taken into consideration when the medication was prescribed. It would be beneficial to follow this up when researching the effectiveness of this approach in the treatment of long term obesity.

CONCLUSION

From the interviewer's perspective, use of the Talking Mat retrieved more in-depth information and created a more rapid rapport with participants than a 1:1 verbal interview. Participants appeared to appreciate having their opinions sought and be given time to express their beliefs. Opportunities were also given to enable them to change their minds, and for the interviewer to explain her interpretation of the Talking Mat to ensure it truly reflected the client's opinions. Results from the Talking Mat were then used to involve the client in active decision making around their care plan to lose weight - ensuring a person centred focus.

Implications

1. It was not essential to represent each category from the original text, screening tool with a symbol. For example, participant's self-esteem is reflected in their answers to sections on 'relationships', 'decisions' and 'about you'.

2. Results from the Talking Mat cannot be taken in isolation from discussion covered during the process. Prior to commencing the project the interviewer anticipated that areas for change would be highlighted in the 'disagree' column. However, as indicated from the results, factors important to the client in losing weight could be placed under any of the three emotions. It is therefore imperative when summing up the Talking Mat to identify the participant's main concerns – no matter where the symbols are placed on the Talking Mat. (Although not used in this project, velcro dots would be useful markers during the process, to identify areas for action on summarising the mat).

3. The length of time to respond was not a reflection of the person's cognitive abilities - the longest deliberations were made by a participant who had only borderline learning disabilities. Both the participant and the author gained much from this interview that would not otherwise have arisen through oral and written communication alone. The offer of alternative and augmentative forms of communication should therefore be made, no matter how mild the client's level of learning disability.

This project also highlighted the potential for sub-mats. Originally, the interviewer envisaged the Talking Mat covering some questions around diet, but this became too unwieldy. The dietitians have, therefore, created a separate Talking Mat – 'Diet History' – that consists of 20 symbols on food and drink. This sub-mat is completed at the first dietetic appointment and used to determine the client's knowledge on healthy eating, as well as gauging their likes and dislikes. The various topics covered by the Talking Mat 'Important things to losing weight' extend beyond the dietitian's remit, therefore this resource has the potential to be used by other health and social care professionals. The next stage of the project would be to trial the Talking Mat with other disciplines.

The project identified some slight changes to enhance the effectiveness of the Talking Mat. It also resulted in many positive responses from both participants and the interviewer, with regard to the depth of information provided by using the Mat and the enthusiasm created from sharing the process and working together. The effect of the Talking Mat 'Important things to losing weight' is best summed up by the response from one of the parents, "You managed to get through to him: to hit all the right buttons." This client then went on to lose a stone in weight, in one month.

FUTURE RESEARCH

- To trial the designed Talking Mat "Important things to losing weight" with a combination of dietitians and other disciplines e.g. community learning disability nurses and care managers. This project would determine if the resources developed could be used as a multi-disciplinary assessment tool.

- To trial the effectiveness of more client involvement in decision making through the use of Talking Mats to achieve weight management.

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