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Introducing 'sugar'¹

by

Barbara Wingard²

I'd like to tell the story of 'Sugar' because to me it is a story of trying to find new ways of working, of trying different things, taking new steps. In early 1996, as a member of the Aboriginal Women's Health and Healing Project,³ I had the opportunity to watch a video of the work of the CARE counsellors of Malawi.

The ten of us involved in the Aboriginal Women's Health and Healing Project really enjoyed watching this video. It really touched me very strongly and I couldn't wait to come home and work with the ideas. I specifically thought about how this sort of work could be used with diabetes as it is an illness that is causing a lot of harm within Aboriginal communities. Not long before watching the video, a doctor had asked us here at Murray Mallee Community Health Centre to organise something for three people who were very sick with diabetes and constantly coming into hospital.

I said to Jenny Baker, who was one of the other members of the Aboriginal Women's Health and Healing Project, 'Jenny, wouldn't this be fantastic to use with diabetes?' And she said, 'Yeah Barb, we should do it

together'. We went away from that day with a sense of excitement, with a feeling of, 'Wow, we've got to use this'. I couldn't wait to get to Murray Bridge, where I work, to try it.

I developed an exercise which I first of all showed to the other members of the Aboriginal Women's Health and Healing Project. It worked very well and I couldn't wait to give it to the people. That was going to be the big test.

Setting the scene

In the exercise I played the role of diabetes or 'Sugar'. I carefully set the scene in ways that I felt were culturally appropriate. As an Aboriginal person I knew that it would be wrong to put other Aboriginal people on the spot, or single people out. To avoid this I came up with a number of questions that I gave to the participants which they could ask me and I would respond. The participants were very happy to start by asking these simple little questions I had already come up with. If I had expected them to come up with their own questions straight away it might have been difficult to get people to participate. Giving them questions took away the uncomfortableness. I had hoped that after they had asked me these set questions that a general conversation would begin, and this is what happened. At the end people came up with their own questions that they would have been afraid to ask at the beginning.

I had been impressed at the way the CARE counsellors of Malawi had invited communities into conversations with one character representing AIDS: Mr/Mrs AIDS, and one character representing community care: Mr/Mrs CARE. As I was doing this work on my own I only developed the one character: 'Sugar'. I thought it would be too complicated for me to play two characters, although I had seen how well this had worked in the video from Malawi. Just having the one character, 'Sugar', meant that she had to be very versatile. She spoke of the ways she was affecting people, but also at times played the role of an educator.

Perhaps we will explore using two characters later on - who knows what future directions will hold. This is just a starting point. It's not perfect. I wouldn't want to put it across as perfect. It is just to give people ideas. I want people to go off and develop their own ways of working. If it came across as

perfect it could scare people - expectations might get too high. Every situation is different and every community is different. I'd like everyone to have the freedom to develop things in their own way.

Talking to 'sugar'

The group: *Who are you?*

Sugar: *My name is diabetes but a lot of people call me Sugar. You can call me Sugar. I can be anybody's disease but I do my best work with Nungas⁴ because they can't quite control me yet.*

There was a man in the group and when I said they could all call me Sugar it created a lot of laughter!

The group: *How do you work?*

Sugar: *It's my job to make sure you don't get enough insulin or none at all. Most people know about my condition. I'm very popular and I'm all over the world - I'm pretty sure of having a job until I retire. Years ago it was hard for me to get a job with you people because there were great hunters who lived off the land, good tucka [food] and plenty of exercise. You people were healthy.*

At this stage I referred to a poster about 'healthy bodies' that I made for the program.

Now though, thanks to this thing called urban living, you have heaps of shops to go to and are tempted by the smell of food, by television, books that always show cakes, chocolates and fatty foods. You have very little exercise. All this just makes me so happy.

The group: *How different are you from a healthy body?*

Sugar: *To explain that I need to introduce you to my family. I come from very strong kin relationships as I know you do. Aboriginal people have strong family relationships and I totally rely on my blood relatives.*

There's my Mother Heart - without her I'm a goner, and three sets of twins - Cousin Kidneys, Cousin Pili's [eyes] and Cousin Feet except they're

not here today - gone walkabout. My main man is a gland called Pancreas. This is where I do my best work. I affect all these parts of the body - all my relatives. This is what makes me different from a healthy body.

At this point I refer to a poster about 'unhealthy bodies'.

The group: *What don't you like about your job?*

Sugar: *Well I come in two types of diabetes and I don't like this part of my job. I have to remember the families that have my history.*

First of all there is Type 1, or Juvenile Onset Diabetes. My work here is usually with young people below the age of thirty, but it can happen at any age. With Type 1, the pancreas produces no insulin because the cells that make it have been destroyed by the white cells of the body. People therefore require insulin injections to control their blood glucose levels.

Then there is Type 2, or Mature Onset Diabetes. This usually happens in people who are over 40 years old and especially if they are overweight. Type 2 often responds to diet, appropriate exercise and weight reduction, but sometimes tablets and then later, insulin, may be required.

I would give out a handout at this point.

The group: *What makes you powerful?*

Sugar: *I become powerful when people are shamed, divided, and isolated. I become powerful when people are overweight, including pregnant women with big babies; when Nungas over 40 never get their eyes tested, neglect sores, don't eat properly, don't use medication and injections, don't visit diabetic clinics or programs, don't have blood pressures taken, never have urine tests; when they do no exercise; and when they stay home and away from people who know about me.*

The group: *What weakens you?*

Sugar: *It weakens me when Aboriginal people have a chance to ask questions, to talk together in their own ways. It weakens me when people are no longer alone, when they stand together. Other things also weaken me - people taking responsibility for their own health, weight loss, diets, blood pressure checks, foot care, trachoma clinics, people controlling their blood sugar glucose levels. All these things weaken me.*

As Sugar answers what weakens her she becomes weaker and weaker until she is almost under the table!

Different conversations

What we got out of it was quite magical. The most important thing was that, after we had been through these questions and answers, the participants started asking their own questions of Sugar. The conversations afterwards went on for an hour and a half, just discussing the issues that came up. The exercise seemed to lead to the possibility of people asking their own questions, questions that they had never felt free to ask before, and this led to new sorts of conversations.

It was obvious by the end that some people had never understood diabetes before. Maybe professional people had tried to explain and they'd been too ashamed to say 'I don't know' or, 'I don't understand'. I think we learned that we need to break diabetes down so that the people can understand.

When I asked one woman who is normally very quiet what she thought of the poster she said, 'I'd never understood what Sugar was about. That's given me a real vision.' She wasn't responding to me, she wasn't responding to the diabetic sister or the dietitian, she was responding to Sugar. It was just so different. It wasn't about me, Barb, it was because she could have a direct conversation with Sugar. Another woman was giving herself injections and she was wondering why it was so difficult. She wasn't moving the needles from place to place. We talked and talked. At the end of it I just went 'like wow!' (thumbs up)

Humour

It was really good to play Sugar. I am naturally a bit of a clown, and for a lot of Aboriginal people that is our survival tool - our humour, our joking. To create that sort of environment with Sugar was really good. They really loved it. It was because of the humour that they were able to pick it up better. The male who was there, when he sees me walking down the street, he still says, 'Here

comes Sugar!' It's really rippled.

Curiosity

The relationship of the participants to Sugar was one of curiosity. Anger didn't creep in at all even when Sugar was extremely boastful. At times Sugar said really, really awful things like: 'If you don't look after your feet you'll get sores and your limbs can drop off'. After I said it I felt quite awful for saying it, but it wasn't me, it was Sugar speaking.

I think using imagery of weakening or strengthening Sugar was better than showing aggression. The idea of asking 'what makes you strong?' 'what weakens you?' was an excellent idea from the Malawi video. When Sugar was answering the question 'what weakens you?' she actually started to go down, to wilt. It was making her weak. When I ran the program here I actually got under the table - it weakened Sugar so much.

Professional relations with 'sugar'

It was wonderful to see how the other health professionals entered into a relationship with Sugar. They started to call me Sugar, and to ask questions of Sugar. To see professional people come into it and accept this whole new process, I think that warmed me the most. The diabetic sister now uses 'Sugar' in some form with mainstream clients. They have also been using the video that we made with other health professionals. The podiatrists send me very positive feedback on coloured pieces of paper in the shape of little feet! I send my notes back in black, yellow and red - Nunga coloured feet!

Culture

I wanted to bring in some cultural aspects so that they could really relate to Sugar, so they felt they belonged to Sugar. Otherwise it would have been far too mainstream and that's often the problem with other programs. That's why our people are getting lost because often there are no attempts to talk about these things in culturally appropriate ways. By talking about our people's

history, we made the link between them and Sugar.

I tried to make the exercise culturally appropriate. By giving them the questions first meant that everyone was a part of the process in a non-threatening way. By not using jargon, people felt that we were all speaking the same language.

I think that often Aboriginal people have felt shamed at asking questions, or that Sugar is just too complicated to understand. The way the questions were given reduced shame - they became a part of talking with Sugar. The fact that we were talking about Nungas and our history and our culture also reduced shame.

Togetherhness

Perhaps the biggest thing that reduces shame is doing something all together - breaking down the isolation. Sugar is just one of many issues facing Aboriginal people's lives. This offered a different way of seeing Sugar. They looked at Sugar that day as something that should be taken notice of, something that is affecting the Aboriginal community. It's a community problem. If it's not affecting you it's affecting your grandmother, uncle or aunty. Every family is effected by diabetes, one way or another. By all talking with Sugar it gave the feeling that together we need to take notice, and that together we can take action.

Notes

1. First published in the 1996 No.3 issue of the *Dulwich Centre Newsletter*. Republished here with permission.
2. Barbara is the proud mother of three grown-up adults, is blessed with eight grandchildren, and is fortunate to have her elderly mother living with her. When not working, Barbara enjoys being with her grannies [grandchildren], and her other passion is to be involved in narrative practices. Barbara can be contacted at the Murray Mallee Community Health Service, PO Box 346, Murray Bridge 5253, South Australia.
3. In 1994 funds were allocated from the South Australian Health Commission to the National Women's Health Program to assist in the area of health and healing. With

these funds an Aboriginal Women's Health Forum was established which in turn initiated the Aboriginal Women's Health and Healing Project. This project involves ten Aboriginal women from different areas within South Australia - Maggie Charles from Berri, Leta Sullivan from Goodwood, Maureen Williams from Coober Pedy, Christine Franks from Coffin Bay, Jenny Baker from Torrensville, Rosie Howson from Greenacres, Barbara Wingard from Murray Bridge, Shirley Grocke from Blyth, Terry Stewart from Angle Park and Anna Caponi from Port Augusta.

The Aboriginal Women's Health and Healing Project is currently exploring a wide range of issues including training and the development of culturally appropriate ways of working.

4. Nunga is an Aboriginal word which is widely used to describe Aboriginal people of South Australia.

Reference

- 'Reclaiming Our Stories: Reclaiming Our Lives.' *Dulwich Centre Newsletter*, 1995 No.1 (special issue).