Supporting Parents and Infants in Neonatal Intensive Care

Dr Deanna Gibbs
BAppSc(OT), MOT, Grad Cert Res Meth, PhD

Churchill Fellow 2013

Winston Churchill Memorial Trust Travel Fellowship

April-May 2013
Contents

Acknowledgments .................................................................................................................. 3

1. Introduction ..................................................................................................................... 4

2. Objectives ......................................................................................................................... 5
   2.1 Objectives specific to fellowship period ........................................................................ 5
   2.2 Objectives arising from knowledge acquired during fellowship ................................... 5

3. Itinerary .............................................................................................................................. 6

4. Summary of Organisational Visits ................................................................................... 7
   4.1 Women and Infant’s Hospital, Providence, Rhode Island .............................................. 7
   4.2 Cincinnati Children’s Hospital Medical Centre, Cincinnati, Ohio .............................. 14
   4.3 University of Cincinnati Medical Centre, UC Health, Cincinnati, Ohio ..................... 17
   4.4 Washington University School of Medicine/St Louis Children’s Hospital, St Louis, Missouri .20
   4.5 Baylor University Medical Centre, Dallas, Texas .......................................................... 24
   4.6 National Association of Neonatal Therapists Annual Conference, Fort Worth, Texas ....... 26

5. Post-Fellowship Activities ............................................................................................... 26

6. Conclusions ....................................................................................................................... 27
Acknowledgments

Firstly, I would like to unreservedly thank the Winston Churchill Memorial Trust for granting me a travel fellowship for 2013. It was a long held ambition of mine that I would be successful in obtaining one of these prestigious fellowships to support me in undertaking some focused development and learning around an area of clinical practice close to my heart, and one where I believe that as health professionals, we can make such a difference to the lives of children and their families. The ability to spend four weeks immersed in such a valuable opportunity to travel and observe best practice in an international context would simply not have been possible without the support of the WCMT.

I also extend my gratitude and acknowledgement to each of the neonatal therapists and centres who kindly hosted my visits, and were so generous with their time and information: Dr Rose Bigsby and colleagues at the Women and Infant’s Hospital in Providence, RI; Sue Ludwig and colleagues at University Hospital Cincinnati, OH; Brenda Thompson and colleagues at Cincinnati Children’s Hospital; Dr Bobbi Pineda and colleagues at Washington University Medical School/St Louis Children’s Hospital, St Louis, MO; and Sandra Carroll, Chrysty Sturdivant and colleagues at Baylor University Medical Centre, Dallas, TX. I particularly wish to thank Sue Ludwig, who in her role as President and Founder of the National Association of Neonatal Therapists (US) was instrumental in helping in the planning and co-ordination of my fellowship travels.

My gratitude also extends to Professor Kay Riley, Chief Nurse Barts Health NHS Trust, who supported my fellowship application and my study leave for the period of my travels. It is an unusual privilege to have the luxury of stepping out of one’s daily work role for an extended period and immersing oneself in the benefits of a travel fellowship. I am truly grateful to Barts Health NHS Trust in supporting this opportunity.

Finally, and as ever, I am grateful to have experienced and shared the stories of the babies and parents I encountered as I visited each of the neonatal intensive care centres. It is their bravery and courage which continues to inspire me as I undertake research to determine how we can best meet their needs at such a vulnerable time.
1. Introduction

The birth of a premature baby that requires admission to an NICU can represent a major crisis for parents which may influence how they participate in parenting activities and acquire their parental role. The NICU is acknowledged as a difficult place to establish meaningful and positive parent-infant interaction. In reflection of this crisis and in recognition of the importance of parent-infant attachment, there has been increasing advocacy for the adoption of family-centred care principles in the NICU environment. However there has been limited exploration with regards to what strategies are most effective in terms of supporting parental engagement in caregiving within the NICU setting.

In 2011 I completed a PhD which explored parenting occupations in the NICU, and how understanding the experiences of parents may help identify opportunities through which parents and infants can be supported. This study provided an in-depth understanding of the phenomenon of parenting occupations and adaptation in the NICU. It contributed to the knowledge base by articulating the experiences of parents as they traverse the journey of the NICU experience and adapt to a re-visioned role of being a parent. The novel use of an occupation-focused approach served to move the acknowledgement of parent involvement in the NICU beyond purely involvement in basic caregiving activities, and highlighted the importance of transforming parents’ involvement into meaningful opportunities within which they can nurture and care for their infants.

The provision of occupational therapy services into NICU settings in the UK is inconsistent. There are some well-established practitioners in some units; however some are employed as developmental specialists working within a Newborn Individualised Care and Assessment Programme (NIDCAP) model. In many other centres (including the tertiary level unit in the hospital in which I am based), OT provision is non-existent. Similarly, despite the evidence, the provision of developmental care is not fully integrated in all units.

Currently I am interested in the development of co-occupations between parents and infants in the NICU setting. I’m particularly interested in exploring how a specific focus on occupation-centred practice can assist in the delivery of both developmental and family-centred care. With an intention of embarking on a post-doctoral research programme (via an application to the National Institute of Health Research for a post-doctoral fellowship) I was keen to ensure that any future research I undertake is in tune with the current landscape of knowledge and research regarding NICU-based occupational therapy practice. Although I don’t currently work in as an occupational therapist in this setting, I want to maintain my clinical/research focus in the profession, and produce research outcomes that are meaningful to clinicians. By increasing my knowledge of the scope of neonatal OT provision in the United States I hoped to identify current best-practice examples and refine ideas for a post-doctoral research programme that will identify how best to support preterm babies, their parents and the clinicians who work with them.
2. Objectives

2.1 Objectives specific to fellowship period

1. To increase my understanding of the role of parent-occupations in NICU in the context of:
   a. Providing family-centred care
   b. Providing developmental care/NIDCAP
   c. OT domains of practice
2. To increase my understanding of OT best-practice in NICU, particularly in relation to supporting parent-infant co-occupations.
3. To increase my understanding of how medical care of infants can be balanced with supporting parents to transform their involvement in caregiving into opportunities with which they can nurture their infants in ways that are meaningful to them.
4. To share the best-practice examples gained with other OT’s working in NICU in the UK.
5. To identify the drivers for future research that will best support OT’s providing services in NICU, and therefore result in best outcomes for infants and their parents.
6. Contribute to the development of UK occupational therapy practice in neonatal settings by sharing the knowledge and best-practice service examples obtained as a result of the fellowship via a range of dissemination strategies.

2.2 Objectives arising from knowledge acquired during fellowship

7. Based on the learning achieved though the travel fellowship, prepare and submit a NIHR post-doctoral fellowship application to undertake research into the impact of supporting infant and parent co-occupations on the provision of family-centred care in neonatal intensive care units in the UK.
8. Undertake UK-based research that supports occupational therapy practice in neonatal care settings that result in improved outcomes for premature infants and their parents.
9. Build an international network of OT clinicians and researchers working in this area to foster ongoing learning and practice development.
# 3. Itinerary

<table>
<thead>
<tr>
<th>Dates/locations of travel</th>
<th>Organisations visited</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friday 5 April: London – Providence, Rhode Island, USA</td>
<td></td>
</tr>
<tr>
<td>Monday 8 April – Friday 12 April: Providence, RI, USA</td>
<td>Dr Rosemarie Bigsby – Ass professor of paediatrics, Brown University/Women’s and Infant’s Hospital (3 days)</td>
</tr>
<tr>
<td>Saturday 13 April: Providence, RI – Cincinnati, OH, USA</td>
<td></td>
</tr>
<tr>
<td>Monday 15 April – Friday 19 April: Cincinnati, OH, USA</td>
<td>Sue Ludwig – Occupational Therapist University Hospital, Cincinnati – Neonatal Intensive Care Unit (2 days) Cincinnati Children’s Hospital Neonatal Intensive Care Unit (3 days)</td>
</tr>
<tr>
<td>Saturday 20 April: Cincinnati, OH – St Louis, MO, USA</td>
<td></td>
</tr>
<tr>
<td>Monday 22 April – Fri 26 April: St Louis, MO, USA</td>
<td>Dr Bobbi Pineda – Ass professor of occupational therapy and paediatrics, Washington University School of Medicine, St Louis (5 days)</td>
</tr>
<tr>
<td>Saturday 27 April: St Louis, MO – Dallas, TX, USA</td>
<td></td>
</tr>
<tr>
<td>Monday 29 April – Tues 30 April: Dallas, TX, USA</td>
<td>Chrysty Sturdivant/Sandra Carroll – Occupational Therapists Baylor University Medical Centre, Dallas – Neonatal Intensive Care Unit (2 days)</td>
</tr>
<tr>
<td>Wednesday 1 May: Dallas, TX – Fort Worth, TX</td>
<td></td>
</tr>
<tr>
<td>Thursday 2 May – Sat 4 May: Fort Worth, TX</td>
<td>3rd annual conference – National Association of Neonatal Therapists, Fort Worth (3 days)</td>
</tr>
<tr>
<td>Sunday 5 May: Fort Worth, TX – London, UK</td>
<td></td>
</tr>
</tbody>
</table>
4. Summary of Organisational Visits

4.1 Women and Infant’s Hospital, Providence, Rhode Island

The first hospital to visit as part of my fellowship was the Women and Infant’s Hospital in Providence, RI.

My visit was hosted by Dr Rosemarie Bigsby, an occupational therapist who holds a co-joint appointment as associate professor of paediatrics at Brown University. I anticipated that this visit would be the perfect start to my fellowship experience as Dr Bigsby is one of the most-esteemed occupational therapists working in a neonatal intensive care setting in the international arena. She is the author and co-author of a significant number of peer-reviewed journal publications regarding NICU care and preterm infant outcome, and has also co-authored one of the landmark clinical textbooks used to guide occupational therapy practice in the NICU setting. Finally, Dr Bigsby is one of the authors of the competency standards for occupational therapists working in neonatal settings on behalf of the American Occupational Therapy Association.

Women & Infants Hospital of Rhode Island is one of the leading specialty hospitals for the care of women and newborns in the United States. It is also the major teaching affiliate of The Warren Alpert Medical School of Brown University for activities unique to women and newborns. Women
& Infants is the ninth largest stand-alone obstetrical service in the country with nearly 8,400 deliveries per year. In 2009, Women & Infants opened what was at the time the country’s largest, single-family room neonatal intensive care unit. The NICU, which covers two floors of the hospital, is designed to provide 80 single rooms for the care of preterm infants.

It was the single-room design of the NICU that was my first opportunity to be immersed in the different care practices evident between the US and UK neonatal settings. There has been discussion regarding the use of single-room NICU design in the literature for a number of years. The premise of a single-room design (as opposed to an open-bay area where between 4-10 babies may be accommodated in one large open space), is to promote both developmental and family-centred care. The philosophy of care driving single-room design is that it not only promotes family-centred care by having designated space for parents to spend with their infant, but by having an enclosed room in which light and noise exposure can be individually managed for each baby, preterm infants will not be unnecessarily exposed to potentially noxious environmental stimuli for which their brains are not developmentally ready to process. Although I had read of single-room design, this was my first opportunity to see a unit designed and functioning with this care philosophy. Many NICU’s (and hospitals in general) in the UK are designed around limited space footprints. Therefore, having the floor space allocated to redevelop existing NICU’s into incorporating single room design is virtually impossible.

Floor plan of Woman and Infant’s Hospital NICU – containing 40 single rooms. The footprint is repeated on a second floor of the hospital.
Dr Bigsby reported that the hospital took special efforts in preparing NICU staff for the transition from open-bay neonatal care to single room care over a period of several years as the designing and building work was completed. This included flying staff to visit centres in which an existing single room design was already in use, establishing a mock-room based on the planned design and footprint, so that nursing staff could both trial the equipment that would be used when the unit was commissioned, but also begin to consider how nursing practices may change. Although a care transition of such a degree will always be significant for staff and the way in which care is provided, Dr Bigsby reflected that the planning process undertaken ensured that the transition proceeded as smoothly as possible. At the time of my visit, the new unit had been opened for two years, and the unit staff were both proud of the unit itself, but particularly in terms of how the change in design and fostered parental participation.

Nursing work stations are positioned between each room, giving good visual access into both rooms.
The rooms themselves are spacious and each contain a couch that can be used as a sofa-bed for parents who are choosing to stay overnight with their infant. There is a curtain to enable privacy for the parent when sleeping, but also for mothers who are expressing milk or breast-feeding their older preterm infant.

The rooms are also of sufficient size to allow twins to be co-roomed as in the above photograph.
Parents are encouraged to personalise the space for their infant/s and themselves as many will spend weeks and months visiting the hospital whilst their infant is in the NICU.
The NICU at Women and Infant’s employs three occupational therapists to provide services to all infants in the unit and also on some of the post-natal wards (e.g. newborn infants with neonatal abstinence syndrome). Unlike other centres (and in the UK), the NICU does not include physiotherapists and speech and language therapists. In the US, both occupational therapists and speech and language therapists are trained to provide assessment and intervention for infant feeding. Therefore, the occupational therapists are competent to provide this service in the NICU at Women and Infant’s Hospital. Equally, NICU’s in the US employ respiratory therapists who manage both the respiratory support equipment and the lung status of the infant. Therefore, the traditional role of physiotherapists in UK NICU’s to provide chest physiotherapy is not required. Much of the other areas of input for preterm infants focuses on neurodevelopmental support – for which all three therapy professions are trained to provide. Women and Infant’s Hospital elected to employ one profession to provide this integrated role.

In order to access occupational therapy services, infants are specifically referred by the consultant neonatologist. Approximately 50% of referrals are to focus on support for the introduction of oral feeds, and the remaining 50% is for infants with developmental concerns. The occupational therapists provide formal assessment for all infants for whom they receive referral using the Neonatal Intensive Care Unit Network Neurobehavioural Scale (NNNS). This is a standardised assessment (to which Dr Bigsby contributed to the development) which assesses and scores an infant’s neurobehavioural performance in the areas of:

- Infant stress, abstinence and withdrawal
- Neurologic functioning
- Gestational age assessment
- Behavioural state

At Women and Infant’s I was also introduced to the use of infant massage by the occupational therapists as a core intervention technique in their support of infants at risk. I had not seen formalised infant massage provided to this population before, as often preterm infants can be intolerant of increased sensory input which can subsequently impact their physiological stability. Following assessment for appropriateness, the therapists would include massage as an intervention for supporting the development of the growing preterm infant. It was also a standard intervention for babies with neonatal abstinence syndrome who typically have significant difficulty with settling. This was an interesting introduction for me, as all of the units that I visited provided massage in some degree, though their approach and timing of intervention differed.
**Key Learning Points – Women and Infant’s Hospital, Providence**

- The decision to employ occupational therapists as the key neuodevelopmental therapy providers in the NICU was built on the evidence of previous research conducted in the unit.
- The use of a single room design can have a significant impact on parent engagement.
- The therapists have a large focus on feeding – in the UK context (to respect professional delineation of speech and language therapists) this could be translated as an opportunity to focus on co-occupation – pacing and reading infant cues.
- The importance of ‘asking permission’ to interact with infants (from the infant)
- Developmental positioning has been incorporated as the ethos of the unit – it does not require direct input from the occupational therapy team.
- Use of Dr Brown bottles to improve preterm infant pacing with feeding. The NICU approach is to allow parents to practice bottle feeding with a bottle that is commercially available (and which they can continue to use at home), rather than hospital-specific equipment.
- For parents wishing to introduce breast feeding, Dr Bigsby advocates to allow the baby to be brought the breast at 31-32 weeks. This is not meant to be a nutritive feed, but supports bonding, milk-production and gives the baby an introduction to breast-feeding. At this stage the actual feed (milk) is provided by gavage tube with non-nutritive sucking. Dr Bigsby’s experience is that if infant starts being exposed to breastfeeding this was then feeding progression is better (gradually titrating the amount of given by gavage as breastfeeding volume increases) than trying to increase volumes by bottles. It appears to result in less apnoeic and bradycardic events for the infant.

At the conclusion of my time at Women and Infant’s Hospital I had already begun to generate ideas for my potential post-doctoral research application. My observation of the occupational therapists prompted me to question whether my research could focus on exploring the benefits of bedside teaching/support for parents in relation to:

- Decreasing the incidence of parental depression
- Increasing rate of the infant’s progression to full oral feeding (a precursor generally required for hospital discharge
- Improving parent-infant attachment.

I also began to consider including an element of a scoping study for neonatal therapists employed in the UK in relation to how best to define parent-infant co-occupations in and NICU setting.
4.2 Cincinnati Children’s Hospital Medical Centre, Cincinnati, Ohio

Week two of my fellowship was spent in Cincinnati visiting two different NICU’s. The first of these days were spent at Cincinnati Children’s Hospital.

Cincinnati Children’s Hospital Medical Centre is a world recognised centre of excellence for paediatric care. It is consistently ranked in the top ten paediatric hospitals in the United States and accepts complex international referrals in the specialties of airway reconstruction, cancer and blood diseases, cardiology, colorectal surgery, gastroenterology and nutrition, neurology and respiratory medicine.

It comprises of 587 inpatient beds (including NICU and psychiatry) and provides almost 1 million outpatient appointments each year.

The NICU at Cincinnati Children’s is a 50-bed Level IV unit (a level IV unit provides the highest level of medical care to premature and critically ill newborns). As a children’s hospital, infants are born at maternity centres and then transported to the hospital for intensive care services. It comprises a mix of 6-bed bays (of which there are six) and 14 single rooms. The unit also provides the Newborn Individualised Developmental Care and Assessment Programme (NIDCAP). The NIDCAP is provided by a specially trained neonatal nurse and is in addition to the other therapy services provided in the unit.
Unlike the NICU at Women and Infant’s, the unit at Cincinnati Children’s provides all three therapy disciplines (occupational therapy, physiotherapy and speech and language therapy). Each profession has a discrete area of expertise, with some areas of overlap.

- Physiotherapy – assessment and intervention for babies who have reached post-term corrected age and have known musculoskeletal or neurodevelopmental concerns
- Speech and language therapy – feeding
- Occupational therapy – feeding, developmental assessment, neurobehavioural state assessment and support, parent education.

The therapy manager identified that this is a unique unit in its provision of all three therapy services. Historically, the unit employed occupational therapists and has added the other professions over time. The inclusion of all three therapies is successful as each therapist is respectful of professional boundaries and collaborate on areas of specialism that cross-over.

The unit employs four full-time equivalent occupational therapists. The cohort of infants admitted to the NICU consists predominantly of babies requiring surgical intervention (e.g. congenital diaphragmatic hernia, neurosurgery etc) and preterm infants who require a greater degree of intensive care and are transferred from smaller hospitals.

Observing the practice of the occupational therapists in this unit provided an interesting contrast. They appeared to have retained some of the more specific elements of paediatric occupational therapy service provision that is less evident in other units. This was particularly evident in their use of soft-splinting. When indicated they will use neoprene soft splinting for infant’s hands to promote thumb abduction. Similarly they have devised and implemented the use of an abdominal wrap for infants with congenital diaphragmatic hernia to correct abdominal displacement and limit the growing infant’s postural adaptation to the hernia prior to and following surgery. It is perhaps because the unit is located within a children’s hospital with a large paediatric OT department that has assisted in keeping this focus on more traditional elements of OT service provision, in addition to more generic neonatal therapy interventions.

The occupational therapists do not use a standardised tool in their assessment of preterm infant neurodevelopment (e.g. NNNS), but do complete a structured OT evaluation of each infant which includes some similar elements – neurological assessment, behavioural state and feeding readiness.

The occupational therapists are also key in supporting the provision of ‘positive touch’ in the unit. This is an intervention that encompassed some elements of infant massage with containment holding. The therapists provide this intervention to critically ill infants. The premise is that the provision of positive touch assists in balancing the exposure to noxious stimuli which is an unavoidable part of neonatal intensive care. The therapists also advocated using positive touch as a teaching tool for parents.
All of the therapists (along with the NIDCAP nurse) also take a role in educating nursing staff with regards to developmental care principles. The therapists report that the need for this education is cyclical as a result of changes in staffing in the unit, and does contribute to how well integrated developmental care principles are as part of general nursing care provision for preterm infants.

In contrast to Women and Infant’s Hospital, the 14 single rooms at Cincinnati Children’s all ran off a single corridor. There was a single nursing station located centrally in the corridor, and the rooms were of a more traditional single room hospital design. They each contained an ensuite bathroom but were of smaller floor space and had a wooden door (with a viewing window). There was space for a comfortable chair beside each cot, but limited space for a parent to sleep. To improve the visual monitoring of the infants (a consistent concern with single room design and the care of preterm infants), the hospital had installed a video system in each room. A camera was located above each cot with images relayed to a central screen in the nurse’s station.

Key Learning Points – Cincinnati Children’s Hospital Medical Centre

- Although historically employing only occupational therapists, the NICU now provides OT, SLT and PT services.
- This works successfully due to respect for professional boundaries and collaboration.
- The use of positive touch with critically ill infants is a key opportunity to provide parent education/support and provide a means of articulating the parental role with these very fragile infants.
- There is a role for soft splinting for musculoskeletal or emerging neurodevelopmental concerns in the preterm infant population.

At the conclusion of my three days at Cincinnati Children’s Hospital my thoughts about potential research focused on:

- ‘Pacing’ for parent education – when is parent ready for different types of information, how much, and in what order of introduction
- How do parents come to know their baby?
- Acquisition of enhanced neonatal OT skills – how is refined clinical reasoning developed.
4.3 University of Cincinnati Medical Centre, UC Health, Cincinnati, Ohio

The remaining two days of my week in Cincinnati were spent at University of Cincinnati Medical Centre, Cincinnati.

The hospital is a 665 bed teaching hospital offering tertiary level care with particular emphasis on cardiovascular disease, neurology, burns, cancer care and neonatology.
The NICU at University Hospital is a 50-bed Level III Nursery. It is comprised of four large open bays and two small shared bays. The unit was last redeveloped in the 1980’s. It has double height ceilings which provides a feeling of spaciousness in the bays, but which has implications for noise transference in the unit.
Being of open-bay design there is a good amount of distance between each cot space. Comfortable visiting chairs were not available at each cot – during the time of my visit the bed occupancy rate were low, and chairs were all available in each bay and could be pulled to the cot of each baby as required. The open design also has implications for privacy for parents, but wheeled screens were available to be placed around each cot when privacy was required.

The therapy provision to the NICU is two full time equivalent therapists (one occupational therapist and two job-share physiotherapists). There is additional occupational therapy provision called in if bed occupancy is high and greater therapy input is required. The therapy team have a shared approach with both professions providing services to infants within a transdisciplinary model. Specific referrals are made to speech and language therapy if a swallow study (imaging) is required.

The therapists provide services within a developmental care model. Oral feeds are generally commenced at around 33 weeks, but this is based on the individual assessment of the infant on a feeding readiness scale (developed by one of the therapists who work in the unit – S Ludwig). Infant massage is also readily employed as a parent education and positive touch intervention. Assessment and intervention of infants is only practiced around their feeding/care times to prevent unnecessary disruption to the infant’s rest. The NICU therapists also provide a range of accessible parent resources via the hospital website.

The therapists who work within the NICU generally come from working within an area of adult speciality. They are provided with a supportive lengthy training programme to build their skills and knowledge for working with a neonatal population. This consists of both the provision of lectures and bedside teaching.

**Key Learning Points – University of Cincinnati Medical Centre**

- Productive transdisciplinary relationship between OT and PT professionals.
- The necessity of a formalised teaching and induction programme for therapists.
- The use of positive touch as a means of articulating the parental role is supported – with the therapists having undertaken NICU specific infant massage training (Neonatal Touch and Massage Certification, NTMC).

At the conclusion of my two days at University Hospital my thoughts about potential research focused on:

- Infant massage is an opportunity for parents to play a key role in supporting their infant’s well-being. What are the guidelines and risk factors for introducing massage techniques with such a vulnerable population?
From Cincinnati I travelled to St Louis to spend a week working with Dr Bobbi Pineda at the Washington University School of Medicine. Dr Pineda works as a member of the Washington University Neurodevelopmental Research Team which is lead by Dr Terri Inder (a neonatologist). The University Medical School is located adjacent to St Louis Children’s Hospital, and conducts it’s research with infants who are being cared for within the NICU at St Louis Children’s or the special care baby unit (SCBU) at Jewish Barnes Hospital.

The WUNDER (Washington University Neurodevelopment Research) laboratory is a multidisciplinary team working to better understand the effects of the environment, medical conditions and interventions on brain structure and functional outcome of the developing infant. Most of the current work involves premature infants born prior to 30 weeks gestation, but work is also being conducted on term-born infants with brain injury, as well as full-term, healthy newborns. Routine neurobehavioural examinations are conducted in the NICU at St. Louis Children’s Hospital, Barnes Special Care Nursery, and on the labour and delivery floor of Barnes-Jewish Hospital. EEG and MRI measures complement the assessments of behaviour during infancy. Infants receive developmental follow-up at 2 and 4 years of age. In addition, maternal, social, and medical factors are collected. The large collection of variables allows for multiple projects within the ongoing cohorts. In addition, projects investigating specific interventions can be conducted within the overarching study.
During this week in the WUNDER lab I was able to draw on the work of Dr Pineda and Dr Cynthia Rogers (a psychiatrist who works with the team) to identify relevant outcome measures that might be useful to consider including in my own research design. These included infant and child neurodevelopmental assessments (Preemie Neuro, Network Neonatal Neurobehavioural Scale and the Bayley Scales of Infant Development); child social/emotional scales (Infant and Toddler Social and Emotional Adjustment Scale, Modified Checklist for Autism in Toddlers); and parental adjustment (Parental Stressor Scale (NICU form), Parenting Stress Index).

What most impressed upon me from spending the week observing the work of the research team was the importance of positioning my research within an existing neonatal research programme. This will not only ensure that my own research programme aligns with current research in the UK context, but will also provide professional development and support as I increase my skills as a researcher.

During the week at St Louis Children’s I also spent 2 sessions shadowing an occupational therapist in the neonatal intensive care unit. The hospital has a 75-bed NICU. Thirty-nine beds are located in 4 open bays, and the remaining 36 beds are of single room design. Redevelopment is planned that will transform the unit fully into a single-room design. Infants are cared for on a 1 nurse to 2 baby ratio.
The NICU has a multidisciplinary therapy team incorporating occupational therapists, physiotherapists and speech and language therapists. There are five occupational therapy positions in the unit (2 full-time and 3 part-time; approx 3.5-4 FTE).

The assessment and management of infant feeding is shared between occupational therapy and speech and language therapy. The NICU uses a cue-based feeding protocol, and oral feeds are generally commenced at around 33 weeks. The occupational therapists begin providing developmental assessment and support from 30 weeks gestation. Initial evaluation incorporates range of motion, reflexes and positioning. Intervention is then individually determined and can include ROM/stretching (particularly neck and shoulder girdle), infant massage, and a range of positioning experiences (e.g. prone). A further evaluation is conducted at term age which includes reflexes, tone, ROM and upper limb function.

I also met with Renee Fishering, a neonatal nurse who chairs the ‘Partners in Caring Committee’. This is a programme that has been running for approximately 8 years. It is used to support parents whose infants are approaching discharge or post-discharge. The committee was initially instigated by an infant’s grandparent who wanted to learn how to deliver all aspects of their grandchild’s care. The committee meets every second month and is a key opportunity to engage with parents and ask them:

- What was good about their NICU experience?
- How could the NICU make things better?
- What could the NICU do differently?
Some of the outcomes of the Partners in Caring Committee over the eight years has been the inclusion of 24-hour visiting; parents ability to stay with their infant during a serious deterioration in their health (a health care professional is assigned a specific role to stand beside the parents and explain the interventions that are occurring); no exclusion of parents during ward rounds; and involving parents in the design of communication mechanisms to feedback updates on the infant’s status if the parent was unable to present during the ward round. The committee also organises the annual NICU reunion in May when all ex-NICU graduates are invited to return to the unit.

**Key Learning Points – WUNDER Laboratory and St Louis Children’s Hospital**

- A sustained example of how public/parent participation can transform care experiences.
- The use of a feeding readiness scale as a parent teaching/participation tool.
- Single room design can also have less positive effects on infant’s developmental status – care provision needs to be designed to ensure that infants do not spend long periods in isolation.

At the conclusion of my two days at University Hospital my thoughts about potential research focused on:

- Needing to align my own research programme with an existing neonatal research centre in the UK.
- Starting to identify specific methodology and selection of outcome measures to include in my research design.
4.5 Baylor University Medical Centre, Dallas, Texas

In the final week of my fellowship I travelled to Dallas where I spent the first two days at the NICU at Baylor University Medical Centre in Dallas.

The NICU at Baylor consists of 83 beds – all of which are in open bay designs. The footprint of the unit is quite small, leaving a cot layout that it is quite cluttered. The available space beside each cot was more reminiscent of the types of care environments more typically seen in the UK.

However, despite these environmental challenges, there is a strongly developed neonatal therapy team which is committed to both the quality of care provision to infants and their families, but also to ensuring that therapists working in the units are highly trained and competent. The neonatal therapy team is led by Sandra Carroll (OT) and employs occupational therapists, physiotherapists and speech and language therapists. However, all professions are trained to work in an interdisciplinary manner and all provide core neonatal therapy skills. Sandra, along with Chrysty Sturdivant, are highly experienced practitioners and have developed both the service at Baylor along with both teaching and clinical resources.

When a new therapist commences work in the unit they undertake a therapy internship. This constitutes the provision of four-hours of lectures per week, and one day per week of clinical hands-on training. After the initial training period, 1:1 mentoring is provided for a further 6-week period. Key concepts introduced in the training include Als’ synactive theory, an integrative versus a rehabilitative model, and intentional caring.
Sandra and Chrysty have also developed the FENNS framework and it is used to underpin therapy assessment and intervention in the NICU (FENNS – family, environment, neurobehavioural, neuromotor and sensory). Each interaction with an infant and their family is guided by this organising framework, ensuring that a truly comprehensive and sensitive engagement occurs.

Linking with my own research interests, it was interesting to see how comprehensive the assessment and prompting for family intervention was conducted. Elements included:

- Guided participating in care
- Anticipatory guidance provided
- Support parent-infant nurturing
- Suggested non-stress interactions
- Kangaroo care
- Identified coping strategies
- Provided and/or referred for psychosocial support
- Recommendation for parent classes.

Having seen the benefits of FENNS as an organising framework in action, I am interested to see how this can be incorporated into my own future research plans.

**Key Learning Points – Baylor University Medical Centre**

- Full transition to a ‘neonatal therapist’ role, rather than professional delineations.
- The inclusion of a formalised teaching and induction programme for therapists, with ongoing mentoring and support.
- FENNS organising framework.

At the conclusion of my two days at University Hospital my thoughts about potential research focused on:

- Incorporation of FENNS into my own future work
- Ongoing research collaboration between UK and US by building and maintaining research team links with Baylor.
4.6 National Association of Neonatal Therapists Annual Conference, Fort Worth, Texas

For the final three days of my fellowship I travelled from Dallas to Fort Worth for the annual conference of the National Association of Neonatal Therapists (NANT). NANT was founded by Sue Ludwig, who continues as president of the association. It brings together occupational therapists, physiotherapists and speech and language therapists working in neonatal intensive care into a virtual community of practice. The development of a virtual community has served to provide links between therapists who may work in sole positions, and provides multiple ways for neonatal therapists to connect, learn, mentor and inspire while advancing this focused field of therapy on a national level. This includes the provision of education, networking resources, and products unique to the neonatal population to empower neonatal therapists in the advancement of their knowledge, skills and practice.

For practitioners working in such a specialised area of practice it was incredibly refreshing to spend three days with several hundred therapists working across the US (and a further two from the UK). There was a significant breadth of keynote presentations ranging from epigenetics to parent perspectives of neonatal intensive care.

For the first time in my entire clinical career, I was able to feel truly connected to a group of fellow therapists who have also chosen to work in this unique area of practice. The energy and drive that carried through the conference is a testament to NANT, and the recognition and vision to develop such a community of practice.

During the conference I was privileged to meet two further therapists working in neonatal care settings in London. We spoke during the conference about the lack of such strong networking and connections in the UK, with a commitment to work to developing a small-scale version of NANT for the UK context over the coming year.

5. Post-Fellowship Activities

Since the completion of my fellowship and my return to London, I have undertaken a number of dissemination and development activities:

- Article published in OT News (the national magazine of the College of Occupational Therapists). The focus of the article was to share the learning of my fellowship experience with other occupational therapists working in this area, as well as highlight the Winston Churchill Memorial Trust Fellowships. (Gibbs D 2013. Supporting parents and infants in neonatal intensive care, 7, 36-37).
- I have continued to link with the other London-based occupational therapist I met at the NANT conference. We have met several times, the culmination of which has been the establishment of a London Neonatal OT Group (which encompasses approximately ten
therapists). The first meeting of the group was held on 18 July 2013. The planned actions of the group are to extend the focus to a national base and seek recognition as a subsection special interest group within the College of Occupational Therapists; to develop a web-based presence; and to work towards planning a conference for Autumn 2014.

- In the development of my own post-doctoral research application I have also recently met with the lead neonatologists from Barts Health NHS Trust and University College London for preliminary discussions. As I refine my research proposal I will continue to work with these centres to develop the required partnerships for my application.

6. Conclusions

Becoming a Churchill Fellow has been such a privilege. Completing my fellowship has provided me with a unique opportunity to undertake a period of focused travel to see best practice first hand and consider how this knowledge can be used to support practice development for the benefit of the local and national UK communities.

At this early point of reflection I feel that the fellowship has provided key developments in relation to refining my research proposal ideas for a post-doctoral research application, forged connections with key contacts in the United States for ongoing dialogue and collaboration, and the development of the London/UK neonatal occupational therapists group. Overtime, I hope that these developments continue to grow so that through my research and the clinical practice of my UK based colleagues we can build services that focus on supporting both the infant and their family during the experience of neonatal intensive care.