1. Introduction

2% of people in have mental retardation (18). People with mental retardation (PWMR) often have syndrome specific disorders. Additionally they have the same health problems and chronic diseases as the rest of the population. Consequently they have poorer health status. Diabetes is one of the chronic diseases that people with mental retardation (PWMR) share with others in the community (5). Their multiple health issues cause below-average quality of life and can make people feel disempowered (8, 14).

1.1 *Characteristics of having disability and diabetes*

Health wise, these people are complicated. If they have diabetes, PWMR often feel that it "controls their lives" with the additional limitations that it brings (10). Care providers as well can feel inadequate when faced with the high level of care that is often needed in this situation (10). Diabetes is a chronic condition that requires high levels of attention. Care providers in residences, who are often the people most responsible for PWMR's everyday health, are often uneducated in the area of diabetes care.   They are mostly unprepared to deal with the extra demands that this disease places on them. Their lack of education in diabetes is generally the result of shortfalls in both time and funding (12, 13). To cover the shortfall in education there are few if any, resources available (2). In a review of websites for patient education in diabetes mellitus patient on the Internet, a total of 214 sites were found (15). Not one was able to give guidance to people with mental retardation.

1.2 *Learning needs in disability*

Both PWMRs and their caregivers need to learn about managing diabetes when it is present. Clearly it is frequently difficult for PWMR to learn. They have specific needs in education materials - for example, information that is graphic and repeated frequently (10). Care providers as well have their own requirements. They need information that is easy to access, relevant to their working lives and can be used by co-workers from a wide range of educational backgrounds (1). There is little material available for them on the topic of diabetes, except for material produced by support organisations for the general public. The management skills needed by a carer

of a person with mental retardation and diabetes are different from those of the general population of people with diabetes.

1.3 *Possible solution to needs*

We decided a web-based tool would cover most of the requirements of the field. Web-based learning has a number of advantages over other methods of learning - most importantly its low cost. It can also be formatted for both the people with disability and their care providers. It is suitable for micro-populations of any type (15). However, web-based learning does have its disadvantages in that computers are so far not an educational resource commonly used by those of low socio-economic status. That group includes most people with mental retardation, and their care providers. (15):

1.4.1 Operational principles

We wanted to involve final "end-users" as much as possible in the consultation and development processes of our tool, as recommended by the health promotion literature (3, 4). We used the information collected from the consultation stages to develop our guidelines. Theoretically, therefore, we felt this active involvement should create a greater sense of "ownership" by the population of PWMR for which the material is intended (17).

1.4 *Aims*

The aims of the project were to develop and evaluate a web site to enhance the education and management of diabetes. We wanted to base it on the needs of people with mental retardation and their care providers, as assessed in the focus groups. We also aimed to use a consultative process as the basis for the development of the web site. We aim to promote diabetes self-management skills and provide support in the website. We then wanted to evaluate the website with a prospective observational study using the tool as the intervention.

2. Methods

2.1 Participants characteristics

The project was conducted in Southeast Queensland, Australia, in an area covering both urban and rural settings. Inclusions criteria for both the focus group discussions and the intervention were that either being or being the caregiver for a person with both mental retardation and diabetes. Caregivers provided either professional or personal care for the PWMR.

2.2 *The Intervention*

2.2.1 *Literature review*

To develop our guidelines, we firstly conducted a literature search using the terms "mental retardation / intellectual disability AND education AND diabetes". The search gave zero hits. We then used a literature review of resource design for PWMR that we had prepared for another project. We also used criteria developed by our specialist educator (6, 7, 9, 11).

2.2.2 *Advisory group*

We formed an advisory group of people with experience in mental retardation. The group of nine people met twice throughout the development process, and consisted of people with mental retardation (2), support workers (2), parents (2), diabetes educators (2) and an occupational therapist (1).

2.2.3 *Focus groups participants*

To determine the content and format for the intervention package, we held 39 focus groups meetings and semi-structured interviews with 76 people (mean meeting size two people; range one to nine people). We contacted 150 service organisations to find people to participate in our discussions. These groups included people with mental retardation (9), support workers (56), parents (6), psychologists (2), GP (1), volunteer friend (1) and a sister (1). Regrettably, we did not record demographic details on these participants except for their occupations. We held these meetings at peoples' homes, workplaces and at our centre. Five meetings were in rural locations.

2.2.4   *Focus groups methods*

We asked each discussion group a series of general questions in order to determine their opinions of the keys and barriers to good health care of diabetes for people with mental retardation. We wanted to allow for ease of expression but maintain a loose structure of themes about diabetes. There was one set of questions for people with disability, a second set for care providers and a third set for professionals - each at the appropriate level. The questions for people with disability were in plain English and were open-ended. The moderator introduced herself and explained the project to the people with disability using illustrated drawings.

All the meetings were taped, with the permission of the participants, and later transcribed. The moderator was a person with experience in the area of mental retardation. We kept all the information collected in a non-identifiable format. Data was recorded and systematically collated according to the topics discussed. Records were kept separately for each group – person with disability, carer or professional. Using grounded theory analysis, two researchers independently extracted the most common themes found in each group for each topic, and refined these through consensus discussion. The justifications for decisions made were recorded. We also used counts to clarify the patterns in the data and prioritise themes. Some themes, like fear and insecurity in the carers, permeated nearly all areas of discussion. The themes that evolved from the inductive reasoning applied by the analysers formed the basis for the tone of the tool.

2.2.5   *Focus Group Results*

The results from the focus group discussions are summarised in Table 1. It presents the most common issues raised in order of frequency, and shows how we resolved them when possible. We tried to incorporate all the issues raised. See Table 1.

Table 1

Problem Issues Arising from Focus Group Discussions & their Resolutions
PWMR = Person with Mental retardation; BSL = Blood sugar level

Problem Group	Issues	Resolution
PWMR	Behaviour problems	No resolution
PWMR	Non-compliance	No resolution
PWMR	Lack of education	Very large section for PWMR to learn in own way at own rate – carer support generally needed
PWMR	Exercise	Motivation stressed
Carers	Information is needed about: • Diet & Nutrition • Medication • Glycaemic Index • Hypos / Hyperglycaemic episodes	All topics with sound evidence in the literature presented on website.
Carers	Skills are needed for: • Observation • Taking BSLs • Teaching PWMR to self-manage	• Signs to look for are listed • Instructions for taking BSL given

		• Teaching self-management skills guidelines given
Carers	Interagency communication lacking	Management plan to be available for all
Carers	Fear & insecurity is rife	Emphasise that these feelings are common in diabetes care.

2.3 Medical content

For educational and managerial content we also canvassed widely the material available for the general public. We used recognised websites, material from diabetes educators, journals, books and pamphlets. We searched for evidence for all those recommendations and only included in our content those based on recognised scientific evidence. Areas that are of contemporary interest, such as "glycemic index", without hard scientific evidence of validity were ignored. We presented the material in a simple way. We had a copyright lawyer review our final work. We did not want to simply "dumb down" the material that was already available to the general public as suggested by some diabetes educators. We considered that this would not cover the extra needs of this population as expressed in the focus groups.

An endocrinologist, a general practitioner, diabetes educators, occupational therapists, nurses, nutritionists, podiatrists, service managers, a pharmacist, and a clinical biochemist reviewed the final work. When there was conflict on small matters we obtained a third opinion. We resolved some other issues by defining the need for good evidence to decide one way or another. There was no conflict about any major question. The endocrinologist continues to review and contribute to the website at two-monthly intervals to enure the information is up-to-date.

2.4 Presentation

For presentation we consulted several skilled advisors. Overall, the intervention for PWMR had to be based on images, had to be easy to navigate and had to use plain language. The language had to be "jargon free". We employed a *graphics design artist* to produce 14 drawings – (examples are Table 2 and Diagrams 1 & 2). We contracted *an editor* to review the document before it was placed on the web. The intervention had to have two formats – a hard copy book and a website. This presented challenges for the editor.

Table 2: Graphics Recommendations and their Sources for Illustrator

| Recommendation	Source	Reason
Image overall to be trendy, groovy and upmarket (like on TV)	PWMR	Many adults with ID aspire to be this way
Text to have photos, symbols and illustrations attached	Carer	Many PWMR cannot read
Illustrations should be clean and uncluttered	Carer	Resembling things as they are in real life
Diagrams need to be easy (for example, clocks need clear, long hands)	Carer	Resembling things as they are in real life
Images used as in "Board maker" should be standard, (for example, a stethoscope).	Carer	Resembling things as they are in real life
Images need to be modern (for example, an up-to-date pen)	Speech therapist	Resembling things as they are in real life
Shadowing shouldn't be used	Speech therapist	Resembling things as they are in real life

Diagram 1 (Feeling Thirsty)
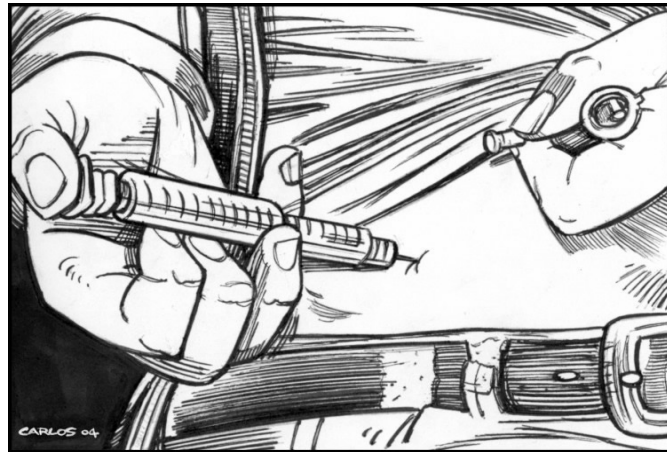
Diagram 2 (Injecting Insulin)

We also contracted *a web page designer* to prepare the material for the web. We stipulated that we wanted a bright, positive and easy-to-negotiate web site. We wanted to present this population in a positive way. The current Webmaster arranged the wording of the site so that a Google search using the terms "diabetes and intellectual disability" comes up with this site at the top of the hit list. ("Intellectual disability" is the term used in many countries to describe mental retardation.) The webmaster has been retained to regularly maintain the site.

2.5 Trial of the tool

2.5.1 Characteristics of participants

After we developed the tool, we ran a trial of its use in a group of 14 people with mental retardation and 31 care providers. These participants were randomly selected from the population of people with mental retardation and diabetes known to our centre and there was no control group.

24 / 31 of the care providers were females and their mean age was 47 years (range 24 years to 76 years). The mean length of time of caring for their PWMR for paid care providers was 3 years (range 3 months to 10 years). 22 / 31 of trial care providers had received either no training or informal training in diabetes care.

Regrettably, we did not record the same demographics of the PWMRs, except for their levels of disability. 11 / 14 people had mild or moderate level mental retardation, as described by their carers.   The level of

independence in skills of daily living for them as measured by the Barthel Index was high with a mean of 96 in a possible range of 0-100, 100 being completely independent (16).

2.5.2 Characteristics of trial

The trial was for one month. All of the participants preferred the hard copy book version provided by the project, to printing their own version from the website. We ran baseline and exit interviews for all participants. Part of the interviews of the carers was a Barthel Questionnaire to assess the levels of independence of the people with disability.

The interviews for the PWMR consisted of open-ended questions to encourage communication. These were reviewed by a speech pathologist before use and a PWMR then fine-tuned them before implementation. A few answers from the PWMRs in the interviews were nonsensical. These were removed from the data before analysis.

The interviews with the care providers were constructed to give both quantitative and qualitative answers and were piloted with a carer before implementation. The quantitative questions incorporated Likert scales and used the Stanford Patient Education Research Centre questions on self-efficacy for diabetes.

Eight PWMRs gave exit interviews and only 21 of the 31 care providers who had consented to be part of the project had reviewed the tool. 5 PWMRs and 5 care providers were lost to follow up. One person decided he was "not diabetic anymore" and withdrew. He had controlled his diabetes with exercise and diet.

3. Results

3.1 *From PWMRs: n=6.*

Analysing the qualitative data from the exit interviews using grounded theory it evolved that PWMR had mostly negative feelings about diabetes. However, they took pride in the jobs they could do themselves in their daily care. Quantitatively, the pictures were the most popular aspect of the tool for PWMR and all (6/6) said that they

understood them. Half (3/6) said the tool was easy to read and one said it wasn't. When asked what they did **not** like about the tool, two people said:

> *"Give up smoking – that's personal"*
>
> *"Clocks – can't tell the time"*

3.2 From Carers: n=21

Qualitative analysis revealed that the carers were enthusiastic about the tool. Most had expressed fear and insecurity about diabetes management in the baseline interviews. After just one month of intervention, one third of the group (7/21) said the use of the tool stimulated changes in the way they care for people. One quarter (5/21) filled out a management plan for diabetes with their doctors. Nearly half (9/21) said the tool had helped in communicating with other health professionals. Nearly all (20/21) said they would use the tool in the future and nearly all (20/21) said the tool would be useful to other people, most commonly families. Its ease of use was what care providers liked most about the tool. They found it easy to read and understand.

> *"Thorough but not complicated".*

When the impact of the changes measured by the Stanford tool were calculated, the effects of the intervention were not strong. There were 16 questions asked about diabetes care. There were positive changes measured in 7 questions, but zero changes in 8 and one negative change. All of these changes were small (mean change +1 in a scale of $0 \rightarrow 10$). The strongest positive response was about the PWMR recognising the symptoms of an abnormal blood glucose level. As the intervention was for a very short time, these are not considered reliable results. However the relatively consistent positive direction of change should be noted.

The tool was used for a mode of 3 times in the month of the intervention with a range of 0 – 12 times.

> *"It has changed how we educate P……..".*
>
> *"It's very good and aimed at non-academic stream".*

Care providers said that the tool was enjoyed by most of the people with mental retardation, particularly the drawings, but they could not tell if they had learned anything from it.   The site is having about 750 pages accessed each month.

4.   Discussion and conclusion

Both the achievements and limitations of this study are important. This population is undervalued and under serviced, and the tool is very welcome. We hope that it addresses some educational inequalities.

4.1 Discussion

The alarming fact that nearly three quarters of the care providers in the pilot who were responsible for the daily management of this medical condition had received no formal training shows a real need for a tool such as this. This could be an explanation of why so many carers felt fear and insecurity in their attitudes to diabetes. This tool possibly allays some of that fear and could explain why it had a positive impact on the daily care and medical management of people. However it had no impact on meal preparation, management of medications or changes in exercise habits, possibly areas where carers feel they are in adequate control.

This tool possibly also goes some way to removing the fear associated with the medical aspects of having diabetes. By using the medical management plan a relatively high proportion of care providers would have professional medical guidance to help them in making daily decisions about daily care. This would indicate better health for the person in the long term. Further research is needed to verify this.

It is disappointing that not one participant in the pilot was interested in using the information directly from the web. We realise that the limitations of a web-based educational intervention favour those of a higher socio-economic group than most people with mental retardation. Some, especially managers and more senior staff, however, say they will use it as a web-based tool. They will print out copies for care providers and people with mental retardation. We also know that the problem of recognition of this tool by the disability community that can use it most is real. This is a sector that communicates most by word-of-mouth and "trust", but we feel that there must be more effective ways of dissemination of information. We hope that this particular format will eventually be acceptable to them.

We see that the web site has potential for further improvement in format. With 30% of people with mental retardation having hearing impairment, audio boards with a voice-over could make the tool more attractive to many; also to those of low literacy skills. The font could be increased for the severely visually impaired – a large font was used in the design to make it easier for those with minor visual impairment. Making the website

interactive would also make it more amenable to this population. We intend to pursue the possibility of catering for a variety of sensory and other disabilities.

4.2 Conclusion

This tool fulfils the aims of the project. It provides a tool that addresses the needs and concerns around diabetes expressed by people with mental retardation and their caregivers. It is based on the consultative process. It provides education and management guidelines in simple and relevant language. It avoids jargon. It covers the real-life needs of people trying to grapple with the daily demands of this serious chronic condition in the presence of disability. It deals with issues that other tools in diabetes care do not. The evaluation of the small pilot study shows that it is probably effective and that it is strongly accepted by its users.

4.3 *Limitations*

The limitations in the pilot are the same limitations of most pilot studies. Most importantly, there was no randomization and no control group. The samples sizes are very small. The group of people with mental retardation who trialled the tool was very small, but they gave opinions that did repeat through the group. In fact, their opinions are very valuable. There are a very limited number of studies in the literature that includes PWMR as participants.

However, their care providers who reviewed the tool were of a higher number.   That number is not large enough or of sufficient diversity to consider that their opinions could be extrapolated to any general community of caregivers.

4.3 Practice Implications

Because of the consultative processes used in the development of this tool, we consider that it highly acceptable by this particular population. We also feel that the tool has real potential in being able to make material available to subgroups in the community. Any people with low literacy skills could find the site useful because of the graphics-based design. It is very importantly of low cost to the consumer; it is empowering and has the potential for a more interactive format in the future. Based on our experiences in this project, we hope to use similar consultative processes to develop more sites for people with mental retardation.

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