The Winston Churchill Memorial Trust of Australia

Report by - Gail Cummins - 2008 Churchill Fellow

The DEPARTMENT FOR CHILD PROTECTION (WA) CHURCHILL FELLOWSHIP to investigate education programs for Indigenous children with Type 2 Diabetes – USA, Canada, and Hungary.

Signed: Dated:

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INTRODUCTION

The DEPARTMENT FOR CHILD PROTECTION (WA) CHURCHILL FELLOWSHIP enabled me to travel to the USA and Canada in order to investigate models of care used in treatment and education programs for Indigenous children living with Type 2 Diabetes. The Fellowship also enabled me to attend the following two international conferences: Therapeutic Patient Education 2008 and The 2nd International Diabetes in Indigenous Peoples Forum. A summary of the information gathered will be provided in this report.

I would like to sincerely acknowledge the following individuals and organisations:

- The Winston Churchill Memorial Trust for its ongoing investment in Australia and the people of this land;
- The Department for Child Protection (WA) for their support and the sponsorship of my Fellowship;
- The Kimberley Division of General Practice, my employer, for their support in granting me the opportunity to undertake the Fellowship; and
- My family and friends, for their support and encouragement, from the initial application through to the completion of the Fellowship.

EXECUTIVE SUMMARY

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Project Description

The Fellowship was undertaken for October 5th to November 23rd 2008. The aim of the Fellowship was to gather information on models of care used in Diabetes Educational programs for Indigenous children with Type 2 Diabetes. I met with staff from Indigenous Health Services and Youth Programs in Arizona, New Mexico, Oklahoma, Alaska and British Columbia. I was able to discuss the development, gather information on composition and see first-hand the delivery of many different programs for Indigenous youth with or at risk of developing Type 2 Diabetes. In addition to these investigations I had the opportunity to attend the *Congress on Therapeutic Patient Education 2008*, which included the *Diabetes Attitudes Wishes and Needs Summit 2008*, in Budapest, Hungary and the *2nd International diabetes in Indigenous Peoples Forum: International Best Practice*, in Vancouver, Canada.

Highlight

Although there were considerable differences in the geographical locations visited on this Fellowship, I found remarkable similarities in the life experiences and beliefs held by those I met with. The highlight of the Fellowship was the opportunity to spend time with people, whose enthusiasm, like-mindedness and passion to effect change, in their area of work was inspiring.

Conclusions, Dissemination and Implementation

Type 2 Diabetes is different for children. The typical medical model for Type 2 Diabetes education and management is not ideal for Indigenous children living in rural and remote Australia. Diabetes Education and management programs for Indigenous children living with Type 2 Diabetes must be holistic, culturally inclusive, and developed for children.

The dissemination of the ideas and information gathered on this fellowship and will be achieved through presentations to groups such as the Kimberley Diabetes Network, North West Nutrition Group, Kimberley Allied Health Forum (KAHF), Australian Diabetes Educators Association WA branch. The KAHF presentation will include an interactive workshop, on incorporating ideas from the presentation into current practice. Articles will also be written for the following national association publications: Dietitians Association of Australia; Australian Diabetes Educators Association; Services for Australian Rural and Remote Allied Health and the National Rural Health Alliance.

I am currently employed by the Kimberley Division of General Practice to provide a Diabetes education service throughout the West Kimberley. The position is funded by the Office of Aboriginal and Torres Straight Islander Health and focuses on service delivery to the Indigenous population of the region. Therefore, I have been able to begin immediate implementation of the information, ideas and insight gained since my return from the Fellowship.

PROGRAM

Date and Location	Activity
5th – 11th October Arizona, USA	• Dr Charlton Wilson, Acting Chief Operating Officer and Bernadine Russell, Diabetes Educator - Phoenix Indian Medical Center • Dr Joyce Helmuth, Paediatrician and Isabel Canez, Dietitian - Salt River Pima – Maricopa Indian Community • Arlie Beeson, Program Administrator and Tori Begay, Youth Lead Educator – Diabetes Prevention Program for Youth, Gila River Indian Community
14th – 18th October New Mexico, USA	• Shaundale Gamboa, Health Promotion Specialist – Navajo Coordinated School Health Program, Northern Navajo Medical Center, Shiprock • Mamie Denetclaw, Registered Nurse, Credentialled Diabetes Educator – Northern Navajo Medical Center's DM program, Shiprock • Lyle Lee, Registered Nurse – Public Health Nursing, School Diabetes Project, Northern Navajo Medical Center Shiprock
21st - 24th October Oklahoma, USA	• Duane Meadows – Tulsa Youth Programs: Type 2 Diabetes prevention; Choices Camps; Community Family Clubs; Indian Youth Council; Community Schools, Tulsa • Cindy Harless, Operation Specialist – HelmZar Challenge Course, Tulsa • Pam Rask, Manager - Its All About the Kids Program, Tulsa Health Department, Tulsa
26th – 30th October Alaska, USA	• Dr Terry Raymer, Alaska Area Diabetes Consultant – Alaska Native Medical Center, Anchorage • Laurie Wiese, Health Education Manager - Southcentral Foundation Primary Care Clinic, Anchorage • Harold Squartsoff, Acting Coordinator – Diabetes Prevention Program, Dena'ina Health Clinic, Kenaitze Indian Tribe, Kenai
4th – 8th November Budapest, Hungary	• The Congress on Therapeutic Patient Education 2008, Budapest • Diabetes Attitudes Wishes and Needs Summit 2009, Budapest
10th – 22nd November British Columbia, Canada	• Lauren Brown and Robyn Boese - Xaaynangaa-House of Life, Skidgate, Queen Charlotte Island • Aboriginal Diabetes Initiative Forum, Vancouver • 2nd International diabetes in Indigenous Peoples Forum, Vancouver

MAIN BODY

What Type 2 Diabetes Mellitus means for Indigenous Children

Diabetes education programs in Australia are developed primarily for an urban dwelling, English speaking, and literate population group. There are some programs that have been modified for minority ethnic groups, including Indigenous Australians, however they are still based strongly on the medical model and the content and resources are aimed at a literate, urban or rural dwelling population, rather than those living in more remote areas. Additionally, these programs have been designed for adults and do not address issues specific to children living with Type 2 Diabetes.

Investigations into issues specific to children living with Type 2 Diabetes suggest that an effective model of care must overcome geographical, economic, political, cultural and historical barriers and provide community focused and holistic care that incorporates traditional healing methods or practices in the program. Programs should incorporate age appropriate strategies for learning, include language and literacy appropriate resources, be delivered on community and involve local community members or leaders.

Type 2 Diabetes is a chronic progressive disease, the complications of which include conditions such as: heart failure; stroke; kidney failure; blindness; limb amputation; and adverse effects in pregnancy. Children developing Type 2 Diabetes will live with the disease for many years longer than adults and therefore, be exposed to its complications for a longer period time and through different life-stages. Education programs for children with Type 2 Diabetes need to be more supportive, engaging and geared to specific development stages throughout childhood and adolescence.

The challenges that remote Indigenous communities in Australia face with regards to Type 2 Diabetes are faced by other Indigenous populations in the world such as the American Indian and Alaskan Native population and the Canadian First Nations and Inuit peoples. Through meeting and talking with the Indigenous people of these regions and observing first-hand the delivery of some of their programs I have been able to compile the following information on components that could be included in diabetes programs for the Indigenous children of Australia living with Type 2 diabetes. My experiences, while travelling on this Fellowship, highlighted the fact that although there are many similarities, no two Indigenous communities share exactly the same needs in a program, and that community involvement is required at all stages of development, delivery and evaluation, to ensure that a program meets the needs its target group.

Non-medical based components of programs

- **Family and Elders**

Many of the education programs for children with Type 2 Diabetes that I visited had linkages with the child's family and / or community Elders. Family was involved so that the Diabetes care was shared amongst the whole family and not seen as just the concern of the individual child. Initiatives that involved the extended family included education days or weekend camps that parents and siblings attended as well as the child with Diabetes.

Linkages with community Elders was a very common initiative used in both American and Canadian Indigenous Diabetes education programs. The learning of historical events and the cultural beliefs and traditions of many Indigenous populations is achieved through stories passed from one generation to the next. In populations where verbal communication is more common than written communication, Elders play an extremely important teaching role.

Some of the initiatives that linked Elders with the Youth and Diabetes programs included: Community gardens growing traditional plants in Arizona; Guest speakers at Kids Diabetes camps; Traditional food cooking classes; Traditional games and sports, including events like the Native Youth Olympics in Alaska; Traditional drumming, singing and dance groups; The Educational Fishery program in Kenai, Alaska; and Canoe carving on Queen Charlotte Island, Canada.

A traditional canoe of the Haida Gwaii people, Queen Charlotte Island, Canada

- **The Acknowledgement and Respect of Cultural and Spiritual Beliefs and Incorporation into Programs**

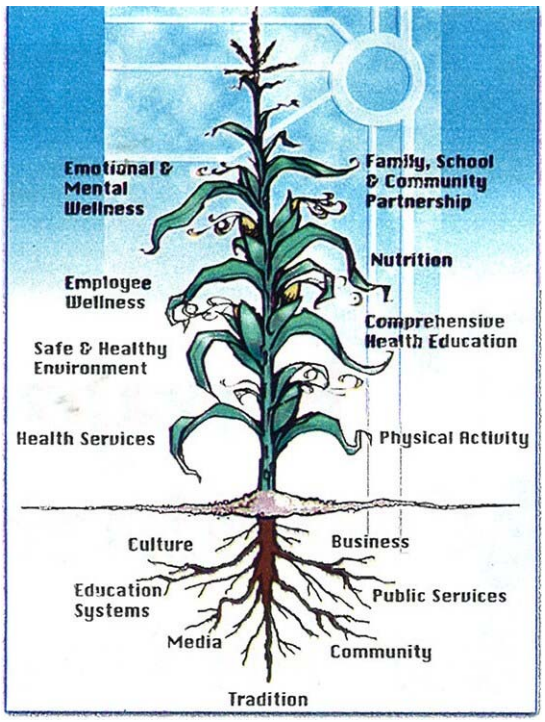
Many of the Indigenous health staff that I met with, believed that a move away from or the loss of traditional cultural practices and spiritual beliefs has left their people vulnerable to diseases such as Diabetes. The strengthening of culture buy re-educating youth in traditional practices and beliefs was seen as an essential component in many of the Diabetes programs investigated.

The inclusion of Cultural and Spirituals beliefs and practices was not limited to the actual Diabetes education programs I investigated but was central to the mission and vision statements for the

Indigenous health services that developed and delivered the programs. Many of these statements were depicted in art work or pictorial models that linked culture and health.

The Navajo Coordinated School Health Program in New Mexico and Arizona is a prime example of a cultural-pictorial model that is incorporated into all the planning, promotional and educational materials of the program. The corn plant is sacred to the people of the Diné Nation and is used to symbolise their way of living and the health of their children. The eight components of the program are represented as eight ears of corn on a corn plant; the symbolism is explained as follows:

"The beauty of the corn we see shining in the sun begins with what lies beneath the surface. To raise healthy, educated children, schools need a strong root system that is nourished by culture and tradition, supported by family, and served by the community."



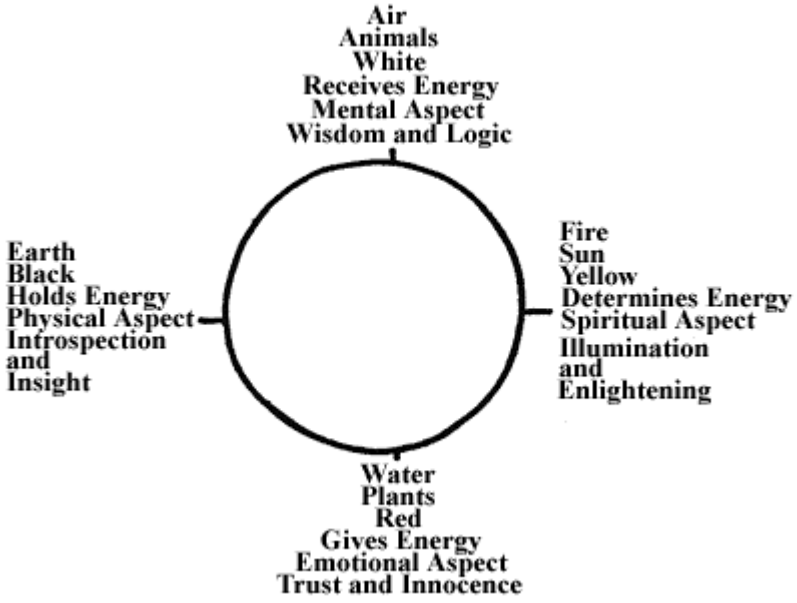
(Source: Navajo Coordinated School Health Program pamphlet)

The Navajo Coordinated School Health Programs has succeeded in developing strong partnerships with schools, state, tribal and federal agencies and national entities.

Another cultural belief used by many of the Indigenous Diabetes programs that I visited was the Four Directions. The four directions are seen as the organising principle for everything that exists in the world, such as the four seasons (spring, summer, autumn and winter); the four elements of the universe (water, air, fire and earth), the four stages of life (childhood, adolescence, adulthood and elders) and the four aspects of human behaviour (physical, mental, emotional and spiritual). The concept is used to explain diabetes care in a holistic manner with the view that all things in life are

interrelated. The Four Directions symbol or principles was incorporated into the planning of numerous programs in America and Canada such as the Medicine Wheel and the Ribbon of life. The Youth Lead Educator of the Gila River Health Care, Diabetes Program in Arizona explained that the psychological components of their program such as acceptance of Diabetes, feeling different, teasing, and self-esteem, where addressed first and medical concepts of Diabetes management were not introduced until the third week of education.

The Powers of the Four Directions



Source: *Loomis, Mary, Dancing the Wheel of Psychological Types, Chiron Pub., 1991, Wilmette, III.* ***http://images.google.com.au/images?client=firefoxa&rls=org.mozilla:enGB:official&channel=s&hl=en&q=four+directions&um=1&ie=UTF8&ei=6tS8SfSuDpK2sAOppNAt&sa=X&oi=image_result_group&resnum=1&ct=title***

The use of cultural beliefs and practices, storytelling, art and traditional foods and medicines in Diabetes programs was evident in many of the programs featured at the *2nd International Diabetes in Indigenous Peoples Forum* in Vancouver, Canada and their inclusion in program models was highlighted as a best practice initiative.

A wonderful example of art used in Diabetes Programs is the *Haida Power* t-shirts, a participation incentive in the Skidegate program. The t-shirt design was done by a famous local artist and can only be won as an incentive award for participation in the program. Motivation and friendly competition has occurred and community members are very proud to wear the shirts once they are gained. Another example is the Yaghali Ch'ulane murals at the Dena'ine Health Clinic in Kenai, Alaska. The murals depict the cycle of life through healthy living and the significance of the land, flora and fauna to the lives of the Kenaitze people. The mural's central feature, the Kenai River, offers daily inspiration

to participants, as they each place a paddle on the mural at the beginning of the program and move it along the river as they meet their goals.

Members of the Diabetes Prevention Program with Gail Cummins (second from left) in front of the Dena'ina Health Clinic Murals, created by April Nyquist and Bunny Swan

- **Developing Sustainable Programs through Community Champions and Leaders and the Promotion of the Indigenous workforce**

In addition to providing Diabetes care it was reinforced to me on many occasions that programs require capacity building and self-determination components for them to become sustainable. A call for Indigenous people to reclaim the responsibility for their own health and wellbeing was made at the Vancouver forum. The metaphor used was that Indigenous people are no longer children that need to be looked after, they are now grown and ready to take back responsibility for self and community.

Promoting community champions, leaders and the Indigenous workforce are initiatives used by many of the programs visited. At the Southcentral Foundation in Alaska, children are involved in the development of educational resources, the delivery of the health messages as mentors and are encouraged to take part in the Responsible Adolescents In Successful Employment (RAISE) Program, which develops leadership skills in Alaska Native and American Indian youth by providing opportunities for work experience in health related careers in the context of Native cultural values.

The Tulsa Youth Program also encourages leadership skills through the Youth Mentor initiative in their children's health camps program. When children reach the upper age for attending the camps they are able to apply to be a Youth Mentor and then continue to attend the camps to mentor the young

children and develop leadership skills. The Youth Mentor initiative can also link children with local and national Indian Youth Councils.

In addition to these initiatives to encouraging future generations to take up a career in Health, the Indian Health Service provides training programs or on-the-job training for careers such as: community health representatives; health records technicians; nursing, dental and optometry assistants; food service supervisors; nutrition aides; and community health aides. The Community Health Aide (CHA) Training Program in Alaska is able to provide Primary Health Care training to selected residents of remote villages where health services are limited. The CHA's provide a wide range of preventative health care in conjunction with local, state and national health care programs.

- **Patient Centred Focus**

Patient centred focus was a key theme in the *Diabetes Attitudes Wishes and Needs, DAWN Youth Summit* in Budapest, Hungary. The summit showcased many resources developed to aid this approach such as a Quality of Life questionnaire specific to children with Diabetes and the Children's Circle Tool. The Children's circle Tool is a pictorial representation of how Diabetes is different for children. It shows the child at the centre, surround then by family, then equally by school, sports activities and friends and the Diabetes Support team, outside this circle is the community and then the final circle of influence is culture.

- **Age and Development Appropriate Teaching Strategies and Resources**

Education based around play was a teaching strategy used by all the Diabetes education programs for children. Games and activities differed for different age groups and development stages. Examples of games used in teaching include: Earning passports to travel on a magic carpet by completing different components of the program; magnetic fishing poles to fish for food flash cards; puppet theatre; a snakes and ladder type floor game; physically activity games based around components of Diabetes education e.g. the movement of blood sugar into body cells. The educators in these programs work more as facilitators, helping the children to use critical thinking and problem solving techniques to discover the answers to their challenges.

Age and development appropriate resources are essential in any education program. An example of a very successful and widely used teaching resource from America is *The Eagle Book Series*. The series comprises four books that bring Diabetes education including healthy eating and physical activity to life through the use of wise animal characters. The books incorporate cultural beliefs and practices and encourage children to learn from their Elders and return to traditional ways. The series was developed in response to the increasing incidence of Type 2 Diabetes among American Indians and the lack of diabetes education materials for children. It was a collaborative initiative between the Centers for Disease Control and Prevention's Division of Diabetes Translation, the Tribal Leaders

Diabetes Committee and the Indian Health Service. Information of these books can be accessed at http://www.cdc.gov/diabetes/pubs/eagle.htm.

Medical based components

- **Alternative curriculums**

For many years now the Indian Health Service, in America has had an alternative curriculum for their Diabetes education program called the Integrated Diabetes education and clinic standards recognition program for American Indians and Alaskan Natives. The curriculum is kept current with updates and a child and adolescent specific version is under development. The information on the program can be accessed at www.ihs.gov/medicalprograms/diabetes.

- **Dental Care**

Unlike Australian Diabetes programs, dental care was included as a component of many of the American Indian and Alaskan Native Diabetes programs.

CONCLUSIONS

The typically adult-onset disease, Type 2 Diabetes, is different for children. Diabetes education programs for Indigenous children, especially those living in remote communities, need to include additional components to those included in mainstream programs. The extended family group should be involved so that the Diabetes care is shared and not seen as just the concern of the individual child. In populations where verbal communication is more common than written communication, Elders play an extremely important teaching role, therefore including community Elders in Diabetes programs is essential.

It is believed that a move away from or the loss of traditional cultural practices and spiritual beliefs has left indigenous people vulnerable to diseases such as Diabetes. The strengthening of culture by re-educating youth in traditional practices and beliefs is seen as an essential component in Diabetes programs. Diabetes programs require capacity building and self-determination components for them to be sustainable and to enable the Indigenous people they serve to reclaim responsibility for their own health and wellbeing.

Modelling a Diabetes program on the holistic concept of Mind, body and Spirit would allow the child to be seen first as a child rather than a Diabetic. Additionally, a patient-centred focus, age and development appropriate teaching strategies and resources, and an Indigenous Youth specific curriculum would contribute to a more engaging and effective model.

RECOMMENDATIONS

The incidence of Type 2 Diabetes in Indigenous children in Australia is increasing exponentially. The rate of obesity, a major risk factor for developing Type 2 Diabetes, in disadvantaged, rural, immigrant and Aboriginal and Torres Strait Islander children is increasing more rapidly than it is in more advantaged groups.

Diabetes is a progressive disease, so education and management programs for children must be more supportive, more pro-active and more engaging than those for adults as any prevention or delay in the development of Diabetic complications will improve the quality and longevity of the child's life.

Involvement of the local Indigenous community in the development of education and management programs is essential if they are to be successful, as it is the community members, Elders, family and the children themselves that can provide insight into the many different components required.

The development of an Indigenous youth-specific Diabetes education curriculum, which allows for the inclusion of local beliefs and cultural practices particular to the area in which it is being used, must also be considered.