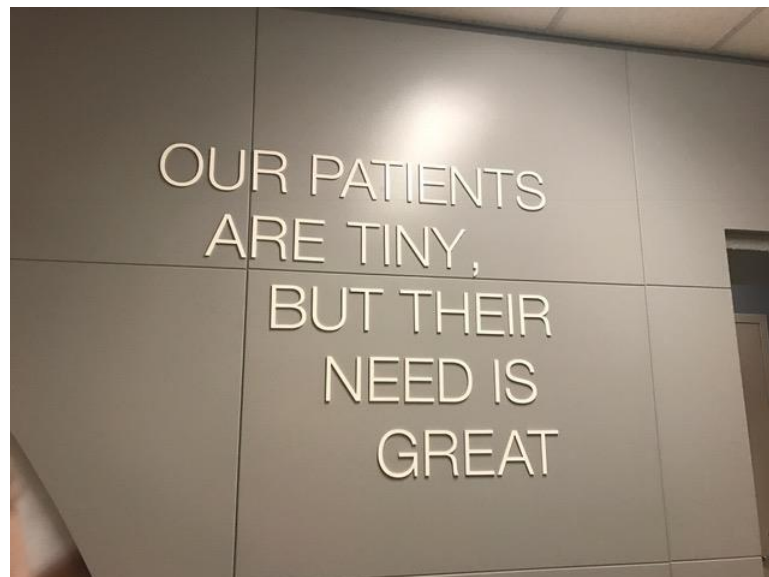




Exploring best practice for medically fragile babies
to promote optimal outcome.



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THE DULVERTON TRUST

Executive Summary

What was researched?

Receiving the Winston Churchill Travel Fellowship afforded me the opportunity to travel to Canada, the USA and Ireland to explore best practices for medically fragile babies, defined as those born sick and/or early. I had over 50 meetings, attended centres, clinics and hospital wards and was also funded to attend an International Conference on the Neonatal Brain. The Fellowship brought together information from experts in the areas, academic, clinical and indeed judicial and as well as highlighting what we are doing well in the UK has also enabled me to bring back knowledge to enhance and develop services and ultimately outcomes for children born sick and/or early. In feeding back on my findings I want to highlight that any misinterpretations or information errors are entirely mine as I piece together all the information gathered and interpret my handwriting.

Main findings

Neurodevelopmental follow-up clinics are seen as standard in the centres I visited. They were usually multidisciplinary and saw children born identified as vulnerable at key developmental points until they were entering school arena.

Family care including the model of family integrated care is seen as invaluable.

We need to have more conversations about infant pain. In my experience its not discussed a lot. There are some differences of opinion as to the best way to manage infant pain in the centres visited but there was unanimous agreement that pain needed to be managed and that contact with the main caregiver was the best way to do this.

The infant brain is amazing and the knowledge we have is informing practice. There are key implications of the immaturity of premature brain and the brain of babies born with congenital heart disease in particular which has long term implications in many areas of development. This information needs a strategy for sharing. Knowledge translation and implementation science have a role to play

Best outcome for babies will involve a full system transdisciplinary approach. A baby is one unit made up of many systems. The systems need to work together not see the baby move from one 'specialist' to the other. Many theories are right but can't operate in isolation. A model needs to be developed to encompass all the key features.

Recommendations

- Strong need for identification and follow-up of children born medically fragile to facilitate assessment and early intervention as necessary. I recommend dedicated neurodevelopmental follow-up clinics using a systemic approach. This could be facilitated by a scoping exercise of whats available now, specific points identified for screening and a way to flag these children in the universal healthcare record.
- Development of a specific suite of tools (in various formats) to enable and educate both parents and professionals in short and long-term.
- Further research in the area and ensure implementation science/knowledge transfer
- Model encompassing all elements to encourage cross-professional working

- Develop strategy in terms of cross discipline, cross organisation connectedness for information sharing and research development.
- Family Involvement and Support as standard and normalised.
- Information sharing strategy

Preliminaries

Contents

Acknowledgements

So many people have played a part in the inception and completion of this fellowship and it would be impossible to thank all of them but I wish to acknowledge the following who all contributed to this report in many different ways. In keeping with the theme of travel, they are truly international.

UK

- Winston Churchill Memorial Trust for providing the travel fellowship.
- Wave Trust and Dulverton Trust
- Robin Balbernie for unknowingly piquing my interest when I noted he was a Churchill Fellow on a conference bio and wondering what on earth that was.
- The Western Health and Social Care Trust for facilitating my time away and for the ongoing support.
- Alison Mc Nulty, CEO of TinyLife, a key collaborator who offered wonderful contacts and ongoing support.
- The infants, children and families who I have had the privilege of working with and through their questions who sparked my interest in these areas.
- My family who shared in my adventure and without whom I am nothing.

Toronto

- Prof Linda Johnston who coordinated my Toronto leg of my journey and made key virtual and actual introductions.
- Mary Gordon, Founder and President of Roots of Empathy
- Dr Bonnie Stevens University of Toronto & The Hospital for Sick Children
- Dr Mary McAllister, Associate Chief of Nursing, The Hospital for Sick Children
- Dr Marilyn Ballanytne, Chief Nurse Executive, Hollandbloorview Kids Rehabilitation Hospital
- Dr Cindy-Lee Dennis, University of Toronto & Li Ka Shing Knowledge Institute – St Michaels Hospital
- Prof Stephen Lye, Associate Director at the Lunenfeld-Tanenbaum Research Institute at Mount Sinai Hospital Mount Sinai Hospital & University of Toronto
- Dr Renee Sananes, Dr Trish Williams & Dr Clare Watt, The Hospital for Sick Children
- Luisa King, Specialist Nurse, Sunnybrook Hospital for Sick Children
- Kasija Putlik, Specialist Social Worker, Mount Sinai Hospital
- Kate Robson, Executive Director of Canadian Premature Babies Foundation and NICU Family Support Specialist at Sunnybrook Hospital for Sick Children
- Chaya Kulkurnia, Director of Infant Mental Health Promotion, The Hospital for Sick Children

Vancouver

- Prof Ruth Grunau, Clinical Psychologist, BC Children's Hospital and key contact for the Vancouver leg and link to all others in this leg.
- Members of the Biobehavioural Research Lab including Shanlea Gordon. Mark Bichin & Kayleigh Campbell
- Julie Petrie, Clinical Psychologist

- Kim Schonert-Reichl is the Director of the Human Early Partnership (HELP) and a professor at UBC Faculty of Education

San Francisco

- Prof Linda Franck with whom I made early contact and who not only coordinated the San Francisco leg of the trip but also showed me wonderful hospitality alongside her husband Bill Sherlock. Many memories were made there.
- Dr Elizabeth Roger, Consultant Neonatologist, UCSF Benioff Children's Hospital.
- Dr Bridget Johnson, Clinical Psychologist, UCSF Benioff Children's Hospital
- Dr Susan Regas, Distinguished Professor & Chair, Family/child and Couple Clinical Psychology Emphasis (FACE), California School of Professional Psychology
- Dr Eren Berkenkotter, Clinical Psychologist and colleagues at Fussy Baby Network, Oakland
- Dr Kelly Ransom, Clinical Psychologist, Alta Bates NICU and We Care Services.
- Bette Flushman, Infant Development Specialist, UCSF Oakland Children's Hospital
- Dr Danielle Roubinov, Clinical Psychologist & Assistant Professor, Dept of Psychiatry, UCSF
- Dr Martha Hernandez, Programme co-ordinator, Ronald McDonald House, Stanford
- Dr Laura Simons, Clinical Psychologist, Associate Professor, Stanford Medical School

New Mexico

- Debora Gerads, Attorney at Law
- Judge Angie Schneider
- Judge Shannon Murdock
- Gary Mitchell, Attorney at Law
- Soledad Martinez, Infant/Early Childhood Program Director, Children Youth and Family Department

Cork

- Catherine Maguire, Clinical Psychologist and IMH Specialist, Young Knocknaheeny
- Irish Centre for Fetal and Neonatal Translational Research (INFANT), Cork especially Leanna Fogarty, Clinical Psychologist and Deirdre Twoomey

Abbreviations and Glossary

CHD – Congenital Heart Disease

NICU – Neonatal Intensive Care Unit

UCSF – University of California San Francisco

QUB – Queen’s University Belfast

CHIP – Congenital Heart Disease Intervention Programme

EI – Early Intervention

WCMT – Winston Churchill Memorial Trust

DClinPsych – Doctorate in Clinical Psychology

IAIM – International Association of Infant Massage

CIMI – Certified Infant Massage Instructor

PHA – Public Health Agency

PKU – Phenylketonuria

IMH – Infant Mental Health

AIMH (NI) – Association of Infant Mental Health (Northern Ireland)

DCP – Division of Clinical Psychology

BPS – British Psychological Society

ACES – Adverse Childhood Experiences

EITP – Early Intervention Transformation Programme

FNP – Family Nurse Partnership

EFCNI – European Foundation for the Care of Newborn Infants

NI – Northern Ireland

CNOC – Cardiac Neurodevelopmental Outcome Collaborative

GA – Gestational Age

FNI – Family Nurture Intervention

ETTN – Early Trauma Treatment Network

About me

I am a Consultant Clinical Psychologist working in the Western Trust in Northern Ireland where I lead the Paediatric Clinical Psychology service for the Trust. I have worked as a Clinical Psychologist for almost 18 years, 12 of which were spent in the Royal Belfast Hospital for Sick Children before moving back to the land from whence I came, and taking up post in the Western Trust.

I am passionate about promoting health and wellbeing in the early years both through intervening early and encouraging professionals to work together with the child in mind. My roles include positions on various trust, regional and national committees including Division of Clinical Psychology- NI (DCPNI), Association of Infant Mental Health (NI) (AIMH-NI), Paediatric Psychology Network (UK) (PPN), RQIA Perinatal Mental Health Recommendations Implementation Group, Family Nurse Partnership (FNP) and Early Intervention Transformation Programme (EITP). I am a certified infant massage instructor via The International Association of Infant Massage (IAIM). I am currently completing accreditation in the use of Video Interaction Guidance (VIG) a clinical tool to help improve relationships. My undergraduate, PhD and DClinPsych research were all related to pregnancy and the earliest years. Since qualifying as a Clinical Psychologist in 2000, I have had ongoing clinical and research interest in various areas, including, paediatric cardiology, diabetes, acquired brain injury, neurodevelopmental conditions, child development and especially infant mental health. I love research, talking, laughing and travelling and was delighted to be able to combine all in my Churchill Fellowship.



"To move, to breathe, to fly, to float, to gain all while you give, to roam the roads of lands remote, to travel is to live"

Hans Christian Anderson, The Fairy Tale of My Life: An Autobiography
(wall art in San Francisco airport on way to New Mexico)

Introduction to the Project

Babies have always fascinated me. From the first time I learnt about reproductive science from Mrs Mc Lucas in GCSE Biology through my undergraduate and postgraduate degrees, babies and the environment that influenced them and their outcome continued to hold me enraptured. I looked at the fetal environment impacted upon by maternal diabetes for my undergraduate and PhD research. I followed up these same babies at 4 years old for my DClinPsych research and my first post had a huge research element looking at babies born with congenital heart defects. We carried out an intervention that could be used to improve outcome whilst looking at all the elements within their system which could be influential (family, neurodevelopmental, surgical etc - see Doherty et al ,,, McCusker et al). The core theme was one where babies who had experienced adversity due to early life medical circumstances. Clinically I noticed an increase in referrals to my Paediatric Psychology outpatient clinic for children in middle childhood with an array of issues which needed understood including feeding issues, sleep issues, school related difficulties and neurodevelopmental issues to name but a few.

Developmental history often revealed that they had had early life hospitalisation for various reasons and that these earliest associated life experiences were influencing their current presentation. For many of these children various diagnoses were aired including ASD, ADHD and Attachment Difficulties but to have labelled them with anyone based simply on presentation would have been to do them a disservice and besides, very few fitted any one diagnostic criteria so instead were often sent from service to service in search of an answer instead of taking an individual view of all the factors impacting on the child from the beginning.

I felt we could do a better job from the start. As above I had been involved in an innovative research project for children born with a congenital heart defect (Doherty & McCusker 2016; McCusker et al 2013; 2012) and knew that there was neurodevelopmental impact for babies born with CHD (refs) and that there were similar issues for children born early (refs) but although there was a service for children with condition like Phenylketonuria (PKU) with identification and follow-up from birth no similar service existed for babies born sick and/or early due to other causes. I felt we were doing these children a disservice.

At the same time there had been significant developments in thinking about Infant Mental Health (IMH) in Northern Ireland with the ethos of the Western Trust being one reason why I moved from Belfast to work there (Western Trust IMH doc). The last ten to fifteen years has also seen the development of trust IMH groups and regional initiatives spear headed by the Public Health Agency (PHA). I was lucky enough to have a role in developing IMH services in children seen within Paediatric Psychology written into my job description in a previous job. More recently we have seen Adverse Childhood Experiences (ACEs) garner a lot of attention in the academic, research and clinical worlds, as a movement to become ACE aware has grown across the globe. Scotland has been at the forefront of this in the UK and in Northern Ireland the Western Trust has been a major driver. While I welcome this movement and an increased awareness and understanding of the reasons children and young people display the behaviours that they do, I constantly issue reminders that there are other ACEs than the ten listed in the original questionnaires, and that we need to understand what has been

happening for any children who have experienced hospitalisation in their earliest years, when their environment has been impacted upon by health related issues.

Aims, objectives and purpose of project

The overall aim was, as per the title of my Fellowship report, to optimize outcomes for medically fragile babies by exploring best practice in centres of excellence. The purpose was to bring the knowledge to the UK to enhance outcomes for our babies via the multiple systems that surround the baby.

The objectives that I submitted to WCMT before setting out on my Fellowship are listed below and are what I referred to numerous times when I was away. I might change born early/born sick to medically fragile which I have found with writing is a more encompassing term but in some ways the report is my academic story document and I wanted to be true to the story.

1. Gain knowledge in the area of infants & young children born early/ born sick & impact on them & the systems around them.
2. Gain specific skills especially in terms of intervention to improve quality of life for this group of young children & their families either directly or indirectly through staff education/consultation.
3. Make links with like-minded professionals regarding clinical & research areas. I want to form foundations for ongoing collaborations. I really think sharing of knowledge/skills essential to progression for these young children and their families.
4. Bring back new knowledge & skills & disseminate in NI / UK.
5. Develop specific clinical, training & research programmes in NI / UK encouraging collaborations & staff working together using their skills, stepping outside silos & putting the child in the centre.
6. Enable staff
7. Ultimately improving outcome for children & families
8. Personal development
9. Enhanced family experience especially sense of adventure

Approach/methods used

Most of the information for this report was gathered via meetings and observations at various centres, clinics and within NICUs. I was also alerted to numerous articles and online resources during my conversations which I followed up afterwards. Some conversations happened in an ongoing manner via email and I even had a virtual meeting via zoom. There should be an unfolding story, one of many parts and overlapping themes.

I will highlight some of the key points and meetings from each location but the majority of my report will be used to pull out these main themes and link them to recommendations.

Findings

I spent quite some time considering how best to present my findings but on rereading my notes I realised that if I collated and summarised I was not going to do justice to the wealth of information obtained. I am therefore documenting key findings, information, links and resources from each place visited before pulling together at the end under general findings.



Toronto

I loved Toronto, not just because as a city it made sense to me but because the people I met and things they said made a lot of sense to me.

Professor Linda Johnson, Dean of Nursing and a previous NICU nurse was my key contact in Toronto, an Australia with strong links to QUB, I found her down to earth with a great sense of humour yet full of knowledge, opinion and direction. She summarised what I have found in my work quite a lot in a quote from a neonatologist colleague, 'babies experience size discrimination'. She suggested that I link in with the chair of the European Foundation for the Care of Newborn Infants (EFCNI) as she felt that they would find my work interesting and that I could learn from them too. Website – www.efcni.org.



Someone who wasn't ever going to discriminate against babies is **Mary Gordon**. We met for lunch along with Chaya Kulkurni. Mary is the founder and President of Roots of Empathy and meeting her not only made me feel bathed in empathy but also brought more links between NI and Canada and highlighted the smallness of the world.



The meeting had been organised due to links I have with the PHA and I brought something for Mary for them and was given documents to return to them. Truly international communication. We spoke about the Roots of Empathy programme and about promoting understanding of all babies including those who were born with chronic illness. The strength of the programme is in the children being taught by the babies, by them respecting what the babies can do and hopefully the next generation, including my daughter who has a roots of empathy teacher in her school, will grow up understanding the importance of the early years and will steer away from any sizeism at all. Mary's kindness extended to giving me a copy of her book which I can recommend, 'Roots of Empathy, Changing the World Child by Child ' It was a short meeting but with longterm impact.

Chaya Kulkurni is the Director of IMHP (Infant Mental Health Promotion) at The Hospital for Sick Children. This is a community based coalition of individuals and professional agencies dedicated to promoting optimal mental health outcomes for infants in the first few years of life. Chaya spoke at length about their work in Canada which includes research, education and developmental support plans for at risk babies. We had a conversation about the court system and a lack of understanding about the impact of early trauma, which links to my last visit with judges in New Mexico. I was going to spend a good bit of time at The Hospital for Sick Children (or Sick Kids as more commonly known) so it was lovely to see the building from Chaya's office.



Dr Cindy-Lee Dennis is a researcher and holds two chairs, in Perinatal Mental Health in association with University of Toronto and Women's Health at Li Ka Shing Knowledge Institute – St Michaels Hospital. A ball of energy, meeting with Dr Dennis required full attention. It was wonderful to hear someone speak with such passion about research and about women's health. Her maxim is that 'Healthy Babies start with Healthy Moms'. Low breastfeeding rates is an issue in NI and we had a long and useful discussion about how things could improve. Although may not seem directly relevant to babies born medically fragile I see so many important links here because we want to ensure and promote the things that give them the best start in life not continue to challenge them. She highlighted the difference in breastfeeding rates in her areas and the impact of multiprong interventions, use of social media, bus stop signs and support right from initiation through to 6months plus. A key indicator is breastfeeding self efficacy and we discussed ways to improve this to promote best outcomes for baby.



Epigenetics and the intergenerational impact of health practices were discussed at length in terms of the developmental origins of health and disease, both with Dr Dennis and then with Dr Stephen Lye. **Dr Stephen Lye** is senior investigator and associate director at the Lunenfeld-Tanenbaum Research Institute at Mount Sinai Hospital. He is heavily involved in uncovering the unknown elements of preterm birth and a recognised leader in women and infant health. As many of us do, he thinks that too much money has gone into treatment and not enough into prevention and his academic and research work is addressing what preventive work can be done to optimise best outcome. We also had a discussion

about breastfeeding as modulating early growth trajectories and its role in modifying the microbiome. It was wonderful to see how academic research could move into clinical practice and ideas of same. One of my favourite parts of the discussion was when we talked about the brain, the complexity of the same and the impact of stress and neglect on synapse formation but that we needed to move away from unidisciplinary intervention and recognise the biology of development from preconception to school. This latter point really reflects how I think.

Dr Bonnie Stevens is a nurse by background and a fascinating academic who provided me with lots of great academic information and useful research tools. We discussed the impact of pain in infants, the fact that there is no gold standard for assessment of pain in infants, the main thing is that it's essential that we treat pain and that we know the best method to do so. As part of this, Bonnie has moved from direct pain research to a focus on implementation science. She highlighted how evidence-based practice never showed us how to implement but simply said we had to do it, whereas implementation science looks at the process of behaviour change of implementing evidence into practice. We discussed the main factor that has been found to prevent change in implementation science and Bonnie referred me to Implementation Pain Practice Change (ImPaC) resource and her work on Sucrose Practices in Neonates (SPiN) trying to identify the least amount of sucrose needed. One of her points really struck with me, that healthcare professionals get very little education about pain and that vets get four times the amount that medics do.



I was shown around the Neonatal Unit by **Carol McNair** who is a PhD student and a Nurse Practitioner. She was able to give me information on their neonatal follow-up programme which was added to by Clare Watts. I was impressed that not only had they a dedicated and signed follow-up clinic but they had two rooms specifically for assessing babies using the Bayley Scales of Infant Development. (*more information*)

It was such a pleasure to meet with two like-minded psychologists and **Dr Renee Sananes** and **Dr Trish Williams** were certainly that. They work with Dr Steven Miller who was out of town when I visited (I happened to be in Canada at a key holiday time). Dr Miller heads up the division of Neurology and collaborating with a multidisciplinary team, his research program focuses on better



understanding brain injury and development in the newborn. I was keen to meet him as much of his work has contributed to our understanding of brain abnormalities caused directly by premature birth, perinatal asphyxia or indirectly by CHD. Renee and Trish were called in to meet me in his stead and proved wonderful sources of immediate and ongoing information.

We had a very productive meeting with a wealth of bidirectional information exchange and also plans for further meetings and ongoing collaborations. They described in detail the neurodevelopmental follow-up clinics that they were involved in and how the cardiac neurodevelopmental programme worked with follow up at 4,8,12 months plus the follow up at 4 years that Renee did. We spoke of the different ways to optimise outcome and how to build a neurodevelopmental programme as part of this overall aim. Renee also told me about the Cardiac Neurodevelopmental Outcome Collaborative (CNOC www.cardiacneuro.org). This group established to determine and implement best practices of neurodevelopmental and psychosocial services for individuals with pediatric and congenital heart disease and their families. It sits so well with the aims of my fellowship and we made plans for a symposium in Toronto June 2019 when the CNOC meeting is held there. Another important link was for The Child Bright (www.child-bright.ca) Network. This is an innovative pan-Canadian network that aims to improve life outcomes for children with brain-based developmental disabilities and their families. They also introduced me by chance to **Claire Watt** who coordinated the followup programmes and was a mine of information in our ad hoc meeting later that afternoon. Clare, a cardiac nurse researcher, works mainly with babies born with CHD and highlighted the importance of remembering that babies born with CHD have immature brains often with white matter injury even at birth. She also reminded me of the many different factors need to be cognisant of including from a medical point of view, nutrition, brain injury, haemodynamic parameters and medication. A key point was that parent really appreciate the cardioneuro programme as the collaborative working avoids treating the child as two different systems. Clare's outline of the neurodevelopmental follow-up schedule is included in Appendix XX.

A truly multidisciplinary meeting with social work, psychology, nursing and parent representative happened on August 1st and I was able to hear about the Neonatal programmes in Sunnybrook Hospital for Sick Children (Sunnybrook) from **Luisa King**, a specialist nurse with a keen interest in promoting breast feeding and in infant mental health, in Mount Sinai, from **Kasiza Putlik**, a specialist social worker and parent programme coordinator and cross-unit views from **Kate Robson**, a graduate parent who is also executive director of the Canadian Premature babies Foundation and NICU Family Support Specialist at Sunnybrook. It was lovely to witness the passion and energy these practitioners had when they spoke about their client group. In particular the alternate ways of working to help parents have as good experience as possible during time on the unit and the use of model such as FiCare (www.familyintegratedcare.com) and parent support to ensure that connection and trust are maximised to improve potential for best outcomes. Luisa was also able to link me with Dr Paige Church who is the medical director of the follow-up programme in Sunnybrooks and who detailed their follow up programme timetable (see appendix XX). Luisa coordinates an initiative



called kangarooathon. It's a fabulous initiative which I have been publicising regionally. Details can be found at <http://www.sunnybrook.ca/kangaroo> and in Appendix XX.

I loved the ideas of 'crafting a conversation' in Kate Robson's narrative and as parent advocates enabling the parents to talk and communicate to staff, to other parents and to babies. She never spoke about one group in isolation but remained cognisant of the



importance of making hospital a safe space for parents, babies and staff.

The experience of being in the hospitals was significant. It was wonderful to see at first hand the facilities and the way they were operated especially in terms of funding. A lot of hospitals, clinics and institutions were named after individuals. It did seem that this was possible if you were a large donator. Monies also came via campaigns that were widely publicised such as this one called 'V's' and reflects the fight with the disease, a recognition for the young person's contribution and the determination to succeed.

A highly entertaining lunch meeting with **Dr Marilyn Ballantyne** and **Dr Mary McAllister** provided as much nourishment for the soul and food for the brain as it did that for the body. Marilyn is a chief nurse executive and clinician investigator at Holland Bloorview Kids Rehabilitation Hospital. She has been in touch about our CHIP research and is carrying out a study involving the intervention which I introduced her to last summer. Cross fertilisation indeed. She also introduced me to the Canadian Neonatal Network (www.canadianneonatalnetwork.org). We discussed the Comfort Promise led by the children's hospital in Minneapolis and which Marilyn involved in, looking at different strategies for pain relief such as sucrose, distraction, numbing or comfort hold.

Mary McAllister is Associate Chief of Nursing in The Hospital for Sick Children, Toronto. As well as discussing what is best for the infant, we also discussed relationship based care as a model, which again reflects the importance of relationship with colleagues and relationship with patients and parents.

Strength based ↔ relationship based care ↔ partnership ↔ practice development

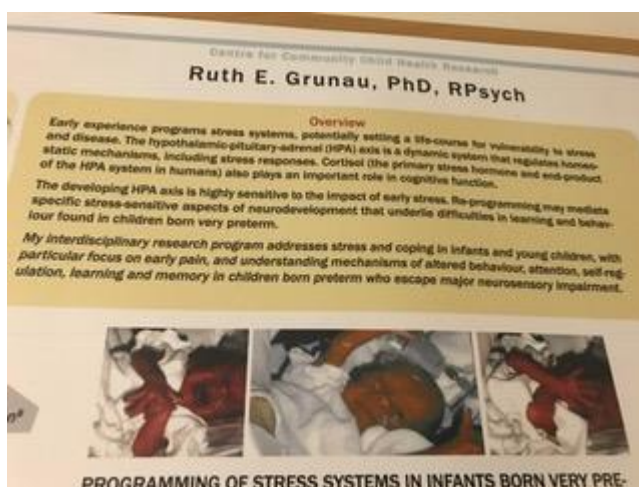
Vancouver

Toronto had been dynamic and changing with lots of different organisations and learning lots about relationships, much about practice and a little about research. Vancouver was different in that I was immediately immersed in the academic and in research. My knowledge about the infant brain expanded at a rate that felt like the proliferation of neuronal connections that we know happens in the earliest years. I loved it. Most of the learning happened in Dr Grunau's biobehavioral research lab. The 'lab' term is a new one for me in this context as it refers to a group of researchers gathered under a lead, in this case, Dr Grunau. I met initially with her and then with various researchers from her's and associated labs. I also met with Dr Julie Petrie, Clinical Psychologist and Dr Kim Schonert-Reichl.

Dr Ruth Grunau is a powerhouse of information and totally dedicated to research in babies born preterm. She discussed her research and why her population is restricted to 32 weeks or less, in great length. Prior to meeting she had sent me some incredibly useful references (Grunau 2003, Grunau 2013). Ruth's lab is found in the Early Human Experience Unit.



Shanlea Gordon is the research co-ordinator for the preterm care study. The study is an MRI one which enrolls babies born between 24-32 weeks GA examining the neurodevelopmental outcome of pain. Shanlea highlighted to me the first professional difference of opinion in that she indicated that I had probably learnt that they liked to use sucrose in Toronto for pain management in this preterm group, however Ruth and other psychologists have concerns about what this will do longterm to metabolism and to neurodevelopment. Instead they use facilitated tucking, when babies are contained and wrapped up to help modulate the physiological response. My awareness of the impact of funding streams grew here as I became aware of how money could make things happen in terms of getting subjects for study as well as provide things such as dedicated research MRI, and the correct technology to collect data for diary management etc. I was also struck by how each project has its own research coordinator and they are all competing within the same group of patients for study participants.



There were lots of great posters from conference on display around the corridors providing additional valuable information from them. Dr Grunau introduced me to several studies which need follow-up, one in particular stood out for me, much of the description is taken from Columbia Psychiatry website as well as information from Shanlea. Dr Martha Welch is associate Professor of Psychiatry in the Department of Pediatrics and Pathology & Cell Biology at Columbia University Medical Centre. She

is also the Director of the Nurture Science Program in Pediatrics as well as Director of the basic research BrainGut Initiative in Developmental Neuroscience. Her work has led her to

posit that the origins and control of behaviour and emotions are based on mother-child autonomic coregulation, rather than the individual's top down central nervous system self regulation. She leads a team understanding the family nurture phenomenon and is testing the 'Calming Cycle Theory' and 'Family Nurture Intervention' (FNI). She is testing the FNI in prematurely born infants and infants aged 0-5 years and is also validating an instrument called the Welch Emotional Connection Scale (WECS). These latter two tools are ones I most definitely want to find out more about especially given the initial findings about the significance of FNI for parent-child dyads in NICU (Welch et al 2015). The Fellowship has provided such a wealth of direct and indirect information.

This and other research suggests that for this population that to optimise neurodevelopment there should be involvement of parents, kangaroo care and closeness. Ruth made the valid point that this works if parents have the resources to be there. However this often isn't the case. The Fi-Care model for example is built upon a Scandinavian model in a society where there is a great value placed on parental leave. Some research from Florida about single room care indicated that babies had worse developmental outcomes as nobody there (unable to be there) so they heard no language. I really like the FiCare model but agree that we need to be cognisant about the supports available to facilitate implementation of this or any other model.

All Ruth's research was carried out with babies born between 24 and 32 completed weeks GA. She was keen to highlight that what's going on in terms of this window cannot be generalised to babies born after 32+6 weeks.

Within this window she described cytotoxic processes and the impact of pain on the cytoarchitecture especially as the gross macrostructure not in place. She more than ably took me through how the brain looks at these different stages and why it is so vulnerable. This slide which I saw at the Neonatal Brain Conference in Killarney summarises her main points.

SLIDE

Any errors in the retelling of information are totally mine as I was trying to absorb so much rich information in a topic area that I am totally fascinated by but admittedly less academically able. The connections between some brain structures are not complete in babies born less than 32 weeks so procedures can cause greater impact than when the structures are complete. Vulnerability varies according to gestational age with cytotoxicity greatest 24-28 weeks then 29-32 weeks and less vulnerability after 32 weeks. A second point is that mature oligodendrocytes produce myelin late in the third trimester but this myelin comes from the premature form so if a baby is born early and compromised this myelin is impacted due to its high vulnerability to excitotoxicity. I suppose it sounds like there's a double whammy, direct and latent impacts on the myelin. Ruth was very clear that babies born before 33 weeks could not be thought of as same as those born after this time due to the differing brain procedures and this includes babies with CHD. She felt that couldn't generalise impact of painful procedures in babies hospitalised as need to be careful of clinical confounders including gestational age. We also discussed how pain is to some extent a modifiable risk factor, can limit its use methods to reduce impact, other risk factors on brain development and outcome are less able to be modified. However there needs to be ongoing attention paid to the idea of better pain management. Do the techniques

discussed stop physiological reactions or simply help baby cope in that moment? Memory for pain tends to be on a physiological and hormonal level



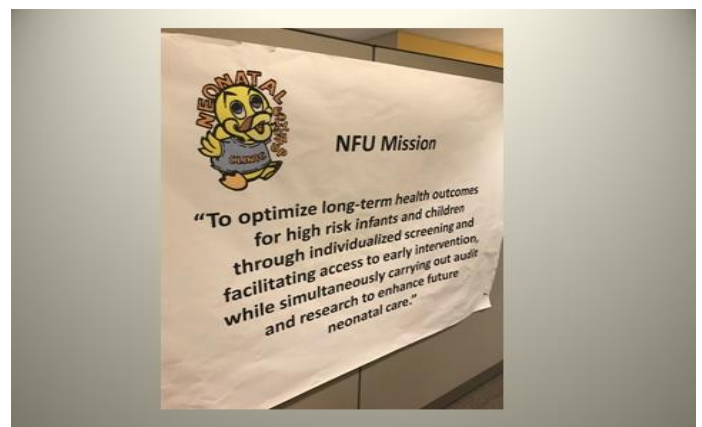
Kayleigh Campbell, a lab member who is completing her PhD with Tim Overlander most definitely has Irishness running through her veins. She actually reminded me when I was doing my PhD which I found incredibly spooky. We discussed the different factors which impact on early brain development including SSRIs and CHD. She described her research in detail and highlighted how serotonin was critical and played a huge role in proliferation and synaptogenesis. (Publishing soon biological psychiatry)

Neurobehavioural assessment of the preterm infant (NABI)

Mark Bichin is another PhD student in the lab and we talked a lot about the HPA (Hypothalamic Pituitary Adrenal Axis) and how preterm infants often have a disrupted HPA. Pain related stress at the start may cause altered pain related trajectories.....but can change the brain via maternal interaction, if change the environment can change the brain. One quote Mark had really resonated with me, one glass of water has more elementary particles than there are glasses of water in the ocean and one brain has more possible connections than there are elementary particles in the universe. He was unsure of the source and so I suppose we can't verify but I loved the image of possibilities that it causes to arise.

They have a million dollar incubator at UBC Vancouver which is MRI compatible and makes scanning babies much easier. At Ruth's lab they do not use sedation for these research scans, they prefer to minimise exposure to sedation. Resources and funding definitely make a difference to what is able to be investigated.

I did wonder if all psychologists office across the world were similar when I met with **Julie Petrie, Clinical Psychologist**, in her office at Children's Hospital at UBC as hers was so similar to mine, filled with books and papers and not particularly neat (as were Dr Grunau and Dr Sananes. Obviously indicators of active minds). She was incredibly kind and came in from leave to meet with me which involved a significant drive. Julie has worked in infant follow-up for over 20 years. She mentioned that the doctors and nurses see babies at the neurodevelopmental follow up clinic for the first two visits at 4 and 8 months and then she sees them at 1.5 years, 3 years and 4.5 years. She described the range of tests carried out and the criteria for followup which seemed slightly more limited than for those seen in Toronto. She did highlight as I have found, that although the children often seem to escape major impairment. She suggested the use of the Sensory Profile 2, a Pearson Test, by Dunn. It was lovely to discuss tests that we each found useful. She also mentioned the ITSEA, the NCAST and Brief-P and she highlighted that they very much used an MDT model in the follow up clinic and there were often articulation difficulties with premature babies. She also gave me links and names to follow up after our meeting including information on working memory



on the Harvard site, Gathercole & Alloway, Holly Ruff re: focused attention. We discussed that executive function issues are often highlighted in children born sick/early and she recommended some and references including work by Adele Diamond (www.neurodevelab) especially for her work on Executive Function and highlighting that executive function is often more important than IQ. A book called Late, Lost and Unprepared: A Parents' Guide to Helping Children with Executive Functioning by Joyce Cooper-Kahn and Laurie Dietzel (2008). Bears sleep questionnaire, Gordon Neufeld, Vancouver based, Neufeld Institute, short sensory profile, sees all CHD at 30 months and at school entry.

Dr Kim Schonert-Reichl is the Director of the Human Early Partnership (HELP) and a professor at UBC Faculty of Education. Dr Grunau had thought we might enjoy meeting up and have like minded interests and she was certainly correct. HELP is a research institute exploring how environments and experiences contribute to inequalities in children's healthy development. As well as looking at ways of helping communities reduced vulnerabilities impacting on child they also hold an enormous amount of population data of children. They have developed early development assessment instrument. They use a community systems approach and use cocreation in what interventions would be.

MDI – listen to the children as they are the teachers and Kim described how they have an ethical obligation to do as they say. We discussed the work of Kylie Hamlyn at UBC who highlighted that infants are smarter than ever thought. She highlighted that at 23 months infants are happier when giving out treats to others and in terms of cognitive skills the use of eyetracking in infants demonstrated that there is sophisticated social cognitive skills at a much younger stage than had been previously thought. She highlighted how the best way to support children is to support adults and that this thinking extends to teachers where a SMART model is used (Self management and resilience in teachers).

Competencies are described in www.curriculum.gov.bc.ca

She described some videos re: communication and the power of saying someones name which is the number 1 thing for teachers to do. We reflected on links between this and the 'Hello my name is' campaign. I was able to mention this and the work of Chris Pointon at my invited lecture at Stanford.



San Francisco

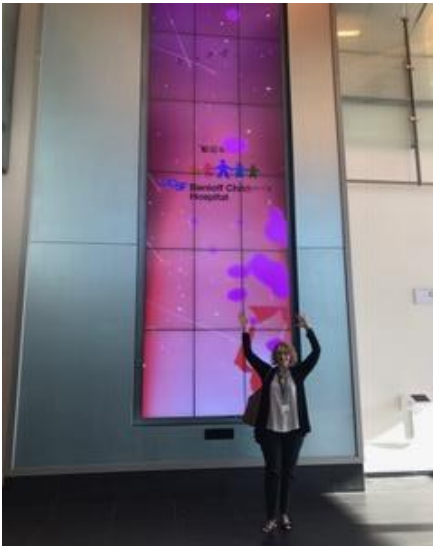
Professor Linda Franck is the Jack and Elaine Koehn Endowed Chair in Paediatric Nursing at UCSF (University of California at San Francisco) and the most marvellous of women. She not only coordinated my San Francisco leg but she also helped look after me when I was there, showing me hospitality well above and beyond the level that she needed to. An incredibly hard worker she is totally dedicated to her research areas. She is based at the school of nursing at UCSF and her program of research focuses on health care for acutely and chronically ill infants and children in primary, secondary and tertiary care settings. This includes research on the assessment and management of side effects of analgesia as well as investigation of the longterm consequences of pain and pain treatments on the developing child and family. She has written a booklet for parents to help them learn about infant pain and the important role parents can play, in partnership with the health care team, to keep their baby comfortable during intensive care (<http://familynursing.ucsf.edu/comforting-your-baby-intensive-care>). She is involved in promoting family-centred care and enhance the partnership between parents and health care providers to ensure children and healthcare providers to ensure children receive optimal care before, during and after hospitalisation.

She leads the Preterm Birth Initiative (www.pretermbirth.ucsf.edu) in UCSF. This is a joint transdisciplinary platform which covers basic science to epidemiology and everything in between. She is implementing FI-Care in the US context supported by technology and exploring numerous different ways of implementing technology to promote health and wellbeing.



Linda has an honorary appointment with QUB. I had met her in Belfast previously when she was over in the QUB role. We discussed the fellowship and possibility of visiting UCSF. From that initial meeting I was asked to contribute to an online resource for parents whose children were about to leave hospital (www.lifeathome.tinylife.org.uk), Linda is a co-principal investigator on this project, so the impact of the fellowship had started even before I began my travels.

Linda also took me on a tour of the UCSF Benioff Children's Hospital in Mission Bay (www.ucsfbenioffchildrens.org), a 183 bedded hospital, 58 of which are in NICU. It was only built in 2015 and its newness is reflected in its beauty, space and technologies. There is a massive interactive plasma screen in the entry hall, there was piano playing further along and on the corridors upstairs robots delivery laundry and medication. It was a new experience to stand back out of the way for an unmanned vehicle. The classrooms and video and editing suites available to the children were equally as impressive and I loved the gratitude tree.



I was able to attend a research meeting when I was in UCSF, led by the Babies who cry consortium. Key messages from the meeting included the fact that some babies have increased sensitivity due to brain based disorders which means they are more sensitive to stimuli and express that sensitivity through excessive crying.

Nurse Judy spoke at the event about Fussy Babies and has a blog which addresses many of the most common parenting issues (www.nursejudynvp.blogspot.co.uk). She also runs a baby boot camp. The baby boot camp offers parents answers to the top twenty questions that new parents tend to seek answers to. She spoke eloquently about the fact that 90% of them are having a tough time and that knowing this means that they tend to feel more normal.

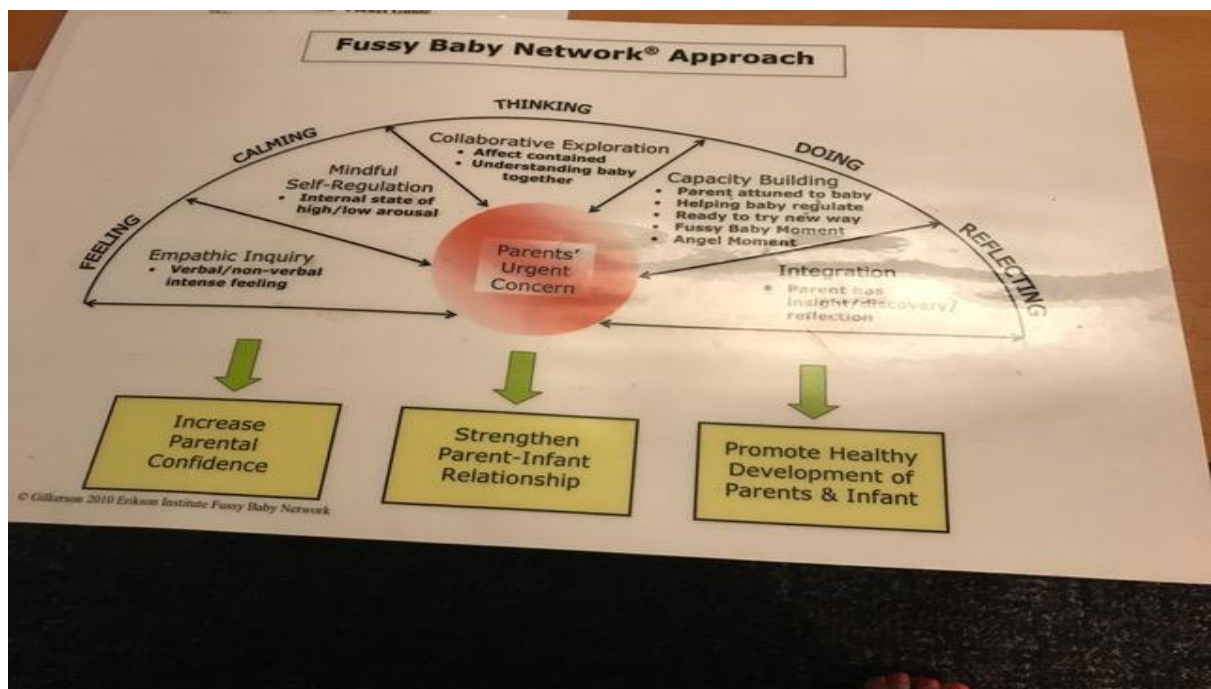
Dr Elizabeth Rogers who is a Consultant Neonatologist and a fireball of energy and who facilitated my attendance at the neurodevelopmental follow-up clinic gave a lovely talk about preterm babies and the fact that they are not just small fullterm babies. She highlighted that the maturation experienced after fullterm birth is very different to maturation of preterm babies after birth. She also highlighted that the crying of former preterm babies is different to that of their full-term peers, both in frequency and function and that there can be underlying brain dysmaturation or injury/impairment which may lead to biological vulnerability and to impaired caregiver/child interaction. She wondered if there are different crying characteristics can act as an early biometer for neurodevelopment in preterm infants. Other points I liked was the differentiation in crying science between spontaneous and induced crying and the highlighting by Hannah Glass, Neonatal Neurologist (who I ended up sitting beside at the conference in Killarney) of the need to think of cry in terms of pitch, frequency and persistency when describing it in order to promote understanding and the use of app based recording to get an accurate description of crying to inform optimal treatment.

There was discussion about the impact on culture and different expectations regarding crying and the best ways to coach parents through the experience of soothing a baby. I was reassured to hear discussion of not fixing or medicalising a baby but a clear message of containment.

I really liked the fact that the research consortium finished with a summary of available research grants both large scale and smaller seed grants organised offered through the university and research group and necessitating interdisciplinary work.

After all the academic and research information related to crying it was lovely to add to the knowledge by visiting the **Fussy Baby Network** in Oakland. It is an arm of the Early Childhood Mental Health programme. They provide short term intervention of 4-6 visits. Their work is based on that of Linda Gilkerson founded the fussy baby network. They work to see how to best to engage with families to identify needs when they have a baby who is crying intensely. (see appendices xx). They replicate the structure they use in discussions with the clients when they are discussing what its been like doing the work The case discussions I was able to sit in on were absolutely fascinating.

- How has it been for you?
- Are you getting to things you wanted to?
- Is there anything you are holding on to?
- What will you take away from this?
- Help me think about this?



As well as the direct clinical work and case reflections the team are involved in training paediatricians and primary care staff. The training of GPs has been particularly effective. In training them in the arc of the visit structure communication is enhanced as is the efficacy of the intervention. All the staff are trauma trained with Alicia Lieberman's team.

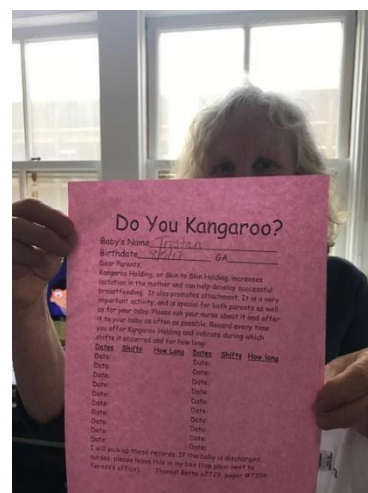
I met **Dr Alicia Lieberman** along with Linda Franck at the lovely Zuckerberg San Francisco General Hospital and Trauma Centre. Alicia is originally from Paraguay and is a passionate advocate for women and infant mental health. She is the Irving B. Harris Endowed Chair of

Infant Mental Health, Professor and Vice Chair for Academic Affairs at the UCSF Department of Psychiatry, and Director of the Early Trauma Treatment Network (ETTN). She is past-president of the board of Zero to Three, is a prolific author, lectures extensively and is a really lovely person. Her passion about her subject area shines through. Her dad was a paediatrician and always said that all kids need is love and protein which is in part the reason for calling a ten week intervention she devised 'Attachment and Vitamins'. Some of her work highlighted the mother-baby relationship as a good predictor of outcome in childhood. The research analysed a five minute speech sample asking the mum to describe the baby. This was carried out before and after treatment and they found a significant decrease in negative attributions and increase in positive attributions. She has trained over 2000 people in child parental psychotherapy (CPP). One of Alicia's workers reflected on the input they provided and said to Alicia, 'It brings out beauty from the darkest of places helping people reconnect with their love' which is a lovely summary of the power of the work. We had a lovely discussion about how both our research findings highlighted the power of the narrative in processing stories. The whole of New Mexico State has adopted the CPP approach and Alicia put me in touch with her contact, Soledad Martinez, Director of Early Childhood Services in New Mexico, so that I could learn more about it when I was there.



Alicia also made connections for me to the Manns-Simms Institute in California who have a lovely tool to enhance attachment between parent and child called cuddlebright. I have since had subsequent conversations with Victoria Simms and Lauren Wagman about ways we can work together to assess the utility of the instrument in an interventional way with populations of babies born sick/early using some of the findings from the CHIP studies.

Bette Flushman, is an inspiration and someone who just lights up the room. She shared so much with me in terms of resources and knowledge. She gave me a reference for a movie



they use about bathing a baby https://offspring.lifehacker.com/heres-a-better-way-to-bathe-your-newborn-1824252740/amp?twitter_impression=true) which is just the loveliest example of being baby centred. Bette has a background in education. She is now an infant developmental specialist. She really stressed the importance of communication and relationship and how everyone has relationship with the baby. It is what everyone does, the mother, the staff, the volunteers. She indicated that the importance of this relationship and her belief in the importance of skin to skin touch resulted in her hospital being the first in the country to do skin to skin care even when the baby is in a ventilator. She spoke of the connection of touch. They use supportive materials to encourage the use of touch but mainly Bette's effusive personality, passion and wonderful respect for all the women, babies and staff seemed to be the driver here. Walking through the unit with her, demonstrated the enormous impact that she has, and the impact of her relationship with all. In her own interactions she models the very tenets that she espouses. This was the most powerful of her lessons. In one afternoon she gave so much.

I had the pleasure of sitting in on a clinic of the **Intensive Care Nursery (ICN) Follow-Up Programme**. Dr Elizabeth Rodgers (Liz) runs the programme and she described how it is embedded in neonatology and as such it has given neonatology more presence within the hospital and fellows gain more and get better training while families love seeing the follow-up results. The children have Bayley's assessments at 6 months, 12 months, 18 months, 2.5 years, 4.5 years, 8 years and between 10-16 years. I shadowed Bridget Johnson, the Clinical Psychologist on the team and I had the privilege of observing several assessments across the day as well as see how the supporting systems, decision making and team works. Bridget, not a native Spanish speaker was able to carry out an assessment in Spanish.



I was struck by several things including the innate desire of the children to please and how they seemed to be driven by the desire to communicate using whatever means they had available.

Bridget kindly spent some time with me giving further detail of her work. She explained that the clinic I had sat in on was just one that she was involved in. As well as that one at UCSF, she travelled to Santa Rosa and to Medista to provide the ICN followup assessments. There was a great follow-up protocol and I was impressed by how the clinic was organised and ran so smoothly via the administrator. Everyone knew what had to happen and all the

paperwork was ready and waiting for each stage. It was lovely to see how the various professionals all worked together and the feedback given back to parents immediately. I did notice some limitations in that it was entirely child focussed with limited ability to reflect on the system around the child. In one particular case it was clear that the mother wanted to tell her story and although Bridget managed this beautifully in the time available she was unable to follow-up as she would have liked with the mum the structure and way that funding work seemed to prevent further input from happening.

I spent an afternoon in the lovely leafy Berkeley. I met with **Eren Berkenkotter**, a Clinical Psychologist who works on the Fussy Babies Programme described above. As well as her role with the Fussy Babies Programmer Eren is involved in the **Special Start Program**. The Special Start Program at Children's was designed to address the needs of parents caring for a premature baby while facing intensive and psychosocial environmental challenges for the children ranging from pre to post discharge. The aim of the programme is to maximise the health and development of enrolled infants and strengthen families to cope with future challenges. Services start when the infant is still hospitalised and continue until the infant is 3 years old. The set-up of the programme reminds me of the Family Nurse Partnership in that it's a dedicated service to families who could be considered at risk. Special Start has a multidisciplinary staff including nurses, social workers, infant development specialist, physical therapist, nutritionist and psychologist. The program is relationship based; flexible and family driven; trauma-informed; responsive to race, place, class and culture; systemic (beyond baby) and overseen by a highly trained multidisciplinary staff. There are home visits, frequency determined by the family need, by the primary case manager (with support, input and consultation from other team members) is an umbrella approach so that those in special start have everything connected rather than disparate specialists. I loved the model and could see its benefit not least from the benefits we saw from a MDT preventative intervention approach we used in CHIP (Doherty & McCusker 2016).



Eren also offered to take me to see Alta Bates NICU and to meet her colleague who has a unique role there. Her colleague is **Kelly Ranson** who is also a Clinical Psychologist. Interestingly the room we initially met in is a multipurpose room. It has all the facilities a family would need at night to allow them to be close to their child, then during the day they are easily converted into meeting rooms and a booking system allows staff to know in what way they should be getting the room ready. Kelly's role has changed more recently and she is no longer at Alta Bates full time. She was able to give us a tour of the unit which was wonderful and I was especially glad to be able to see some volunteer cuddlers at work. We well aware of the importance of a baby being held to enable containment and when parents aren't available these volunteers come in to provide this wonderful service. Kelly described the multidisciplinary team who work together in NICU to support health and wellbeing of the infants and their family. It includes an occupational therapist, physiotherapist, infant development specialist and an expert in infant mental health (Kelly). Kelly works to promote a stress inoculation model. They use a developmental care model involving parents in the infant's care. There are lovely videos on utube about Alta Bates NICU and on their website along with other information and useful links

(www.altabatessummit.org). In particular see the information about the Compassionate Beginnings™ Program which focuses on the parent-infant relationship and promoting it through the power of touch.

Linda Franck had met **Dr Laura Simons** at a conference and thought that a meeting between us might be useful and it was. I travelled to Stanford to meet her at her Biobehavioral Pediatric Pain Lab (www.bppplab.stanford.edu). I had also been invited to give a talk at Stanford University School of Medicine about my work and my fellowship and delivered that en route to Laura's lab. Laura's PA had kindly picked me up from there to meet Laura and her team at the pain lab where I also did a presentation to those in the room and virtually to colleagues in other parts of America. Laura is Associate Professor Department of Anesthesiology, Preoperative, and Pain Medicine (Pediatrics). I realised before we met that I had read many of her emails as Laura is our American link person on the Paediatric Psychology Network on whose UK committee I sit. She is on the board of the Society of Paediatric Psychology and is building partnerships with sister organisations including PPN. I will be meeting her in Ghent for the European Paediatric Psychology Conference which is really an International Affair now. We had great conversations about the impact of pain on the parent/child relationship. Laura discussed the social communication model of pain and described how child pain affects the parent's pain due to the effect on empathic circuits and thus affects the parental response. Her research finds that the parent brain modulates the impact of pain on the child pain. Basically empathy modulates pain, its like connection is medicine. Laura doesn't work with infants but her reflections in her papers, completely reflect the power of parental touch and connection as a modifier of pain and reinforce the practice of babies being held by parents for procedures, hearing their voice, feeling their touch, being regulated by their parents (Simons (2016); Simons, Goubert, Vervoot & Borsook (2016)).

The **Ronald McDonald House** in Stanford was a place I would quite happily have moved into. **Dr Martha Hernandez** acted as my tour guide. Top designers had given their time and it most definitely showed. Linda Franck had carried out research into hospital



accommodation and how this related to families experience and it was clear that families who stayed at a Ronald McDonald house had a significantly more positive overall hospital experience (Franck et al 2015). I have been told that not all Ronald McDonald houses are to this standard and that this particular one has benefitted greatly from its Stanford location and local investment. Ronald McDonald houses as an entity were started in Philadelphia in the late 1960s when an American Football player who noted the

needs of a family when a child is in hospital (www.rmhc.org). There are some similarly funded houses in the UK (www.rmhc.org.uk) but none of the scale of the Stanford one (www.rmhstanford.org). This particular one is for parents of children attending the Lucile Packard Children's Hospital, Stanford. They are on their 3rd renovation and have 123 bedrooms. I found the most interesting element of the house to be the Family Support Services (FSS) work. The Stanford house is one of three service locations they provide input to. They support families, staff and volunteers 24 hours a day, 7 days a week and 365 days a year. The family support is largely provided by predoctoral and postdoctoral trainees in



Clinical Psychology under the direct supervision and guidance of the training faculty. These placements are highly sought after and they take 8 a year in RMH Stanford. They use a matching system to ensure the best fit candidate gets the placement. Martha who showed me around is the Program Director with responsibility for trainees on placement and **Dr Susan Regas** is the training director for the Californian School of Professional Psychology.

I had an early morning virtual meeting with Susan via Zoom, an app I was able to download to my phone and worked really well. She is based in Southern California so a face to face meeting wasn't possible. She talked me through how the placements work operationally and the challenges that can arise in the work with a divergent populations as well as the huge benefits for the trainees. We also discussed the possibility of Clinical Psychology trainees from my local training course at QUB availing of a placement opportunity.

New Mexico

New Mexico offered a different landscape, a different pace and different focus. I met with two trial attorneys, **Debora Gerads**, and **Gary Mitchell** and two judges, **Judge Angie Schneider** and **Judge Shannon Murdock** all with a passion for infant mental health and a belief that the system needed to change to consider the impact of experiences on the infant. In fact to help move this forward Deb Gerads has written an article based on our discussions called 'The Long Term Cost of Poor Infant Mental Health to Taxpayers Everyone Should Know'. It raises awareness of IMH among those that normally don't care about these issues or see as irrelevant by demonstrating how it hits them in their pockets. They felt that the law needed to catch up with science and that staying with the parent was not always in the best interest of the child. The judges told me that they need the attorneys to bring the law to them and the need test cases to challenge existing law and then make links to new law. It exemplified the need for joined up thinking, of people wanting to think outside their allotted box for the benefit of others and it really demonstrated, as I said in my blog (www.nicoladohertyblog.wordpress.com) the desire of good people wanting to do the right thing and working very hard to make that happen.

Via Alicia Liebermann I was connected with **Soledad Martinez** who continued to exemplify the findings at the end of the previous paragraph. Soledad is the infant/early childhood program director for the children's behavioural health division of the children youth and families department for the State of New Mexico. Part of the reason for the awareness of IMH needs amongst the judicial system must surely lie with training that has been provided via Alicia Liebermann's team in New Mexico. Soledad spoke of the importance of Judge Schneider especially because she was setting up the juvenile programme.

Soledad again described the CPP programme and highlighted that they are now on their 3rd cohort of CPP and as a result they are building infrastructure and internal resources. It sounds like a whole movement has started. We discussed how the knowledge is being used to implement change. The target for CPP is an improvement in the relationship. She referenced a tool called DIAPER (Developmental informed assessment per each

relationship). This assesses progress in development in terms of the relationship. There is a host of wonderful resources on the website <https://cyfd.org/behavioral-health/infant-and-early-childhood-mental-health-services>.

Soledad reinforced the thoughts we have, it's the importance of connection, its not rocket science and not expensive. This is why the State of New Mexico are training all relevant professionals with hope of prevention of difficulties.

Ireland

It might seem strange to include Ireland on the itinerary for a fellowship that could take you anywhere in the world but I was aware that there was an international conference on the Neonatal Brain being held in Killarney and the Infant Centre in Cork with whom I felt it really important to make links that could be developed. At the Irish Centre for Fetal and Neonatal Translational Research (INFANT) I was met at by **Dr Leanna Fogarty**, Senior Clinical Psychologist. Leanna is working with the INFANT team to establish an Early Life Lab for the neuropsychological and developmental assessment of young children from birth to early childhood.



INFANT is Ireland's first dedicated perinatal research centre. It was launched in 2013 and is of the 12 world leading Science Foundation of Ireland Research Centres. INFANT studies pregnant women and children from the ages of 0 – 5 years, including pre-term and term new born babies. The majority of their studies contain a neurodevelopmental follow up at 2 and 5 years of age. Multi-disciplinary team includes clinician's, scientists, engineers, nurses and research support staff.

Amongst the plethora of research areas that they are looking at that I have particular interest in includes how to improve outcome in early brain injury. BASELINE is the first Irish longitudinal birth cohort study and this SCOPE study is currently recruiting 3000 first time mothers, gain very important information about mothers from early pregnancy. This is used to develop ways of predicting which mothers are at high risk of pre-eclampsia, pre-term birth and poor fetal growth. It collects important information about babies postbirth as well as their mothers. The BiHIVE Study examines the Investigation and Validation of Predictive Biomarkers in Hypoxic-ischaemic encephalopathy

Leanna took me on a tour of the centre, told me all about their work and introduced me to some of the Psychology researchers who in turn told me all about their work. I was heartened to hear that some of the research being carried out by Dr Conal Wrigley on visual attention in infants and seems to use very similar model to that which I used in my PhD 20 years ago. I was also delighted to meet **Dr Deirdre Twoomey** who described her research looking at touchscreen apps for assessing cognitive function in 18 month olds called Babyscreen. She spoke with lots of passion about her research and as with Conal her passion for psychology was infectious. I have maintained contact with Leanna and Deirdre and Deirdre has been organizing for me to return to the centre to give a talk about my work

and research and to make collaborative links with researchers there. They have many international links but none with Northern Ireland so I am hoping to change that. An Early Life Lab opened last year so I am also keen to see that.

I was delighted that I would be able to spend some further time with Leanna and Deirdre the next two days in Killarney at the International Neonatal Brain conference. It was a whirlwind of academic and research information in both oral and poster format and a chance to reinforce my emergent thoughts about some of the findings from my research and associated recommendations.

How do findings relate back to the UK? Challenges in implementing them

Joining the dots – Findings

Establishing connection

- Professional to professional

 - Information sharing

 - Cross professional

- Professional to parent/child

- Parent to child

Ongoing connection

- Red flagging

 - Psychoeducation of parents and professionals

 - Lots of academic information, doesn't exist in vacuum, connect the science to the practice (law, health, education, parenting)

 - Neurodevelopmental followup is key

 - Support

 - Emotional – hearing the story, connect the experience to the impact. Validate what happened

 - Practical - information

 - Financial (not just for parents), money matters –

 - The importance of a movement - kangaroo care

Challenges in implementing them are the same as the same challenges we face on a daily basis, time and money. Think outside the box. Lots of good work ongoing, just need to connect it. Use technology

Money talks

Conclusions

To what extent did you achieve your aims and answer your qs?

The Fellowship really allowed me to see the power of people, passion and places and in doing so opened my eyes and filled my brain in more ways than I could ever truly verbalise.

I had a broad range of aims and questions within my objectives when I embarked on my fellowship. I was worried that they were too broad and indeed was a query that was raised at my interview. However I am convinced of the utility of such breadth because it has helped reinforce the fact that there is much overlap when thinking of work for babies born sick and/or early and there is commonality in what is needed moving forward. This is the main reason why I am proposing the development and testing of a relevant model to incorporate all the factors that feed into outcome. Indeed there are many disparate views in this area but when they are looked at in an overarching manner one realises that the views are all right but just feed into a model in different manners.

Reviewing the aims as outlined below makes me smile as although the recommendations don't map directly onto the objectives I do think that the objectives are met in each area of the recommendations. It feels a little bit like baking a cake, the objectives are the ingredients (alongside the funding from WCMT/Wave Trust/Dulverton and support and time from work) and the recommendations are the cake. It's the same information but presented differently and with more structure.

1. Gain knowledge in the area of infants & young children born early/ born sick & impact on them & the systems around them.
2. Gain specific skills especially in terms of intervention to improve quality of life for this group of young children & their families either directly or indirectly through staff education/consultation.
3. Make links with like minded professionals regarding clinical & research areas. I want to form foundations for ongoing collaborations. I really think sharing of knowledge/skills essential to progression for these young children and their families.
4. Bring back new knowledge & skills & disseminate in NI / UK.
5. Develop specific clinical, training & research programmes in NI / UK encouraging collaborations & staff working together using their skills, stepping outside silos & putting the child in the centre.
6. Enable staff
7. Ultimately improving outcome for children & families
8. Personal development
9. Enhanced family experience especially sense of adventure

The report details the findings and recommendations linked to objectives 1-7 but it would be remiss of me if I didn't mention that 8 and 9 were totally fulfilled too. The Fellowship has proven to be the most rounded of experiences, impacting on all parts of my system and reminding me of what is important professionally and personally.

Emergent Themes

Writing the Fellowship report and reflecting on the experience has resulted in the emergence of several themes linking the findings and recommendations in a common framework. Its all about the C's - Big cs and the little cs. The cs also link prior knowledge with new knowledge cementing the importance of previously held beliefs.

Connection

This is the biggest yet the most basic and to me the most important of all the C's. Connecting people to each other by the simple act of introducing themselves. I had spoken a lot about the use of the 'Hello My Name Is..' campaign in the two or so years prior to my Fellowship but from conversations I had during my time away I am even more convinced of its utility in all walks of life. I was able to introduce it to most people I met and I recommend that it continues to be promoted within my trust, in Northern Ireland and in the UK. And more than there should be an audit of the implementation of it as we need to follow through on campaigns and any type of training to ensure that implementation and good practice continues to occur. Things like this are too important not to use. And it should be used right across the lifespan irrespective of the recipient's ability to communicate

We need to continue to think about parent-child bidirectional connection, think about ways of removing barriers; emotional barriers such as anxiety and fear often helped by psychoeducation; trauma which is often helped by telling the story; self-doubt and attachment concerns which can be helped by Video Interaction guidance and physical barriers by continuing to facilitate skin to skin and engaging in the 'kangarooathon'

Connect staff and parents to information to increase understanding of the numerous impacts of a baby being born medically fragile on the system and appropriate ways to provide support

Connect professional to professional (nationally and internationally for sharing of clinical and academic information). The world is a small place and there is a lot of similar practice and interest. So often there is competition about being the best, publishing first, being seen as experts. We should connect to share expertise to be the best for the patients.

We should consider how our systems operate, health and social care are integrated in Northern Ireland so some advantage but too often decisions are made in one part of the system without considering all the other parts involved. There needs to be greater connection locally and regionally various involved clinicians to discuss child as whole system instead of sending the child to different parts of the system. In the US and Canada there were excellent examples specialists come together to share research knowledge and hold joint clinics. This is in practice in the UK in pockets but should be standardised.

Connection can be supported by but not replaced by technology.

Connect people with the importance of babies and early years and brain development especially in the context of a child who is medically fragile.

Collaboration

A major realisation was that lots of people are looking at aspects of my Fellowship topic, everyone I spoke to was incredibly passionate about their areas and all were right even when they had opposing views. There needs to continue to be a way of working together – academics in the research world looking at different aspects but joining up to help see the overall jigsaw, academics creating the knowledge base working with clinical staff who are implementing the knowledge; voluntary and community sectors working together with health and health working with education; and the globe is very small; with today's technology we can share knowledge easily.

There are great examples of shared networks in both Canada and the USA and even the research meetings attended highlighted the power of collaborations. In fact some of the research monies available were only available to collaborative efforts.

Implementation science ...

Communicate

Consider how we communicate information about the babies that its important for other people to know

- Child health records - red flag (practice change)

Language used

Construct a model

Biopsychosocial model to bring together the elements to help predict best outcome for babies born sick/early

Containment

What do we do to manage pain

Manage parental distress – Solihull trained workforce

Facilitating conversations – recognising impact on MH (training issues)

Cash

One of the smaller C's but money talk. It was striking to see the impact of funding in Canada and the USA on what was available in terms of resources, equipment, ... Neonatal fund Scotland –replication to NI?; grants

Cuddlers – making it ok; and when parents aren't around

Interpretation of your findings – what is their relevance back to the UK?

Part of the joy of this type of work is the worldwide relevance. The findings hold significant relevance for the UK. There are babies born sick and born early here everyday. There is already much excellent work being carried out in the UK especially in terms of both clinical work and (refs) but we need to have joined up approach and to think about how findings are implemented.

The finding of the importance of neurodevelopmental follow-up for babies born sick and early has already weight behind it here as when I was away NICE guidelines (NG72) came out recommending follow-up until 4years old for children born before 28 weeks <https://www.nice.org.uk/guidance/ng72>. Having a clear guideline from the national institute of clinical excellence will make the argument for this much easier.

Gil Wernovsky (Wernovsky 2018; Wernovsky & Licht 2016) has also recently published a paper on neurodevelopmental follow-up of babies born with Congenital Heart Defect which highlights the importance of follow-up children born with CHD not only for them and to monitor impact on brain but also because of need for the family system to be supported. We need to continue the systemic approach we began in Northern Ireland with the CHIP studies described by Wernovsky as 'seminal work' in his 2016 paper. Travelling on the Fellowship and talking to people about the CHIP work and seeing their excitement and enthusiasm and request for papers reminded me of how important this work was. We are now about to commence further follow-up with the initial infant population so the story continues there. It also reminded me of the need to believe in our work and sell it as despite the passage of time there are few if any similar studies. Northern Ireland is not part of the CNOC group and although there is a cost I am making a case with our Paediatric Cardiology consultants to join as we need to be members of such an influential group and ensure our voice is heard.

There is a movement to address IMH in general and the specific needs of babies born sick and early and in NICU with various recommendations emerging in recent years in Northern Ireland (Bliss report 2018; RQIA recommendations 2017) and in UK (British Association of Perinatal Medicine (BAPM) Services Standards for Hospitals providing Neonatal Care 2010); High Quality Neonatal Standards (2009); All Wales Neonatal Standards (2013); Neonatal Care in Scotland; A Quality Framework (2013) and NICE Specialist Neonatal Care Quality Standards all provide evidence which help further support report findings and which should also help provide policy support. Scotland have recently introduced funding for parents in NICU to help meet the recognised financial impact of a baby born early.

Recommendations

Bullet points of recommendations and then expand

- Identification and followup.
 - Scoping exercise of what's happening now
 - Neurodevelopmental follow up clinic for children born sick/born early
 - Identified points for screening
 - Flagging in universal health care record
- Suite of tools
 - Professionals toolkit
 - Education workshops for parents/professionals
 - TinyLife website
 - CHIP materials (increase dissemination)
- Research and implementation science/knowledge transfer
 - (infant centre, mann simms, QUB, vic simms)
- Model encompassing all elements to encourage crossprofessional working
- Connectedness
 - ACES/IMH
 - Cross professions – NWRC/Health/Education/law
 - Research findings and clinical practice
 - In info about young person
 - Join CNOOC
 - Twitter
 - Publicise what do...
- Family Involvement and Support
 - FIC
 - Link to CHIP
- Information sharing
 - Blog
 - Conferences
 - papers

Developments to date

Conferences

Talks

Website

Research

Meeting with PHA

Linking in people visited

Kangarooathon

Academic knowledge

Trainee ops

Collaboration with Vic Simms at UU.

Ongoing collaboration with Mann-Simms and Linda Franck

QUB school of nursing invitation to join advisory board for research prematurity

Next steps

Scoping exercise re: clinical practice in UK units

Dissemination

Conference in London organised by Robin Balbernie about Churchill's Babies

Speak to Senior Management Team at Trust

Talk to DCPNI Child Faculty meeting

Talk at HV NI Conference

Research

Apply for symposium funding to attend CNOC conference in Toronto on June 2019

Research studies and new research collaborations; identify funding streams

New QUB study accepted and about to start looking at experiences of parents whose babies have been born medically fragile.

Looking at research funding opportunities in collaboration with Dr Victoria Simms, Research Coordinator and Developmental Psychologist from Ulster University (UU).

Research study in early planning stages with Mann-Simms Institute from California

Links

Silke Mander, EFCNI

RCPCH – requesting meeting

Tools

Development of Toolkit for Parents and Professionals

Postscript

Contributed to the TinyLife resource, presented on the WCMT Fellowship at the Association of European Paediatric Psychology Psychosocial Conference and Invited Speaker about Fellowship at the NIBPS conference, invited to be part of a study advisory board for a project on infants attention at 12 months when the baby has been born early. I have developed links with lecturer in University of Ulster and we are working on a joint clinical case study paper of a boy who was born at 24 weeks and was a patient of mine, as well as a research study involving secondary data analysis. Developing training in conjunction with local technical college to promote information about IMH, expansion of virtual under 5s team, links with Mann-Simms Institute.

Its been over 6 months since I finished the travel part of my fellowship and I continue to be amazed by the ongoing ripples that have resulted from it. In fact at times its seemed more like a tidal wave. I've tried to do justice to the experience in the report but its fair to say it can't begin to encapsulate the experience that it was. I have some advice for any fellows embarking on their report, start it before I did! Due to a number of reasons I wasn't able to submit mine within three months and WCMT and Tristan have been particularly patient with me. I don't recommend this length of delay but I do recommend dedicated time to think about it, to ponder the musings that you've made, yes muse on the musings. Protect time at work/home to initially reread your findings, consider materials gathered and simply gather your thoughts. The narrative will then emerge and you will be surprised by the continuing wealth and depth of information that seems to present itself. For any fellows planning their visits, leave lots more time between meetings than you think you will need. The experiences you will have and the information you will gather need assimilation time. And for anyone reading this and considering applying, just do it. I hate to sound like a reality talent show contestant but it really was the experience of a lifetime and continues to offer rich rewards. I am absolutely delighted, proud and privileged to be a Fellow of 2017 and look forward to what the future years hold.

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Ending

Appendices

Talks given

Full Itinerary of Trip

Belfast to Heathrow to Toronto

Toronto to Vancouver

Vancouver to San Francisco

San Francisco to New Mexico

New Mexico to San Francisco to London to Belfast

Belfast to Cork

Cork to Killarney

Killarney to Belfast

Index of Organisations (poss including URL)