The Winston Churchill Memorial Trust of Australia

Jack Brockhoff/Churchill Fellowship 2005/6

Report by Simone Griffin

The Brockhoff/Churchill Fellowship to investigate a range of service delivery models and communication approaches/techniques used to assess and provide intervention for children with autism spectrum disorders (ASD).

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Signed

Dated

SIMONE GRIFFIN
28th April, 2006
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Précis

This report provides an overview of the many findings, highlights and confirmations arising from the 2005/6 Jack Brockhoff/Churchill Fellowship visit to the United States of America, Canada and United Kingdom which investigated a range of service delivery models and communication approaches/techniques used to assess and provide intervention for children with autism spectrum disorder (ASD). The report addresses the theoretical, practical and clinical issues surrounding the following topics:

- Service delivery models for children with ASD;
- Training, education and support for staff working with children with ASD;
- Dissemination of information regarding best practice with children with ASD; and
- Future research required in the area of ASD and intervention.
Acknowledgements

I am deeply grateful to the Jack Brockhoff Foundation and Winston Churchill Memorial Trust of Australia for the amazing opportunity afforded by their support. In particular, I wish to thank the committee members of the Winston Churchill Memorial Trust for identifying and acknowledging the importance for further investigation into the area of autism spectrum disorders (ASD). I would like to thank Kem Mayberry, Pam Oakes and Meg Martin for their encouragement and support throughout the entire process of my study tour, and also Frank Mensforth, for his patience and flexibility with the organisation of all my flights.

I sincerely thank all the people I visited throughout the USA, Canada and the UK who gave so generously of their time and openly shared their skills and knowledge. Specifically, I would like to thank Andy Bondy, Luigi Girolametto, and Mary Draffin for their guidance and help in identifying key centres and people to visit in order to get the most out of my study tour. I would also like to thank Colleen Baker and Mary Fleming for their guidance and supportive references and the staff and parents at Southern Autistic School for their encouragement and interest in my absence.

Last, but by no means least I wish to thank the two boys who inspired me to work in the area of ASD in the first place, Sam and Ambrose.
Executive Summary

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**Project Description:**
To investigate a range of service delivery models and communication approaches/techniques used to assess and provide intervention for children with autism spectrum disorder (ASD), including the identification and analysis of theoretical, practical and clinical issues that arise from each model/approach.

**Project Highlights:**
- Visit to 6 ASD schools in the USA that have/or are in the process of introducing the Pyramid Approach to Education in Autism (see Bondy & Sulzer-Azaroff, 2002) and the Picture Exchange Communication System (PECS) (see Frost & Bondy, 2002) and discussions with the co-developer of these approaches, Andy Bondy, about the issues he has experienced with introducing these approaches into established settings;
- Discussions with Wendy Roberts in Canada about research projects that are working towards combining ASD schools/programs with research and educational units (i.e., providing clinical experiences for health professionals and teachers);
- Visit to 5 National Autistic Society (NAS) certified schools in the UK and discussions with speech pathologists and teachers about assessment and intervention approaches, and the importance of having a national body/organisation that represents ASD and advocates for services and creates awareness within the community;
- Discussions with Fern Sussman in Canada about the process and the issues surrounding the development of the parent training program *More than Words* (see Sussman, 1999) and the new parent program for children with ASD, *Small Talk*;
- Discussions with Peter Szatmari and colleagues about the clinical research projects that are currently underway comparing some of the intervention approaches for children with ASD in Canada;
- Discussions with Gary Mesibov about various approaches used to provide intervention for children with ASD and the difficulties associated with widely disseminating information and training parents and professionals and maintaining the quality of a service and an approach;
- Observations and discussions with Deborah Hayden regarding the holistic approach to communication intervention (including the importance of motor programming and speech development in children with ASD—see Hayden, 2003) and the difficulties associated with widely disseminating information and training speech pathologists and maintaining the quality of services and a designed approach.

**Major Lessons and Conclusions:**
Working with children with ASD is still a relatively new and highly specialised area for many teachers, clinicians and researchers. Within specific areas of Australia, USA, Canada and the UK there is some leading research and centres providing specialised services for children with ASD. From my readings, observations and discussions with numerous parents and professionals of all the centres that I visited there are some common themes that emerged as being crucial when providing services for children with ASD. These included:
- Flexibility within the funding structures and approaches/techniques used to accommodate the individual needs of children with ASD (i.e., centres may need to adopt numerous approaches/techniques to meet individual needs);
- Specific and ongoing education, training and support for teachers, assistants and health professionals working with children with ASD;
- Incentives for teachers, assistants, health professionals and researchers to strive for excellence and continue working in the area of ASD;
- The importance of networking and disseminating clinically (i.e., not yet proven in the research domains) useful approaches and techniques used with children with ASD; and
- The need for research to identify specific characteristics of ASD and match them up to the most appropriate service delivery models, techniques and approaches.

**Dissemination and Implementation of Information:**
I have specific strategies in mind for disseminating and implementing the knowledge gained. Specifically, I plan to:
- Continue to work directly with 120 students, 68 staff members and 108 families at Southern Autistic School;
- Continue to supervise and guest lecture speech pathology students;
- Submit a paper to a journal outlining my findings and recommendations;
- Make recommendations to various ASD organisations in Australia and to Speech Pathology Australia;
- Enroll in a PhD program (i.e., topic area will be ASD and communication) within the next 18 months.
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<td>September 30th</td>
<td>Orange County, California USA</td>
<td>Pyramid Autism Centre (PAC) Program Director: Stacey Kochonowski</td>
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<td>October 3rd to 4th</td>
<td>Hartford, Connecticut USA</td>
<td>River Street Autism Program Program Director: Kathy Dyer Pyramid Consultant: JoAnne Maetto</td>
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<td>October 6th to 7th</td>
<td>Albany, New York USA</td>
<td>The Centre for the Disabled Contact Person: Sue Brizzell</td>
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<td>October 12th to 13th</td>
<td>Turnersville, New Jersey USA</td>
<td>Glouster County Special School District Child Developmental Center Program Director: Megan Daly</td>
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<td>October 17th</td>
<td>Newark, Delaware USA</td>
<td>Pyramid Consultant Contact Person: Diane Black</td>
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<td>October 20th</td>
<td>Newark, Delaware USA</td>
<td>Delaware Autistic Program Contact Person: Laura Gangloff</td>
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<td>October 21st</td>
<td>Lewes, Delaware USA</td>
<td>Sussex Consortium (Lewes) Program Director: Kris Battaglini PECS &amp; Pyramid founder: Andy Bondy</td>
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<td>October 24th to November 11th</td>
<td>Greenville, North Carolina and Raleigh, North Carolina USA</td>
<td>Greenville TEAACH Centre (Treatment and Education of Autistic and related Communication-handicapped Children) Meetings/Observations with: Gary Mesibov (Director of Division TEAACH) John Dougherty (Greenville Program Director) Tracey Lancaster (Speech Pathologist in Greenville) Elisabeth Kulsar (Child Psychologist) Linda Watson (Associate Professor in Speech Pathology at University of North Carolina)</td>
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<td>November 14th</td>
<td>Toronto, Ontario CANADA</td>
<td>The Hanen Centre: Contact Person: Tom Khan</td>
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<td>November 15th</td>
<td>Toronto, Ontario CANADA</td>
<td>University of Toronto Speech Pathology Department Contact Person: Carla Johnson</td>
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<td>November 18th and 21st</td>
<td>Toronto, Ontario CANADA</td>
<td>The Hospital for Sick Children Contact Person: Wendy Roberts</td>
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<td>November 22nd</td>
<td>North York, Ontario CANADA</td>
<td>Speech Pathology Clinic - PROMPT Contact Person: Margit Pukonen</td>
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<td>November 23rd</td>
<td>Toronto, Ontario CANADA</td>
<td>CASLPO (College of Audiologists and Speech-Language Pathologists of Ontario) Contact Person: Colleen Myrie</td>
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<td>November 24th</td>
<td>Montreal, Quebec CANADA</td>
<td>Giant Steps (ASD Program) Contact Person: Eric Beaupre</td>
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<td>Date</td>
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<td>November 25th</td>
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<td>McGill University Health Centre</td>
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<td>December 2nd</td>
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<td>Daldorch House School (National Autistic Society School)</td>
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<td>January 9th and 10th</td>
<td>Rotherham, South Yorkshire UK</td>
<td>Robert Ogden School (NAS School)</td>
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<td>January 10th</td>
<td>Barnsley, South Yorkshire</td>
<td>National Autistic Society – Early Bird Project</td>
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<td>January 16th and 17th</td>
<td>Radlett, Hertfordshire UK</td>
<td>Radlett Lodge School (NAS School)</td>
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<td>January 18th</td>
<td>Southall, Middlesex</td>
<td>Sybil Elgar School (NAS School)</td>
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<td>January 20th and 23rd</td>
<td>Meopham, Kent UK</td>
<td>Helen Allison School (NAS School)</td>
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Background

Autism Spectrum Disorder (ASD) is a developmental disability characterised by impairments in communication and social interaction together with the presence of repetitive behaviours (Kanner, 1943; Rutter, 1983; Wing and Gould, 1979). Some common characteristics displayed in people with ASD include hand or finger flapping, difficulty initiating or maintaining a conversation with others, a delay or total lack of spoken language and often difficulty with eye-to-eye gaze. The interested reader is referred to the DSM-IV\(^1\) (1994) for a more detailed explanation of the diagnostic criteria. A more personal account of ASD was given by Crawford (2004) where she described her child’s ASD characteristics and likened it to being from an imaginary country called Schmolland (i.e., not quite like Holland).

“Where in Schmolland, it’s perfectly customary to lick walls, rub cold pieces of metal across your mouth and line up all your toys end to end….it’s quite normal to repeat lines from videos to express emotions…”

(Crawford, 2004 p.12)

Over the past 15 years, ASD has received a lot of media coverage with concerns of an increase in prevalence (Davis, 2002). Controversy exists as to whether this increase reflects a real change in the numbers of children with ASD or whether more flexible diagnostic criteria and increased awareness have resulted in children being diagnosed at higher rates (Davis, 2002). Epidemiologic studies suggest that the rate of ASD in preschool age children is currently at 6 per 1000 (McConachie, Hammal, & Le Couteur, 2005). A dramatic growth in the treatment programs available to children with ASD has also occurred, but so has the chaos about how to carry out treatment (Siegel, 2003). Siegel summarised the position we are currently in today:

“We are at a very difficult point in ASD treatment. We have very good description of ASD spectrum disorders. We have better and increasingly early diagnosis. We have a mandate for early intervention. We have good empirical research that describes specific symptoms and specific ways in which skills acquisition for children with ASD may be deficient. We do not, however, have very much empirical, truly scientific, treatment outcome research.”

(Siegel, 2003 p.1)

So as professionals, what do we recommend for treatment for children with ASD if there is little outcome research? What perspectives/approaches to the treatment of children with ASD do we recommend? Do we use a developmental, behavioural, educational, cognitive or medical approach or a combination of these approaches? These are the questions that underpinned the purpose of this study tour and led me to practically and clinically investigate a range of service delivery models and communication approaches/techniques used to assess and provide intervention for children with autism spectrum disorders (ASD).

\(^1\) Diagnostic and Statistical Manual of Mental Disorders Edition 4
Findings

The following is a discussion of the themes that summarises the many lessons learnt on my 4 month study tour. These themes provide the foundation of the conclusions and recommendations in this report and have changed my way of clinical thinking and practice. These themes include:

1. The importance of flexibility within approaches/techniques and funding structures used to accommodate the individual needs of children with ASD.

It is well documented in the literature that all children, although might have the same diagnosis of ASD, are individuals and therefore have different abilities and needs across the lifespan. Having had the opportunity to visit numerous ASD schools, centres and clinics across the USA, Canada and UK it became very clear the importance of providing flexible services to cater for individual needs. In other words, providing services that target the specific needs of individuals with ASD and ensuring that they continue to change as the children’s needs change.

Some of the schools, centres and clinics that I visited were attempting to provide such flexible services that targeted the specific needs of the children. These schools, centres and clinics were often using a collection of well known service delivery models, techniques and approaches such as: the Picture Exchange Communication System (PECS) (see Frost & Bondy, 2002); the principles of the Pyramid Approach to Education in Autism (see Bondy & Sulzer-Azaroff, 2002); the techniques used in the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) (see Mesibov, Shea & Schopler, 2004); the principles of Applied Behaviour Analysis (ABA) and Lovass based programs (see Maurice, Green & Luce, 1996); Prompts for Restructuring Oral Muscular Phonetic Targets (PROMPT) (see Hayden, 2003) and More than Words/Hanen principles (see Sussman, 1999) to cater for the children’s individual needs. For example, some of the places visited provided flexibility in their programs to target specific skills needed in the areas such as education, vocational skills training and leisure/recreation. Some centres had the flexibility to provide ongoing support and training to assist children transitioning to mainstream schools and also inviting mainstream school children to centres for children with ASD to assist with social skills development.

Unfortunately, it was reported on numerous occasions by health professionals, clinicians, researchers and parents that the funding source and structure for many of the programs dictated how flexible they could be in providing individualised programs and ongoing services. For example, it was commonly reported that one service would be funded to provide the diagnosis and write a report, while another was funded to provide early intervention services, while another was funded to provide school aged services while another was funding to provide out of hours respite care for the families etc. This furthered highlighted for me the importance of flexibility required in the funding structures before we can provide individualised programs and seamless service for children with ASD and their families.

2. The importance of specific and ongoing education, training and support for teachers, assistants and health professionals working with children with ASD.

Working with children with ASD is clearly a specialised area where a range of skills, knowledge base, and creative ideas are paramount in providing a quality individualised service for the children. It became clearer throughout my study tour that the quality of services provided to children with ASD were often dependent on the people actually working on a daily basis with the children. At many of the centres that I visited, the children spent most of their time with assistants or support staff that have had little or no training in the area of ASD (i.e., the programs were generally developed and monitored by teachers or health professionals and implemented by assistants or support staff). In other centres it was commonly reported there were specific staff trained and skilled up in certain areas but not others, or were trained years ago and had forgotten various skills. The observations and reports really highlighted the importance of specific training for all staff on a regular basis in a range of techniques, strategies and approaches/models used to teach children with ASD. That is, not a once off training for a couple of hours or days, rather ongoing support and problem solving from internal and external ASD specialists so that the children are getting quality, non-diluted, individualised services (i.e., best practice). There were a couple of centres that I visited that were very focused on the training of all of their staff and had put in place strategic plans that outlined how changes were going to be made from the overall approaches/models of the centres through to regular training and support of the staff members working on a daily basis with the children. Incorporated in these strategic plans were accountability measures to ensure the implementation of specialised skills and to also identify any additional training/support required or changes needed to the plan.

It is not within the scope of this report to outline each of these techniques/programs/service delivery models the interested reader is referred to the references provided.
3. The need to provide incentives for teachers, assistants, health professionals and researchers to strive for excellence and continue working in the area of ASD;

Building upon the previous theme of the importance of training and supporting staff working with children with ASD, is the issue of retaining those staff and encouraging clinicians and researchers to strive for excellence in the area of ASD. During the 4 month study the issue of staff retention and the need to provide incentives to work and strive for excellence in the area of ASD was brought up numerous times. Australia is currently in a similar position with a shortage of qualified and experienced teachers, health professionals and assistants working in the area of ASD. I discussed the possible causes of these problems and possible solutions with many professionals throughout the tour. Some of the suggestions included:

- Increased awareness in the community about ASD and the potential employment opportunities in this area ASD;
- Increased wages;
- Strategic career development outlined to all staff members (i.e., including assistants) so that there is always the potential for professional and career development and movement;
- More funding towards research; and
- Seed grants and scholarships for short term study for all professionals to extend their knowledge and clinical experiences in the area of ASD.

4. The importance of networking and disseminating clinically (i.e., not yet proven in the research domains) useful approaches and techniques used with children with ASD;

When working directly with children with ASD it is important to have many ideas and strategies that can be adapted and used to accommodate the individual child’s needs and motivations. Traveling to the USA, Canada and UK for 4 months was a wonderful opportunity where I learned countless theoretical, practical and clinical things about ASD. The people and places I visited were very open to sharing their ideas, knowledge and gave so freely of their time. There were hundreds of good practical and clinical ideas and strategies shared with me that I will use regularly in my practice that can’t be found in books or journals. This reiterated for me the importance of forming networks with people in similar settings, so that we can share resources and ideas, problem solve and build upon from each others experiences and eradicate that notion of ‘reinventing the wheel’ when it comes to intervention and children with ASD.

5. The need for research to identify specific characteristics of ASD and match them up to the most appropriate service delivery models, techniques and approaches;

Throughout my career, and particularly on the study tour, there has been a lot of questioning and discussions regarding what is the ‘best’ intervention for children with ASD. In agreement with some of the literature (see Sigel, 2003), I professionally don’t think it is a question of finding one ‘best’ intervention that is suitable for all children with ASD but rather a continual process of identifying the needs of an individual and matching them up with appropriate and available services. There are many great service delivery models, approaches and techniques used across the world in the area of ASD, of which I was privileged to visit some of them on my study tour, but unfortunately there is no one solution to providing intervention for all children with ASD. This very issue highlights the need for research to identify how we can match up specific needs with available approaches/techniques so that parents and professionals can be guided in their decisions to determine what services are best for a particular child with ASD. These issues were discussed at length with numerous professionals and researchers during the study tour and there is currently some preliminary research looking into this area however, it is a very difficult area to research with statistical confidence (i.e., difficult to do randomised controlled studies for ethical reasons).
Conclusions

The ASD centres and people that I visited on my fellowship tour have provided me with a wealth of knowledge, opportunities, experiences and hundreds of practical ideas for working with children with ASD. At a service level, I have had the opportunity to compare and contrast various models of service delivery for children with ASD and experience the issues that arise from theoretical, practical and clinical levels within these models. Some of the issues that emerged have changed my way of clinical thinking and therefore practice when working with children with ASD, and others have affirmed that some Australian practices and services are in line with current research and trends. Overall study tour highlighted the importance of:

- Flexibility within the funding structures and approaches/techniques used to accommodate the individual needs of children with ASD (i.e., centres may need to adopt numerous approaches/techniques to meet the needs of individuals);
- Specific and ongoing education, training and support for teachers, assistants and health professionals working with children with ASD;
- Incentives for teachers assistants, health professionals and researchers to strive for excellence and continue working in the area of ASD;
- The importance of networking and disseminating clinically (i.e., not yet proven in the research domains) useful approaches and techniques used with children with ASD; and
- The need for research to identify specific characteristics of ASD and match them up to the most appropriate service delivery models, techniques and approaches.

At a more clinical level, I have accumulated hundreds of practical ideas, activities and resources that will make me a much better speech pathologist working with children with ASD. I am committed to promoting not only the awareness of ASD in the community but also committed to promoting the importance of continuing professional development for teachers, health professionals and researchers about best practice in the area ASD so that the services provided to children with ASD can be improved.

Dissemination and Implementation of Information:

I have very specific strategies in mind for using the knowledge gained – in particular sharing this information with therapists, teachers, assistants, health professionals and researchers; implementing skills at my current place of work with the children and their families; and starting some research projects. Specifically, I plan to:

- Implement new knowledge gained in my everyday work with the children (i.e., 120 students) at Southern Autistic School. Including sharing the hundreds of practical ideas, activities, techniques, strategies and resources that I was privileged to learn about on my fellowship;
- Provide training to the staff (i.e., 68 staff members) at Southern Autistic School and share the knew knowledge (e.g., various techniques and service delivery models) and how they can apply them within their classrooms and as a whole school approach (i.e., with ongoing support from me);
- Provide training and information to parents (i.e., 108 families) so that they can make informed decision about various communication techniques and strategies suitable for their children and how they might implement these techniques and strategies within the home environment (i.e., with ongoing support from me);
- Continue to guest lecture undergraduate speech pathology students and share the knowledge from the study tour and provide supervision to speech pathology student in implementing this knowledge in a clinical setting. I plan to contact other universities in Australia to see if they are also interested to set up a similar situation with myself and Southern Autistic School;
- Continue to present workshops in rural Victoria and provide ongoing support to them by sharing freely of resources, experience and advice;
- Present the knowledge to Southern Autistic School’s school council (which I am a member) so that they can make informed decisions about how best to provide a service to the students (e.g., at a policy/vision/school charter level);
- Advocate that ASD be included as an additional component of the Competency Based Occupational Standards (CBOS) (i.e., syllabus) for graduate level speech pathologists so that all Australian speech pathologists that graduate will then have sufficient understanding and experience with people with ASD so that they can make informed clinical decisions that are of current knowledge, evidence based and best practice;
- Submit a paper for publication or acceptance for conference presentation outlining my findings and recommendations from my study tour;
- Enroll in a PhD program within the next 18 months and use the knowledge gained to provide the foundations of some initial research into service delivery models and communication assessment/intervention techniques for children with ASD.
Recommendations

The experiences and findings from my fellowship have led me to the following recommendations that I will continue to explore and advocate for in the future. The recommendations include:

- Promotion of the benefits and joy of working in the area of ASD to encourage interest and therefore enthusiasm and excellence in the field;
- Incentives for teachers, assistants, health professionals and researchers to strive for excellence and provide better services for children with ASD;
- Encouragement of Australian ASD organisations/support groups to work cooperatively and collaboratively towards providing better awareness and services for people with ASD and their families;
- Ensuring there is equal access for people with ASD and their families across Australia (i.e., particularly families living in rural and remote areas) to individualised services that meet their specific needs;
- Advocating for flexibility in the funding structures that support children with ASD so that they have access to seamless and individualised programs and services;
- Financial support for research in Australia in working towards providing better services and intervention for children with ASD;
References


