THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA

Report by - Dr Stephen Withers - 2003 Churchill Fellow

THE BOB AND JUNE PRICKETT CHURCHILL FELLOWSHIP to study

"Paediatric Health Care Delivery in Areas of Social Disadvantage"

1September 2003 - 12 October 2003

Signed Dated

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Stephen Withers

Executive Summary

There are areas within Australia in which there are significant levels of social disadvantage. In 2003, I undertook a Churchill Fellowship to look at levels of health care delivery in places such as the United Kingdom and the United States to ascertain how communities were dealing with like problems. It was evident from the study that paediatricians worldwide are highly motivated to bring to their communities the finest quality health care. The limiting factors in providing this care are not only financial and all need consideration in building successful programs.

In the United Kingdom the outstanding programs were:

1. SureStart – a nationally funded program to improve the long term outlook for all children
2. Health 4 U – a program to provide user friendly health services to adolescents
3. Baby Express – newsletters sent monthly to new parents to provide parenting information
4. Community Parents – training paraprofessionals who live in disadvantaged areas to help their communities

In the United States the outstanding programs were:

1. HeadStart – a program designed to help children from socially disadvantaged backgrounds
2. In-School Health Centres – health care facilities based within the school environment, with doctors providing care with other health professionals
3. Community Paediatric Clinics – specialist doctors based in the community delivery care at the coalface
4. Parenting Programs – an extraordinary number of clever and innovative programs to deal with the challenges families are facing in our society.

The key lessons learnt were to collect good data to establish and resource programs, gain funding beyond the life of any one government and consult widely recognising the strengths and limitations of all interested parties. A lifetime experience which has already influenced my thinking and plans to address the needs of children in areas of social disadvantage. I propose to reformulate several of the projects and present them to senior leaders in the Departments of Health, Families and Education as programs which may offer the ability to change how we may change direction for the benefit of all communities.

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CHURCHILL FELLOWSHIP REPORT – DR STEPHEN WITHERS

"PAEDIATRIC HEALTH CARE DELIVERY IN AREAS OF SOCIAL DISADVANTAGE"

1 September 2003 to 12 October 2003

Abstract

There are areas within Australia in which there are significant levels of social disadvantage. A key issue has become the delivery of health care to these areas. In the field of paediatrics, we are now seeing multigenerational problems arise as a result of poorly empowered communities who lack the ability to provide adequately for their children.

In 2003, I undertook a Churchill Fellowship to look at levels of health care delivery in places such as the United Kingdom and the United States to ascertain how communities were dealing with like problems. It was evident from the study that paediatricians worldwide are highly motivated to bring to their communities the finest quality health care. The limiting factors in providing this care are not only financial.

In addition to small programs which are being run in different centres, there are also some programs which are being implemented on a national scale. The United Kingdom has some significant advantages in being able to introduce, with the assistance of the NHS, a very large-scale program in an attempt to address such issues. It was heartening in the United States (the home of private medicine) to see that in areas of social disadvantage, there were in place many programs to provide for the health needs of children.

Introduction

In 2003, the Churchill Fellowship provided an excellent opportunity to travel overseas to look at different forms of paediatric health care delivery in areas of social disadvantage. The area in which I am working has very high levels of unemployment, public housing, single parent families, drug use, domestic violence and child abuse. Within these poor areas, ability to access health care is sometimes limited. Local government health facilities are often stretched to capacity and there is

little incentive for private practitioners in either general practice or paediatrics to establish practices within the area due to low levels of income available to provide health care and very low levels of private health insurance.

Within the Department of Paediatrics at the Logan-Beaudesert Health Service District, we are seeing a very large number of children who are presenting with significant behavioural problems, which may be attributed to both nature and nurture factors. This has a significant impact on families and also on the schools and community as a whole. The state school system within the District has considerable levels of movement of students between schools and many children who have significant levels of learning disabilities.

There has been a significant shift in the nature of paediatric practice in the last 20 years. With improved treatment regimes for a wide range of paediatric disorders such as asthma, we are finding now that in fact the majority of paediatric care is delivered in ambulatory settings. In many ways, this reflects a trend towards what is now being called "community paediatrics". With this in mind, it seemed appropriate to visit a range of centres in the United Kingdom and USA, which would provide some insight into how these services were being provided in a system not dissimilar to our own.

United Kingdom - England

CPRG, Yorkshire Sculpture Park, Leeds

The first port of call upon arriving in the United Kingdom was to attend a meeting of the Community Paediatrics Research Group. This was certainly an extraordinary opportunity which was afforded to me. This was a group of community paediatricians who have over the last 25 years undertaken some of the benchmark work in community paediatrics. Attendees at this meeting included Dr Tony Waterston, Dr Nick Spence, Dr Mary Rudolph, Dr Simon Lenton, Dr David Elliman and Professor Sir David Hall. The group was a small and select one which totalled around 20 in all. It was a residential program that was undertaken in the Yorkshire Sculpture Park, Leeds. The ability to meet with this group provided an exceptional opportunity to meet world leaders in their field. For those who have an interest in childhood poverty, they would recognise many of these names as being the authors of several eminent books on these subjects.

What became evident from the CPRG meeting was that there was a considerable number of very interesting projects which were being undertaken throughout the UK and I appreciated I would be learning more of these in the following weeks. A point of particular note was the enormous value in the collection of data to make decisions regarding the future directions of any health care program. The United Kingdom has a long history of data collection and by revisiting the people involved, the participants in these programs at intervals allowed one to build a complex socio-demographic picture over many generations. The need for such data becomes evident when one recognises that to adequately fund some of the large programs which are required, the cooperation of all of government is required. To be persuasive, this data needs to be not only significant in terms of size, but also needs to be intellectually robust, for it to be accepted.

Newcastle-upon-Tyne – Dr Tony Waterston

The week spent in Newcastle-upon-Tyne was particularly valuable. Dr Waterston is a community paediatrician who has a great interest in the delivery of paediatric health care within his own community. Additionally, he has been involved in programs to establish paediatric health care with Palestinian groups who are working to deliver paediatric care in the Gaza Strip. Dr Waterston visited the United States in 1998 on a project not dissimilar to my own. It was interesting to see the projects he had assessed and taken on board following his overseas venture.

Dr Waterston was able to provide an overview of the interesting historical issues which had been influential in the Newcastle area. During the week with Dr Waterston, I had the great privilege of being invited to a local presentation of community projects which were being undertaken. What was fascinating was that for those who were actively participating in the program, many of them were unaware of other programs within their own district.

Youth Networks

This was an innovative program where a series of volunteers, typically in their late teens or early twenties, who had experienced mental health problems in the past themselves, volunteered to attend local high schools or technical colleges to speak to groups of between 10-12 fourteen-year-olds. The presenters of the program were then able to work with the students through some of the difficult issues in mental health. As an example, they discussed issues such as perceptions of themselves, body image and extended to the point of discussing issues such as depression and suicidality. This was certainly a very bold program. What was unique with this program was that

there was a series of trained counsellors who were available at the conclusion of each of these sessions. From their experience in delivering this program, they said that from each group of 10-12 students, there would invariably be one who would come forward at the end of the discussion period, which was typically 1½-2 hours and would disclose some significant problem that they had perhaps experienced. What was then unique about the program was that the trained counsellors who had not actually participated in the program, were available then and there to engage these students. The youth counsellors were able to simply say "I have a friend who is available right now to talk to you about some of these issues; I think this would be worthwhile". By having them right on the spot at the time, this allowed engagement to occur. This was certainly a great program which, if it could be rolled out on a national basis, would be certainly groundbreaking. As anticipated, the feedback from such a program had been excellent.

Health 4 U

Another excellent program was called the Health 4 U Program. This was a terrific program which had been put together by a group of child health workers over coffee. They in fact designed the symbol and logo for the program on a napkin at the coffee shop and were able to tell us that they still have it. What they were able to do was to put together a sign which indicated that this was a general practice which was happy and available to provide health care for young people. If they were able to see this, then it meant that this was essentially a youth-friendly practice which would welcome their attendance on a booked or drop-in basis. This had met with considerable success and there was an additional symbol which could be added (+), which indicated that they would also provide contraceptive advice. Absence of this symbol did not mean they would not discuss contraception but its inclusion meant the subject could be broached without judgement. The program had been rolled out in Newcastle-upon-Tyne and there were plans that it would be able to roll out over a much greater area in the fullness of time. To me, this was certainly a great indication of the ability for a small group of individuals to take a small but excellent idea and to have it moved to a level of acceptance where there were real prospects for its national rollout.

SureStart Program

Perhaps one of the best programs which I was able to see at close hand in both Newcastle-upon-Tyne and in Birmingham, was the SureStart Program. The SureStart Program is a major initiative of the UK government to improve the health and well being of families and children before and from birth, so children flourish at home and when they go to school. It does this by setting up local

SureStart programs to improve services for children under four and spreading good practice learned from local programs to everyone involved in providing services for young people. Local programs work with parents and parents-to-be to improve children's life chances through better access to family support, advice on children's development, health services and early learning. The SureStart Program runs in different ways in different places. They try to adapt the program to specific communities and recognise fully that what may be acceptable for one community may not be appropriate for another. This is a major strength of this program. There is a plan to nationally create 500 SureStart sites. They have a strategy for undertaking this with trailblazer, second wave, third wave and fourth wave sites to be introduced over a period of time. The funding for the SureStart Program will be longterm and will not be dependent upon the success or failure of individual governments. Further information on this program can be found at www.surestart.gov.uk.

Baby Express

The Baby Express Program is one which has been trialed by Dr Tony Waterston and his team in Newcastle-upon-Tyne. Dr Waterston first saw a variation on this program whilst on a travel tour of the United States. The program itself is exceptionally clever and offers particularly good value for money in terms of public health delivery. The program itself involves providing information for first-time parents. The basic requirement being a level of literacy equivalent to late primary school education.. What occurs is that for each month of the first 12 months of the baby's life and for every second month of the second year of life, the parents are sent a newsletter regarding care of infants. The information detailed within it is designed specifically for the area and provides an overview not only of the special issues for the parents but also includes a column which says what the baby likes at this time in its growth and development. It discusses many of the common childhood problems and common issues in parenting. It also addresses but also talks about many of the important public health safety issues, including such things as child seat restraints, preventing accidents in the home and immunisation. On the final page of each edition, there is a column which includes of the telephone numbers within the locality of people who may be able to assist if there are significant problems being experienced. An initial pilot of this project was extremely well received by those who received this newsletter.

The overall costs were quite small recognising that after the initial production costs, it required only 18 mail-outs for each family. I believe that this is certainly a program which has the potential

for application in Australia. For those people in rural communities or isolated from services it would be of enormous benefit.

Birmingham – Dr Geoff Deeble

I visited Dr Geoff Deeble, Paediatrician, Birmingham Children's Hospital, looking at the community programs which are available in the Birmingham area. Birmingham has many clusters of migrant populations from places such as Pakistan and Bangladesh. Within these cultures themselves there are subcultures of people from different areas who have differing views and outlooks on many issues. As a direct result of this, it is mindful in the creation of programs and their location. Birmingham demonstrated the significant difference between some of the Surestart Programs and how they had been introduced in different areas.

Community Parents (Para-Professionals)

The Community Parent Program is one which was initiated when it became evident that there was a very real need to have workers who were based in the community who had an excellent feeling for the community itself. The program was set up under a formal business structure to ensure further training would take place by securing funding and to find and mange employment of the newly trained para-professionals. Historically there has been a series of qualified experts who have come from elsewhere to provide their wisdom to a range of different communities. Invariably these are poorly received because those delivering the program, although well meaning, have little concept of the socioeconomic and cultural issues specific to that community. The idea was to take a group of women who had literacy and numeracy skills and to essentially train them to be knowledgeable on a wide number of special issues within each community. The women needed to live in the community and to be prepared to undertake a period of training over one year. The goal of the project is that no woman who participated in the program would be financially out of pocket to participate in this program. With this mind, provisions were made to provide childcare, pay for all tuition and to provide a small amount of money as incentive to complete the program. The women were then given a series of lectures, tutorials and practical workshops (work experience) in such areas as child development, disabilities, positive parenting, creative play, food hygiene and basic nutrition, post natal care, care of babies, working with families, first aid and confidence building.

The women, upon completion of this course, then had a wide range of skills which could be usefully applied within their community. As they were women who were known within the community, it provided for them what would be termed a ticket of entry so that they could visit perhaps women who may be socially isolated as a result of religious or cultural beliefs and to discuss with them special issues which may be of assistance to them. It is endeavoured that women who would complete this program would then be able to fulfil this role as a community parent.

What was interesting was that for some of the women who became involved in the program, clearly they were able to subsequently go on to further education and many of them have gone on to commence university degrees. For others who may defer a period of time of employment, for instance on maternity leave, these are skills of course which they have not lost. Whilst they continue to be in their community, then they remain a constant source of useful information for a variety of people. Because of the significant groups of migrants who have settled in different localities in the United Kingdom, it allows this program to be adapted for individual and specific communities.

The other interesting point of note was that these women who were the community parents were afforded a level of status which was sometimes not otherwise offered to women from their cultures. As an example, women were able to access men within Muslim communities through the local mosque. If there was a particular issue that was of serious concern, the community parent could arrange a meeting with the senior community leaders at the mosque and then information could be passed back through the men, who would then be able to deliver this message to the women of the community without creating disharmony.

Community Renewal Project – The Three Estates Project

I was able to go out to spend a half-day in one of the community renewal projects in the outskirts of Birmingham. The question had been asked "why had inner city regeneration failed despite enormous amounts of money being poured in over generations." Key issues were seen to be funding to span beyond the life of a government and a real need to go beyond the obvious areas of health, employment, crime and education. The community was one which had a long history of unemployment and poverty. There were some fascinating stories regarding community renewal, which I believe are worth retelling. In consultation, representatives of the community had been asked what they thought would be the singlemost-invigorating program for their community. Their

immediate response was the construction of a swimming pool. Clearly it seemed hard to imagine that this would be of any assistance in fact to the community. The question to ask is "what is wrong?" not "what do you want."

The important first lesson I learned from this was that in fact consulting people in areas where there is a high level of poverty and unemployment or perhaps families where there are very low levels of income, is unlikely to be particularly insightful into the necessary factors to stimulate growth and development within their community. For people who may have these skills, in fact they are highly unlikely to have remained in these areas. They are likely to have been motivated themselves to seek better employment and higher levels of education and as a direct result would not find themselves living in these areas.

Equally it is important not to rely upon the opinion of so-called experts in devising specific plans for community renewal unless they in fact have been intimately involved in such projects themselves in the past. Although there may be the hypothetical needs of people within the community, in reality their needs may be very different. It is important to work with agencies already involved in the community. Schools are perhaps the best example. They often have a "feel" for the big issues. Other agencies such as housing and social welfare may be able to bring to the table a unique perspective. Assessing the needs of local industry is another important aspect of community renewal. Running courses which may be prerequisites for employment in the local area may have an overall outstanding effect on the community.

London

In London I had the opportunity to meet with Dr Russell Viner, a paediatric colleague who has taken up the role of providing adolescent health care for the NHS at Great Ormond Street Children's Hospital. With a parallel between the UK and Australian systems this is likely to be an area into which expansion will be necessary. At present in Australia for children with chronic conditions no matter how minor the transition from paediatric to adult medicine is often not smooth. The best example of this is in the area of Diabetes. Within my region this is a major problem and the need for a smooth path for transition may be critical for the long term health of patients.

I took the opportunity to visit the Evidence Based Medicine Program based at the Institute for Child Health which adjoins Great Ormond Street Hospital. This centre is a national and international centre for teaching of EBM methodologies which are today forming the framework for the practice of medicine. I was able to review the courses they had on offer and to get an insight into how this program had been established.

United States of America

The United States is home of privatised medicine. Paediatrics is practised as a primary care specialty (no referral required). In poor communities health funds still dictate/negotiate levels of care. I was surprised to learn that even very low income earners may have health plans but their level of remuneration is often limited. The really poor are dependent on MedicAid, a federally funded system run by the states.

New York City

HeadStart Program

The HeadStart Program is one which was established in the United States to provide for children from poor socioeconomic backgrounds, the basic requirements that would give them the opportunity to be ready for entry into school. The program has a long history and I was privileged to hear one of the founders of this project speak at the Columbia University in Upper Manhattan. The program is run in a variety of areas and to different levels of fulfilment. What is evident are the changing demographics in parts of the United States with the influx of very large numbers of Spanish speaking migrants from Mexico and South America. As an interesting note, it is clearly a pre-requisite in New York City to be able to speak Spanish in an attempt to communicate with the patients who one may be seeing particularly in poorer socio-demographic areas.

Community Paediatric Clinics

In New York City, the community paediatric clinics are run by a strong team of senior and junior clinicians. By having both medical students and junior trainees involved in the delivery of this care, it provides for them a very real taste of practising paediatrics within the community. The clinics I attended were new, modern and well resourced in terms of administrative and nursing staff to provide support to the clinicians.

In-School Programs

I had the privilege of being able to visit the George Washington High School in Upper Manhattan. This high school has a population of around 4500 students. As a result of this, it needs to provide significant health care to this population. The high school itself has students who range in age from 12-18 years. The thing that immediately struck me on entering the school was the very serious attitude taken towards security in these schools. All cases are x-rayed upon entry and all students and visitors must pass through an x-ray device in a very similar fashion to what is currently undertaken at all airports.

The health clinic which is run at this high school is deemed to be part of the Columbia University Health Network. By essentially defining this area as a health care facility, it allows the discussion of a range of topics which may otherwise be more sensitive to those involved in the Department of Education. This may include such issues as contraception and termination of pregnancy. A significant number of the students in the high school are sexually active so with this in mind it is necessary to run clinics which can undertaken screening for sexually transmitted diseases and also undertake Pap smears for those who are regularly sexually active. This is certainly something which has not been the practice in Australia, where typically the cut-off age for paediatrics is considered to be around 13-14 years. Although there has been a push towards adolescent medicine in some parts of the world, in the United States this work still clearly falls under the umbrella of paediatrics. This clinic again was well resourced with two doctors who are permanently posted to the high school in addition to nursing and administrative staff to provide support. Consent is sought from parents for their parents to attend the health clinic. Once this consent is obtained, then this does give the children the ability to freely access the services which are available there. Funding is from the Columbia University Health Network which must lobby government directly for this funding.

Paediatric Trainees in New York City

I was asked to give an impromptu talk to the paediatric trainees at the Columbia University Health Network. This took the form of a lunchtime meeting where I was able to outline for them the structure of health care which is provided in Australia. They were particularly interested in the differences in training programs. In the United States they complete a graduate medical course and would enter into specialty training immediately upon completion of medical school. The American system has always worked upon the concept that trainees will provide a significant amount of after-

hours care, the theory behind this being that of course this allows observation of continuity of care and thereby provides an excellent basis for service. This theory of course has been challenged in many other countries in the world, including Australia. Interestingly, in New York City recent legislation has created for them what is the unusual situation where the maximum number of hours which can be worked in any particular week is 90 hours. This seems extraordinary. However, historically residents might have found themselves working anywhere from 110-120 hours each week. The American trainees were certainly envious of the system of training we have here in Australia. The work they undertake is very similar with excellent options for training and supervision.

Birmingham Alabama - University of Alabama

Alabama is recognised as one of the poorest states in America. It is infamous for racial issues and the capital Birmingham tragically remembered as the site of a church bombing in the 1960's. Despite these issues the University of Alabama is an example of a huge hospital facility providing state of the art care to children and their families through the Children's Health Network. Outside the children's hospital is a bronze football with a message telling the story of how the hospital was built with money from football. On the day I arrived in Alabama a big stock car race was in town and was a major calender event for the year.

Poverty affects three groups african americans, hispanics and whites. Each have their own unique issues. Again speaking spanish is almost mandatory in delivering health care due to the huge influx of migrants from Mexico and South America..

Hospital Health Care Clinics

The hospital runs a series of clinics which are manned by the training medical staff under supervision. When a trainee starts they are assigned families and provide all care and follow-up for the duration of their training (3-4 years). This provides great continuity and allows junior staff to understand the natural history of conditions. For people who are unlikely to be able to afford visits to the doctor this builds a great trust between their doctor and the hospital.

Community Paediatric Clinics

These clinics where run out in the suburbs and provide collocated care for adults and children. The clinic provided continuity of care and was typically able to provide a full range of services.

An interesting feature of these clinics was the ability to undertake a variety of social service matters at the centre. For those people on low incomes it is possible to qualify for a program

Los Angeles

Parenting Programs

In Los Angeles I was able to meet with the Executive Director of the Families First Program, Ms Terri Altwies to review some of the interesting parenting programs which are going on in California. Ms Altwies has been working with the Children's Hospital of Orange County (CHOC) as a consultant over many years for parenting education classes and workshops. She calls herself a Professional Family Life Educator. She is in significant demand and now is finding that large corporations are asking her to deliver programs to their employees. A major corporation which has undertaken this has been the Boeing Company.

The issues which are facing us in Australia are, I believe, universal. In the United States where there are many broken families and in some areas very high levels of poverty, these issues have certainly become paramount.

There are many programs which are similar to the Triple P Program which was originated here in Queensland. This is a positive parenting program which works on a plan over a period of time of working together with parents to come up with meaningful strategies for disciplining children and working with them so that they may achieve their potential. Examples of the programs which are currently run at CHOC include:

- 10 top tips to turn a terrible toddler into a terrific toddler
- Yeah, Whatever!
- Effective discipline without yelling and punishment
- Beyond the Birds and the Bees
- Setting limits and making them stick.

A very interesting and innovative program was one which has been developed on coparenting. It has become increasingly evident that with broken families, different parents have different attitudes as to how they should raise their children and determining what is acceptable, which is

unacceptable and the nature of discipline as it may be applied. This program which is now being requested by the family court to draw parents together to address these issues.

Conclusion

The Churchill Fellowship provided for me a unique opportunity to travel and see how others are addressing the issues of paediatrics in areas of social disadvantage. The programs I saw were clever and innovative. Some excellent and easy to deliver, whilst others were labour and capital intensive. The most important messages were very clear.

1. Good projects are supported with a long term view
2. Great ideas can come from every angle, be receptive and locally support pilot programs
3. Issues of social disadvantage involve the whole community and need to be addressed by the whole community and not individual arms of communities to achieve long term goals.

Recommendations

In Queensland and Australia we need to rethink the issues with respect to social disadvantage. We need to base services within communities and utilise local people to drive these services. We need to more carefully assist young families in putting together a life plan which will see them empowered and with skills. Caring for children is hard work and we need to support parenting programs for everyone. Money which is currently invested needs to be directed at addressing core issues at the roots rather than waiting for problems to emerge. This is the basic principle of public health, the idea of looking upstream to address issues.

Families need to be informed about making the best decisions for themselves and their children. The idea of having 3-4 children as a single parent supported indefinitely by the government and social welfare agencies is unlikely to lead to good outcomes for these children. At very senior levels we need to tackle these hard issues. Failure to do so will see us with a growing underclass of poorly empowered, poorly educated families with few long term prospects.

I believe we need to be introspective and realistically appraise where we are today and where we want to be in the future. With forethought and planning we can improve the lives of all communities.

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