



# IDENTIFY INTERVENE IMPACT

An Australian model of best practice for cerebral palsy

**ACTION**   
CEREBRAL PALSY | IDENTIFY  
INTERVENE  
IMPACT

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Identify Intervene Impact – An  
Australian model of best  
practice for cerebral palsy

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# CONTENTS

Foreword from Paul Maynard MP, Patron, Action Cerebral Palsy	4
Key Recommendations	6
Executive Summary	6
<ul style="list-style-type: none"> <li>• Background</li> <li>• Key Findings</li> <li>• Recommendations</li> </ul>	
Acknowledgements	10
Introduction	10
Cerebral Palsy Alliance – Background and History	14
Cerebral Palsy Alliance – Overview of Structure and Activities	15
<b>IDENTIFY</b>	17
1. <b>How is data on children with or at risk of cerebral palsy in Australia collected and what is the role of the Cerebral Palsy Alliance in facilitating data collection and research?</b>	
The Cerebral Palsy Alliance Research Foundation	17
The Australian Cerebral Palsy Register (ACPR)	18
The Australian Cerebral Palsy Register – systems, methodology and content	20
<b>Discussion</b>	23
2. <b>How are babies at risk of cerebral palsy identified? A model of best practice from the Cerebral Palsy Alliance</b>	26
Cerebral Palsy Alliance screening programmes	26
Neonatal Intensive Care and High Dependency Unit, Grace Centre for Newborn Care	27
<ul style="list-style-type: none"> <li>• Screening at three months</li> </ul>	29

• General Movements Assessments video assessment service	29
• Clinic cases	30
Early detection and diagnostic clinic for babies at risk of cerebral palsy, Prairiewood Marconi Centre for Community-based services for children and adults with cerebral palsy or motor disorders	32
• CP diagnostic criteria	33
• Clinic cases	34
<b>Discussion</b>	37
<i>CP Check-Up</i> screening for at risk infants and children with cerebral palsy	
Discussion	
<b>INTERVENE</b>	43
<b>Research to Practice</b>	
1. Allambie Heights, Cerebral Palsy Alliance Headquarters, Sydney	43
• Research priorities and programmes for intervention	45
• Intervention programmes provided by the Cerebral Palsy Alliance for infants	45
GAME	
REACH	
PACT	
VISIBLE	
• Early Childhood Intervention Programmes	47
2. Federal Systems for Early Childhood Early Intervention (ECEI) services and National Disability Insurance Scheme (NDIS)	50
NDIS Headquarters, Canberra	50
• The NDIS	
• Findings and Cost benefit of the ECEI and NDIS	

3. Government overview of health provision for children with cerebral palsy	55
Richard Temperley, Parliament House, Canberra	55
<ul style="list-style-type: none"> <li>• CP Statistics</li> <li>• Research commitments</li> </ul>	
4. How do Federal/State systems of Education work for children with disabilities? Policy and Standards.	57
Dr Gabrielle Phillips, Department of Education and Training, Canberra	
Arrangements for Special Educational Needs and Disabilities support in Education.	
Melissa Clements, Department of Education, Sydney	
<b>Discussion</b>	63
<b>IMPACT</b>	66
1. Data Collection, the Australian Cerebral Palsy, Research and Practice	66
Impact of early identification and intervention via the Cerebral Palsy Alliance and Early Childhood Early Intervention Scheme	67
The ECEI and NDIS	
2. Impact on Families	67
<ul style="list-style-type: none"> <li>• Susan and Molly</li> <li>• Marjorie Logan, Special Needs Teacher</li> </ul>	
<b>Discussion</b>	70
<b>Summary and Recommendations</b>	71
<ul style="list-style-type: none"> <li>• Key differences between Australia and United Kingdom models of provision for children with cerebral palsy</li> </ul>	71
<ul style="list-style-type: none"> <li>• Recommendations</li> </ul>	74
<b>Conclusion</b>	75

## Foreword by Paul Maynard MP

I am delighted to provide the forward for Action Cerebral Palsy's report for the Winston Churchill Memorial Trust on cerebral palsy provision. My relationship with Action Cerebral Palsy goes back many years, and it is humbling to see the charity rightfully take its place as the leading voice in its field, providing insightful policy ideas, and lobbying parliamentarians to push for real and lasting change.

Cerebral palsy is the most common childhood disability in the world, yet we know relatively little about it. We do not know exactly how many young people in Britain are diagnosed with the disorder each year, where they live, or what the impact of cerebral palsy is on their lives. Too few parents understand the signs and symptoms of cerebral palsy, and who they can turn to when they are concerned, whilst knowledge of the condition amongst Members of Parliament is poor. To this extent, Action Cerebral Palsy's role today is more important than ever.

Action Cerebral Palsy has a history of creating influential and impressionable campaigns. A parliamentary inquiry led by the charity in 2014 heard from over 300 submissions, and many of the ideas which emerged from the discussions went on to be incorporated in to wider Government policy. Later, the *Identify, Intervene, Impact* campaign highlighted that insufficient specialist interventions were taking place for babies and toddlers under the age of two, and urged senior stakeholders in the National Health Service and the Department of Health to ensure prompt diagnosis of young children.

When I suggested to Amanda Richardson MBE, Action Cerebral Palsy's Chief Executive, that she should apply for a Fellowship, I was excited to hear about where she would go and what she would discover. Her final report outlining what she found whilst touring Australia, and available on the Action Cerebral Palsy website, is an outstanding document indicating where the UK can learn from Australia's exemplary record in cerebral palsy.

In Australia, a national cerebral palsy register has made it infinitely easier to map who is diagnosed, what symptoms they have, and what their health outcomes are. This information, coupled with improvements to health and education training for clinicians means not only can extra resources be put in to research and care, but that the rate of cerebral palsy amongst new born infants is now falling. This is remarkable achievement, and if replicated in the UK could have a significant impact on improving the lives of children across the country.

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Australian model of best  
practice for cerebral palsy

I implore all stakeholders, whether from the political, health, education or commercial sectors, to take on board the recommendations in this report. We have a great opportunity to improve the lives of disabled children and those with special educational needs. We must seize it.

**Paul Maynard MP is Patron of Action Cerebral Palsy**

## Key Recommendations:

1. A cerebral palsy register for the United Kingdom
2. Improved teacher training, with a specific module on cerebral palsy
3. Standard national pathways of earlier intervention by health professionals to detect, diagnose and deliver bespoke intervention for children with cerebral palsy

## Executive Summary

### Background

This report describes the research carried out for a Winston Churchill Memorial Fellowship in Australia in October 2018. The aim of the research was to investigate models of best practice in the identification and intervention for cerebral palsy, and to find out how the Australian Cerebral Palsy Register was set up and run.

The Cerebral Palsy Alliance in Australia is a world leader in research into cerebral palsy and the organisation co-ordinates the National Cerebral Palsy Register. The Cerebral Palsy Alliance have also developed and implemented models of early detection, diagnosis and intervention which are based on the latest evidence base research – a direct result of improved systems of data collection. The Cerebral Palsy Alliance proactively disseminate their knowledge on their website for an international audience of researchers and clinicians who work with children with cerebral palsy. The result of the work of the Cerebral Palsy Alliance is to set the standard for national and international protocols for detection, diagnosis and treatment for cerebral palsy which could and should be replicated in the UK and worldwide.

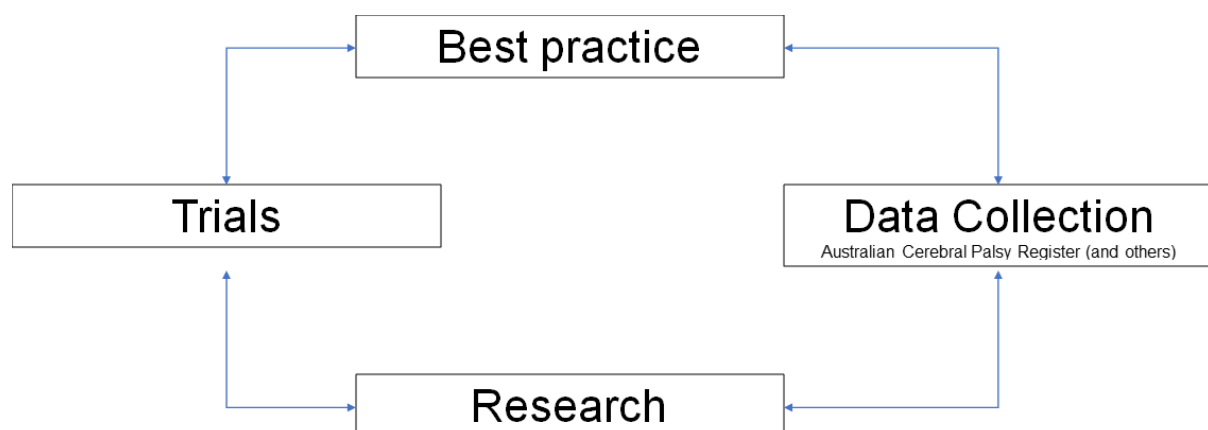
Australia has recently developed a nationwide approach to Early Childhood Early Intervention under the National Disability Insurance Scheme. The approach aims to place the child and his or her family as “participants” at the heart of the decision-making process for support and intervention and a network of “partners” and “providers” has been put in place to support the delivery of services. This is an innovative approach which is still being refined, but which could offer the UK a new option for the delivery of community



services for families of children with developmental delay or disability who may or may not have Education, Health and Care Plans in place.

## Key Findings

- The Australian Cerebral Palsy Register, a collaborative arrangement between the Australian States through which data on children with cerebral palsy is systematically collected and collated by the Cerebral Palsy Alliance and has created an invaluable data bank of cerebral palsy data sets which can be used to inform researchers and strategists. The Cerebral Palsy Alliance would welcome the addition of UK cerebral palsy data to enhance international understanding and knowledge of the condition globally.
- The Cerebral Palsy Alliance models of early screening, detection, diagnosis and intervention deliver a pathway of care for babies at risk or with cerebral palsy which enables them to access high quality clinical and therapeutic intervention at the earliest opportunity. This model could be adopted in the UK to enhance and refine the existing NICE Guidelines on the Management of Cerebral Palsy and Quality Standards and offer a national protocol for early screening, diagnosis and intervention.
- The close relationship between systematic and strategic data collection and robust research has created a virtuous circle leading to improved practice in screening, diagnosis and intervention in Australia



- The Australian Early Childhood Early Intervention scheme under the National Disability Insurance Scheme provides a structured system of community support for families of children with developmental delay or disability in which they are the driving force for decision making about which support services should be put in place for their children. This is a very different approach to that of the UK, in which local authority officials lead the planning and delivery of services for children with additional needs and also control the funding of these services.

## **Recommendations**

- To revisit the development of a national cerebral palsy register with the aim of collecting a minimum data set which will provide information for research, outcomes of clinical practice and policy development.
- To further develop and define clinical pathways for very young babies who require heightened surveillance as a result of their birth history or as a result of surgery as neonates. These pathways to include routine screening at 3 months of age in line with the model adopted by the Cerebral Palsy Alliance, and subsequent follow up checks if they are diagnosed as “at risk of cerebral palsy”.
- To push for improved training and awareness of the risk factors and signs of cerebral palsy in babies and young children for clinical and care practitioners and parents of young babies, and specifically for more specialist health visitors to be trained and employed in the community health workforce.
- To bring about a more family-centred approach to early childhood early intervention, whereby families of children with, or at risk of, cerebral palsy have a more central role in determining vital early intervention provision for their child. This may take the form of the right of referral to specialist providers in the community, private or voluntary sectors who are qualified and able to provide appropriate levels of intensive intervention or for funds to be released directly to parents or guardians for them to access these specialist services, possibly via the personal budget option of the Education Health and Care Plan (EHCP) system.
- To consider the introduction of an appropriately qualified and independent key point of contact and supporter (akin to the “Partner” in

the Australian ECEI/NDIS scheme) for families going through EHCP planning and implementation to ensure that the child and family's needs are kept at the centre of the planning process.

- To push for improved training in cerebral palsy and its impact on learning and development for teachers, pre-school practitioners and learning support assistants who work with children with, or at risk of, cerebral palsy.

## **Acknowledgements**

Firstly, I would like to thank the Winston Churchill Memorial Trust for providing the opportunity to carry out this research through the Churchill Fellowship Scheme. It has been a most valuable and memorable experience, which has been supported every step of the way by the excellent WCMT team.

I would like to also thank my colleague Caroline O'Shea, who accompanied me for the first part of the trip and provided invaluable support and feedback throughout the process.

I would also like to acknowledge the support of the Trustees of Action Cerebral Palsy who encouraged the application and my subsequent work on the project.

The research project would not have been possible without the generosity of those many clinicians, researchers and officials who gave their time to our meetings and conversations. I would like to give a special mention to Dr. Sarah McIntyre, who was a fountain of knowledge, planned a wonderful itinerary and accompanied me to most of the meetings with the Cerebral Palsy Alliance in Sydney.

## **Introduction**

Having worked in the field of cerebral palsy (CP) as a teacher, head teacher and charity chief executive for twenty-four years, I have had the privilege of working with many children and young people with cerebral palsy, their families and fellow professionals who are all united in seeking the best health, educational and social outcomes for people with CP. Whilst progress has been made in the understanding of cerebral palsy and how to best manage the condition and support children and families who are affected, there is still much to do to ensure that all children with CP in the UK have access to the best possible support and intervention as early as possible.

Cerebral palsy is the most common cause of childhood physical disability in the world. An estimated 2 per 1000 live births in the UK result in a diagnosis of cerebral palsy.<sup>1</sup>

Cerebral palsy is an umbrella term for a group of motor disorders usually caused by damage, interference or abnormality of the developing brain. The condition can affect those from all social backgrounds and ethnic groups. It is a permanent but non-progressive condition that has lifelong consequences for those with the condition and their families.

*“Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributable to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsies are often accompanied by disturbances of: sensation, perception, cognition, communication and behaviour; by epilepsy, and by secondary musculoskeletal problems” (Rosenbaum et al. 2007)<sup>2</sup>*

It is now accepted that cerebral palsy usually arises from a sequence of events that when combined can cause or accelerate injury to the developing brain.<sup>3</sup>

For further information about cerebral palsy, please see Action Cerebral Palsy’s report *Enabling Potential – Achieving a New Deal for Children with Cerebral Palsy*.<sup>4</sup>

The cost of managing cerebral palsy in people with the condition in the UK probably runs into billions of pounds. (In 2003, the combined lifetime costs for all people born in the USA with CP was estimated to be \$11.5 billion.<sup>5</sup>) Work on prevention and the alleviation of the effects of the condition is not only vital from a financial perspective, but also to improve the quality of life and life opportunities of people affected. This process, to be most effective and to

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<sup>1</sup> NICE, Spasticity in Children and Young People Final Scope, [www.NICE.org.uk](http://www.NICE.org.uk)

<sup>2</sup> Bax M, Goldstein M, Rosenbaum P, Leviton A, Paneth N, Dan B et al. Proposed definition and classification of cerebral palsy, April 2005. Dev Med Child Neural. Aug 2005; 47 (8): 571-6

<sup>3</sup> [www.cerebralpalsy.org.au/about-conditions/cerebral-palsy/](http://www.cerebralpalsy.org.au/about-conditions/cerebral-palsy/)

<sup>4</sup> *Enabling Potential – Achieving a New Deal for Children with Cerebral Palsy*, 2015, p 11- 15, [www.actioncp.org](http://www.actioncp.org)

<sup>5</sup> *Economic Costs Associated with Mental Retardation, Cerebral palsy, Hearing Loss and Vision Impairment*, Morbidity and Mortality Weekly Report of the Centres for Disease Control and Prevention, 2004.

offer the best outcomes for the individual, must start at the very earliest opportunity.

A key feature of the work of Action Cerebral Palsy is to promote the importance of early identification and intervention for children with cerebral palsy in the UK so that they can have the best possible start in life and opportunities for the future. Closely linked to this objective is the need for high quality evidence-based research on incidence, intervention and outcomes for children with cerebral palsy. However, currently there is no national cerebral palsy register in the UK and relevant data is not collated centrally. This results in a lack of data which can be used for vital research into the condition and for effective provision mapping by health, education and social agencies.

With the publication in 2017 of the *NICE guidelines on Cerebral palsy in under 25s: Assessment and Management* ([nice.org.uk/guidance/ng62](https://www.nice.org.uk/guidance/ng62)), there has been a welcome focus on pathways of care for children with cerebral palsy. However, the guidelines do not offer a clear model or protocol for screening and intervention and there is no standard pathway of early intervention for children with cerebral palsy. This leads to variation of provision across the UK.

These challenges prompted my application to the WCMT for the opportunity to look at existing established models of practice in Australia which could be brought back to the UK, with the aim of informing policy and improving practice in the field of cerebral palsy.

The Cerebral Palsy Alliance based in New South Wales, Australia is an organisation that has for many years been proactive in developing research and practice into the causes, presentation and management of cerebral palsy and it has led the way in the development of a national cerebral palsy register.

The Australian Federal Government has also developed an Early Childhood Early Intervention Programme which is being rolled out for children aged 0-6 with developmental concerns.

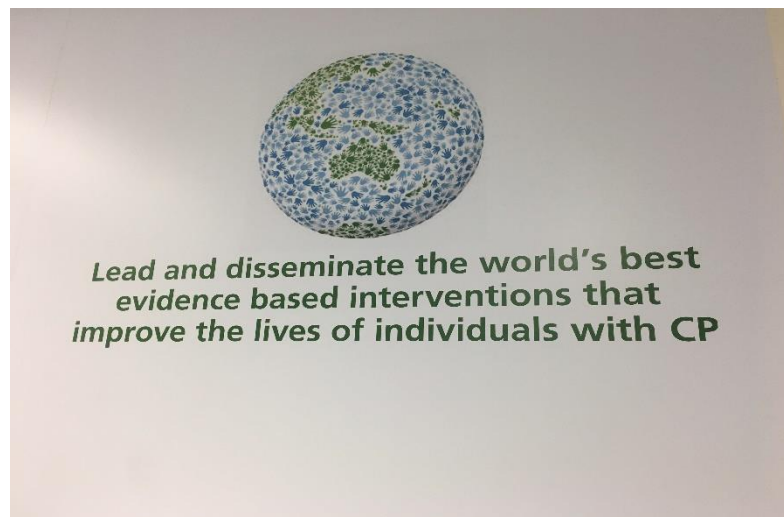
The opportunity provided by the Winston Churchill Memorial Trust to travel to Australia to investigate models of best practice in identification, early childhood intervention, and the Australian Cerebral Palsy Register was therefore welcomed with gratitude and anticipation. The research activities were inspirational, and I was privileged to meet extraordinary individuals who are working hard to further the understanding of cerebral palsy, its causes and

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practice for cerebral palsy

management and to put this knowledge into practice for the benefit of  
children with cerebral palsy and their families worldwide.

## The Australian Cerebral Palsy Alliance

[www.cerebralpalsy.org.au](http://www.cerebralpalsy.org.au)



### Background and History

The Cerebral Palsy Alliance (CPA) (has been in existence for 75 years. Formally known as the Spastics Centre, it was started by parents whose daughter had cerebral palsy. They were unhappy with the poor prognosis given for their daughter and set out to explore what was happening in the world of cerebral palsy. They set up the Mossman Centre and continued to cultivate interested professionals who wished to develop clinical, educational and rehabilitation opportunities for people the condition. The work of the initial Spastics Centre spread across the States of Australia as separate entities.

Today, the CPA, led by CEO Mr Rob White, is a highly innovative not-for-profit organisation with a deep commitment by all of the team from the top down to furthering knowledge and understanding of cerebral palsy and best practice in its management. The strategy and direction of the CPA continues to be led by people with cerebral palsy and their relatives and the CPA acts as an advocate on behalf of people with cerebral palsy.

The CPA has a A\$40 million annual operating budget and, whilst some income is received through research grants and the National Disability Insurance



Scheme for services provided to clients, the organisation relies heavily on fundraising income to provide client services. It employs 1300 people who work in centres and homes across New South Wales (NSW) and Australian Capital Territories (ACT). Services are whole lifespan and are mainly community based.

The CPA is a recognised leader in early identification and intervention for cerebral palsy.

## Cerebral Palsy Alliance – Overview of Structure and Activities

Cerebral Palsy Alliance Research Institute, Faculty of Medicine, University of Sydney	Early Detection Services	Early Intervention Programmes	On-site services at Cerebral Palsy Alliance Centres	Homes and community services for adults
1.Responsible for funding, co-ordinating and disseminating research on cerebral palsy. Key people: Professor Nadia Badawi, Professor Iona Novak, Dr Sarah McIntrye, Dr Petra Karlsson	Providing clinics and monitoring programmes for babies and children with or at risk of cerebral palsy. 1.Grace Centre for Newborn Care, Westmead Children's Hospital; Early detection clinic for newborns (3 months) SCBU HDU Video based screening assessments. (Professor Nadia Badawi, Head of Service)	Home and Centre based programmes for children diagnosed with cerebral palsy or "at risk" of cerebral palsy provided throughout New South Wales and Australian Capital Territories. Some of these programmes are connected to ongoing research trials.	For example, Allambie Heights which offers therapy rooms for intervention programmes, gymnasium providing elite athlete programmes and other activities for people with cerebral palsy, exercise physiologists, engineering workshop producing custom built equipment, dental clinic staffed by volunteer dentists, community café, meeting rooms	Providing workshops, exercise programmes, therapy, home and equipment assessments, mobility assessments and equipment and assistive technology.

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Australian model of best  
practice for cerebral palsy

			and outdoor spaces and play areas.	
2.Oversees the Australian Cerebral Palsy Register, key people: Dr Sarah McIntyre and Dr Hayley Smithers- Sheedy	2.Early Identification Follow-up clinics (6-18 months) e.g., Prairiewood Centre, (Dr Prue Golland- clinical Lead)			
	3.CP Check-up surveillance programme for children who are diagnosed as “at risk” of cerebral palsy – (Dr Petra Karlsson, co- ordinator)			

**IDENTIFY**

**How is data on children with or at risk of cerebral palsy in Australia collected and what is the role of the Cerebral Palsy Alliance in facilitating data collection and research?**

**The Cerebral Palsy Alliance Research Foundation**

[www.research.cerebralpalsy.org.au](http://www.research.cerebralpalsy.org.au)



With Dr Sarah McIntyre (centre) at the CPA Research Institute

In the early 2000s, The Board of the Cerebral Palsy Alliance took the decision to start a research programme in response to the overwhelming need to gain a better understanding of cerebral palsy, its causes and treatments. The Research Foundation was established in 2005 in order to fund Australian and international research into the treatment, prevention and cure of cerebral palsy.

The remit of the Foundation is to accelerate breakthroughs in the understanding of cerebral palsy by building research networks and supporting high quality research projects. The Foundation's Grant programme has awarded over A\$37 million to over 330 recipients, both individuals and group projects from the international community. Professor Iona Novak, Head Therapist at the CPA and then Dr Sarah McIntyre were the first researchers at the CPA Research Institute.

Professor Nadia Badawi, who I was privileged to meet at The Grace Centre for Newborn Care, was appointed in 2009 as first Chair of Cerebral Palsy to oversee projects funded by the Research Foundation and led the team of outstanding researchers including Dr Sarah McIntyre, Professor Iona Novak, Dr Hayley Smithers and Dr Petra Karlsson at the CPA Research Institute at Notre Dame University School of Medicine. Professor Badawi's position is funded by the Macquarie Group Foundation, University of Notre Dame and the Australian Government. Professor Badawi AM, is an internationally renowned neonatologist who has carried out extensive research on the neurodevelopmental outcomes of infants who have received neonatal intensive care, surgery or who have had neonatal encephalopathy and cerebral palsy.

## **The Australian Cerebral Palsy Register (ACPR)**

### **Background**

A cerebral palsy register had already existed in Perth and Western Australia for some years and, as other states recognised the value of a register and the need to increase the number of participant states, there was a drive to make the register nationwide. The Cerebral Palsy Alliance offered to start the ACT (Australian Capital Territory) register in 2004 and were then chosen by the other states to run the national register. As a result, The ACPR was established in 2008 as a collaborative partnership between all Australian state and territory CP registers, and the organisations which support each register. These are;

- Australian Capital Territory and New South Wales Cerebral Palsy Registers – Cerebral palsy Alliance, University of Sydney
- Northern Territory Cerebral Palsy Register - Centre for Disease Control
- Queensland Cerebral palsy Register - CPL- Choice, Passion, Life and Queensland Department of Communities, Child Safety and Disability Services
- South Australian Cerebral Palsy Register – Women's and Children's Health Network
- Tasmanian Cerebral palsy Register – St Giles
- Victorian Cerebral Palsy Register – Murdoch Children's Research Institute, Royal Children's Hospital, Melbourne

- Western Australian Register of Developmental Anomalies – Cerebral Palsy – Department of Health WA

The first birth year cohort registered for the first five of these states was 1993, the Victorian CP register, 1970 and Western Australia (Perth) 1956.

Each State provides funding for their register.

The aim of the Register is to provide a research database to facilitate the study of;

- the distribution, frequency and severity of cerebral palsy
- the causes and determinants of cerebral palsy
- the effectiveness of prevention strategies
- The planning and evaluation of services

and to be a source of data that will support research relating to;

- Monitoring of cerebral palsy
- Identifying interventions that effectively improve quality of life
- Identifying causal pathways to enable prevention
- Evaluating future preventative strategies

## **Australian Cerebral Palsy Register – system, methodology and content**

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Dr Sarah McIntyre and Dr Hayley Smithers-Sheedy explained how the Register is managed.

The Register operates via a web-based platform which has been developed by a data engineer. I was told that whilst the current system works well at present, it would be difficult and expensive to make changes. Security is also expensive. It costs A\$ 18,000 per annum to keep the ACPR data on a secure server. New cloud-based database options are coming on to the market, and these

Data is submitted to the database by the participating states on a three-yearly cycle and can include data from previous years up to 2012. Whilst each state

can collect additional data, the ACPR has a minimum data set and data is collected and reported in a standardised way.

There is a time line for the submission of data and states collaborate over what information is included and the level of compliance and collaboration is reported to be good.

In order to be included in the dataset, a case must fulfil the criteria for CP as outlined in the Rosenbaum definition of cerebral palsy and a child's record is confirmed when they reach the age of five.

Data on all live births is obtained from the National Perinatal Epidemiology and Statistics Unit.

The Australian Cerebral Palsy Register aims to harmonise data sets as much as possible with European and international registers because the combining and collating of data facilitates and strengthens international research. A survey of twenty-seven international surveillance programmes and registers was carried out by Dr Sarah McIntyre, Dr Hayley Smithers Sheedy and others with the aim of describing *“cerebral palsy surveillance programmes and identify similarities and differences in governance and funding, aims, scope, definition, inclusion/exclusion criteria, ascertainment and data collection, to enhance the potential for research collaboration”*<sup>6</sup>.

The CPA proactively supports the development of a network of international register builders and convened a day convention on cerebral palsy registers at the World Cerebral Palsy Congress in 2016. Currently the CPA is supporting the development of CP registers in New Zealand and Bangladesh. The managers of the Australian Cerebral Palsy Register work closely with colleagues running registers in Europe, Scandinavia, America and Canada. Unfortunately, despite the excellent efforts of clinicians and researchers in the UK, we now only have one working register, the Northern Ireland Cerebral Palsy Register, and this is a cause for concern and regret for the CPA.

The survey showed that the majority of international programmes including the ACPR, collected the same data sets with all programmes collecting data on the following domains: date of birth, sex, birth weight, gestational age, GMFCS

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<sup>6</sup> Shona Goldsmith, Sarah McIntyre, Hayley Smithers-Sheedy et al (2016) *An international survey of cerebral palsy registers and surveillance systems*, Developmental Medicine & Child Neurology 2016 Mac Keith Press, 58 (Suppl.2) 11-17

(Gross Motor Function Classification Scale), diagnosis/motor type, post neonatal cause/timing, epilepsy/seizures, syndromes/congenital malformations, magnetic resonance imaging.

The most recently published Australian Cerebral Palsy Register (2016) collected data in the following domains:

**1. All cerebral palsy**

- All children with cerebral palsy
- Indigenous status of mother

**2. Prenatally or perinatally acquired cerebral palsy**

- Prevalence
- Timing of initial cerebral palsy description
- Sex
- Maternal age at time of delivery
- Gestational age at time of delivery
- Birth weight
- Plurality
- Predominant motor type
- Gross motor function
- Congenital abnormalities
- Associated impairments: vision, hearing, speech, epilepsy, intellectual impairment

**3. Post-neonatally acquired cerebral palsy**

- Prevalence
- Post neo natal cause
- Sex
- Maternal age at time of delivery
- Predominant motor type and topography
- Associated impairments

The Australian Cerebral Palsy Register collates the above information that has been fed into a spreadsheet from hospitals, families, schools and treatment centres and the process is designed to make everything as easy as possible for the professional to submit data.



Some states have statutory notification for cerebral palsy but in New South Wales, the Australian Cerebral Palsy Register manager or the child's rehabilitation manager contacts families with an "opt off" letter to ask if the family agrees to the child being included in the register. I was told that goodwill between the staff of the ACPR, families and practitioners across all areas is important for the smooth functioning of the Register.

All actions and developments go through the ethics committee with the support of clinical practitioners.

Data on neonates is collected from hospitals once per year, with information collected on children seen who are at risk of cerebral palsy and/or who have an abnormal MRI reading. There is ongoing concern that some babies and children will be missed. There is therefore a drive to get all high-risk infants under four months of age on to the register or monitored, and Dr McIntyre has set up an advisory group which aims to collaborate with community therapists to identify any babies or children who they might have seen who should be referred for screening and/or and early intervention programmes.

All children on the register are followed up with at age five to see if they continue to have a diagnosis of cerebral palsy or another diagnosis/developmental delay. I was told that currently 50% of children are diagnosed with cerebral palsy in their first year, 75% by their second year and 90% by their third year. There is a push to increase the number of diagnoses of cerebral palsy in the first year to enable intervention specific to the presentation of the child.

Data from the CPA run *CP Check-Up* scheme (a six-monthly check-up for children at risk of cerebral palsy described below) will also be included in the register.

The next Australian Cerebral Palsy Register is due for publication in late 2018.

## **Discussion**

It was clear throughout my discussions with colleagues from the Cerebral Palsy Alliance that they were totally committed to not just working towards a better understanding of cerebral palsy but to be the driving force behind research and development of best practice on the international stage. There has been a

strategic and systematic approach by the leadership as to how this can be achieved, with the Australian Cerebral Palsy Register being the key to new research into the prevention, treatment and cure of cerebral palsy and the provision of cerebral palsy services.

The Australian Cerebral Palsy Register is used by researchers, members of the public, university students, individuals with cerebral palsy and their families, service providers and Government agencies. In other words, the ACPR provides a wealth and variety of information about the condition, which can be used to enhance research, but can also provide a very clear picture about the current and projected requirements for those diagnosed with the condition. I was informed by Government officials that data from the Register was used to inform health policy on disability, and that the ACPR was a respected source of data for the Federal Government. This confidence in the CPA's data was reflected in an A\$2 million Government grant via the National Health Medical Research Council to the CPA Research Institution.

The impact of the Australian Cerebral Palsy Register on supporting the development of knowledge into the causes and treatment for the condition can be seen in the high prevalence of research papers, collaborative international studies, intervention trials and pilots that have drawn on data from the register. In turn, relevant data and results from these activities are fed back into the Register, further enriching the information bank. There is, thus, a virtuous circle created from research to practice and back to research, with an ever-increasing understanding of what causes cerebral palsy and what can be done to prevent and treat it.

There are now approximately 40 cerebral palsy registers and surveillance programmes operating around the world, providing enormous potential for collaboration between registers, for example, to enable the combining of data to increase numbers for robust research inquiry.

It is an indictment of the current level of provision available for children with cerebral palsy that the UK lags so far behind the rest of the world in its contribution to collective information about our own children with cerebral palsy. There is some excellent research and practice taking place in the United Kingdom, but we are over-reliant upon data from other countries for research and information about CP. A 2017 Freedom of Information Study carried out by Action Cerebral Palsy, (*Variations in Care: An analysis of cerebral palsy*

*provision*), which sought information about provision for children with cerebral palsy across the UK, revealed a vast variation in the quality and detail of information collected about children with cerebral palsy with many local areas being unable to provide detail about numbers of children with CP or pathways of care provided for children with the condition.

Other organisations and studies share the concern about the lack of detailed data. For example, Cerebral Palsy Integrated Pathway, (CPIP-UK), which collects data on orthopaedic procedures on people with cerebral palsy, <sup>7</sup> has asked why there is not a cerebral palsy register in the United Kingdom. The influential Francis Report, 2013, called for increased information about clinical interventions and outcomes for patients. Recommendation 263: *“It must be recognised to be the professional duty of all healthcare professionals to collaborate in the provision of information required for such statistics on the efficacy of treatment in specialities”*. Recommendation 268: *“Resources must be allocated to and by provider organisations to enable the relevant data to be collected and forwarded to the relevant central registry”*. <sup>8</sup>

Researchers and clinicians in the UK have worked hard in the past to collect data on children with cerebral palsy but have been frustrated by lack of funding. It is now time to revisit the need for a National Cerebral Palsy Register.

Having spoken to researchers at the CPA about the state of play in the UK, we believe that there is a way forward which could look at how previous UK registers could be revived, and existing ones strengthened, perhaps by initially collecting data in a few key domains. The coding system already in existence for NHS diagnostics may provide a starting point for data collection.

This will require collaboration and consultation with expert stakeholders to ensure that there is an agreed and systematic approach to establishing a National Cerebral Palsy Register, together with support from Government and funding bodies for the project. This will be a key focus for Action Cerebral Palsy, and the example of the Australian Cerebral Register will motivate us in

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<sup>7</sup> <https://apcp.csp.org.uk/content/cerebral-palsy-integrated-pathway-developing-uk-wide-programme>

<sup>8</sup> Francis R (2013) Report of the Mid-Staffordshire NHS Foundation Trust Public Inquiry. London: The Stationery Office.15 Jul 2014

our work. In the words of Goldsmith et al in their paper, *An international survey of cerebral palsy registers and surveillance systems*;

*“In this era of increased research into the possibilities for prevention of CP and achieving better outcomes for those with CP, surveillance programmes will play a vital role in the pragmatic evaluation of treatments that have been found to be efficacious or effective in a research setting. It is important that existing programmes are able to report not only trends in prevalence but also severity, and compare these across different geographical regions, particularly those that differ in their approaches to perinatal care and CP management”.<sup>9</sup>*

## **Cerebral Palsy Alliance screening programmes**

**How are babies at risk of cerebral palsy identified?**

**A model of best practice from the Cerebral Palsy Alliance.**



At the Grace Centre for Newborn Care, Westmead Children's Hospital

### **1. Babies aged 0-3months (neonates)**

I was privileged to be able to visit the Cerebral Palsy Alliance's Grace Centre for Newborn Care and Developmental Clinic, co-located with the Westmead Children's Hospital in Sydney. I spent the day there observing screening clinics

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<sup>9</sup> Shona Goldsmith et al, 2016, *An international survey of cerebral palsy registers and surveillance systems*. Developmental Medicine and Child Neurology, Mac Keith Press, 58, (suppl.2); p 17.

for newborns and discussing the care of newborns and infants in the neonatal intensive care unit and high dependency unit.

Clinical practice in the unit reflects the most recent evidence-based research, much of which was carried out through or with the support of the Cerebral Palsy Alliance Research Institute. For example, the evaluation methodology around screening and assessment for cerebral palsy is discussed in a systematic review of the literature by Iona Novak, Cathy Morgan, Lars Adde, et al in *“Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy”*.<sup>10</sup>

Where appropriate, information on patients treated or seen at the unit is collected for inclusion in the Australian Cerebral Palsy Register.

Dr Alison Laughran-Fowlds, Nurse Manager and Clinical Director of the Grace Centre, explained that the unit is one of two surgical referral units in the state for neonates with complex needs or who have had cardiac surgery. A neonatal intensive care and high dependency ward for these neonates is situated within the Grace Centre.

Due to the link between surgery on neonates and increased risk of cerebral palsy, all neonates who have received an anaesthetic will be referred for screening and assessment. 600 appointments are scheduled, and 200 babies are seen each year, with a focus on surgical cases.

The unit adopts a parent professional partnership approach to screening and surveillance as discussed by Baird et al in *“Screening and surveillance for autism and pervasive developmental disorders”*<sup>11</sup>

### **Neonatal intensive care and high dependency unit, Grace Centre for Newborn Care**

Dr Kathryn Crowe, Paediatric Occupational Therapist, kindly showed me around the NICU and HDU. There are 20 beds in the unit. Neonate babies in the unit are either post-surgery or critically ill. Premature babies stay in the

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<sup>10</sup> Iona Novak PhD, Cathy Morgan PhD, Lars Adde PhD, et al, (2017); *Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment*, 2017, JAMA Pediatr. 2017;171 (9): 897-907

<sup>11</sup> G Baird et al, 2001, *Screening and surveillance for autism and pervasive developmental disorders*, Archive of Disease in Childhood, Volume 84, issue 6.

unit of birth unless they become critically ill in which case they will be transferred to the Grace Centre.

- A NIDCAP approach (Newborn Individualized Developmental Care and Assessment Programme) is used throughout the unit in the care of the babies and all nurses, allied professionals and doctors apply this approach in their clinical practice
- The ward is warm, quiet, calm and cheerful
- A GMs (General Movements) assessment is carried out routinely on all babies in the unit
- MRIs are not done routinely unless clinically indicated
- OTs work on the ward with families and staff to support early development and are part of the weekly developmental ward round.
- The OTs on the ward will carry out the follow-up screening assessment in clinic at 3 months
- Families can stay on the ward which has family friendly facilities
- OTs provide families with guidance, information and support for developmental activities for their babies as appropriate (more in the HDU)
- Volunteers receive training to act as “ward grannies” to be with babies when their parents can’t be.
- A discharge nurse co-ordinates discharge arrangements and community follow up care if required
- All babies on this ward will be assessed at 3 months at the early detection screening clinic



With Professor Nadia Badawi (centre), Dr Kathryn Crowe (2<sup>nd</sup> from right) and members of staff on the NICU at the Grace Centre for Newborn Care.

### **Screening at three months**

The three months screening assessment carried out at the Grace Centre is critical because this is the optimal point to carry out the *Qualitative Assessment of General Movements* (GMs) (Prechtel), which screens for abnormal movements that can be predictors of cerebral palsy. Other assessments used at this assessment are *Hammersmith Infant Neurological Assessment (HINE)*, and the *Bayley Scale of Infant and Toddler Development*. MRI (Magnetic Resonance Imaging) is not carried out at this stage.

If assessment results indicate suboptimal scores, the assessment team will invite the family back for a meeting to explain these and advise that the baby will be referred on to other agencies such as the paediatric and/or surgical teams for follow up. An MRI may be done at this stage or later if clinically indicated. If, *in combination*, assessments indicate signs of cerebral palsy, a diagnosis of “at risk of cerebral palsy” or a firm diagnosis of cerebral palsy will be made.

Developmental check-ups and early intervention are offered by the CPA if the baby is diagnosed as being “high risk”, and the Cerebral Palsy Alliance will support families through the application process to the National Disability Insurance Scheme in order to access early intervention. Early intervention can be provided by the CPA free of charge as a bridging arrangement until NDIS money is available.

If there are no concerns at this stage, a letter will be written to the family to confirm this.

### **GMs assessment video service**

The Clinic offers a service for families who live a long distance from the clinic and who may have concerns about their baby. This is available to families via an App for parents called “*Baby Moves*”. A short video of the baby (optimum age 12-14 weeks after due date) is recorded by the family according to instructions and analysed using the GMs by the CPA multi-disciplinary team.

## Clinic cases

The early detection clinic that I observed was overseen by Consultant Neonatologist, Dr Himansuli Popat, and assessments were carried out by a paediatric physiotherapist, Michelle and occupational therapist, Madeleine. The team work seamlessly together, alternating between mum and baby in a fluid manner. They work calmly and slowly, talking quietly about what they are doing in a relaxed and informal way. I saw three cases in the morning clinic.



Physiotherapist, Michelle and Occupational Therapist, Madeleine, at the Early Detection Clinic at the Grace Centre for Newborn Care, Westmead Children's Hospital, Sydney.

### Baby 1

Female, 3 months of age, born term at 40 weeks, diagnosed at birth with co-articulation of aorta, repaired at 20 days old. Baby spent 2 weeks in NICU, treated with prostaglandin and then discharged. This was the first follow up.

Assessment process:

- Mum welcomed to clinic by the consultant who explained the purpose of screening clinic (to identify any potential developmental problems)
- Mum was asked about general wellbeing of baby
- Assessment explained with opportunity for questions
- Baby was videoed for the GMs Assessment by the physiotherapist. The video is analysed by the team after the assessment
- HINE assessment
- Bayley assessment



Baby scored well (10/9/10) on the Bayley, being in the mid normal range. There was some flattening of the head and a very mild preference for the left side. Dr Popat explained the scores to baby's mother and advice on positioning and play was provided to mum by the OT and physio. No onward referral to specialists.

### **Baby 2**

Male, 3 months of age, born term at 40 weeks. Heart block detected at birth, pacemaker inserted. Mum reported that she felt the baby was making good progress.

Assessment was carried out as above.

Baby scored 8 on Bayley (normal score 8-12) and 58.5 out of 78 on the HINE, which was a slightly sub-optimal score. Baby to be kept under surveillance.

### **Baby 3**

Male, 3 months of age, born term at 40 weeks. Needed respiratory support post birth and diagnosed with Pierre Robin Sequence, which is a genetic condition resulting, in this case, in malformation of the jaw and cleft palette. Received CPAP (continuous positive airway pressure) support and on discharge received "hospital at home" care with nursing support for breathing and sleeping co-ordinated by the GP. Family are waiting for confirmation of date of corrective surgery.

Assessment as above.

Mum asked about developmental risks associated with the condition and whether there was risk of cognitive delay. The consultant explained that the screening assessment would identify any potential problems, and mum asked what she should look for.

Baby scored 5 on the problem-solving element in Bailey (suboptimal), and 7 for motor skills, and 50 for HINE, which was slightly suboptimal overall. The consultant explained how skills in in assessment can be interlinked, for example, vision and fine motor.

Baby will be seen again in 3 months and after surgery, and a follow-up screening assessment, including hearing at 8 months to rule out any other concerns.

The physiotherapist and occupational therapist offered immediate education and guidance for mum, demonstrating with a doll how to support baby with motor transitional movements, for example rolling and sitting to lying to encourage muscle development and head control. They also discussed how to support early learning, hand control and object exploration. Mum was given a print out of these activities.

**The day spent at the Grace Centre left a lasting impression of skill, dedication, compassion, care and best practice from all those involved. The central role of the family and the positive relationship between the family and the clinicians was very evident.**

**The well thought out processes and adherence to a systematic approach to delivering screening and early detection services for neonate babies and their families provides a sound, evidence-based model of best practice in the accurate diagnosis of signs of cerebral palsy in the very young.**

## **2. Early detection and diagnostic clinic for babies “at risk” of cerebral palsy.**

**Prairiewood Marconi Centre for community-based services for children and adults with cerebral palsy/motor disorders.**



CPA Prairiewood Centre Reception

This clinic provides a follow-on screening assessment service for older babies as a next step from the newborn screening at the Grace Centre. This new

service was set up by the CPA very recently after three years of funding applications and collaborative planning between the CPA and Westfield Children's Hospital, which provides the neonatologist for one day per week.

This is a twelve-month pilot project at present with the aim of developing satellites across New South Wales. The project is currently funded by a A\$200,000 grant from a corporate funder, together with some minimal funding from the national medical insurance scheme, Medicare, and subsidy from the CPA charitable funds. The cost of clinic per day including report and follow up is A\$4,000 per day. The assessment sessions are free of charge to families

The team of highly skilled therapists (the most senior in the CPA) is led by Dr Prue Gollard (a Churchill Fellow). The multi-disciplinary team comprises, with the neonatologist, a physiotherapist, occupational therapist, speech pathologist and social worker.

Referrals to the clinic are made via the parents, GPs, community therapists and paediatricians.

Babies come to the clinic for assessment only, and intervention, if required, will take place in the community at home or if the family wish, a CPA Centre. Members of the assessment team can advise about CPA services.

### **Cerebral Palsy diagnostic criteria**

The results of assessment at this clinic ***in combination*** with other information, for example, MRI scan and consultation with other clinicians, may result in a diagnosis of cerebral palsy or “at risk” of cerebral palsy. The final diagnosis will be given by a neonatologist or paediatrician. To assign an interim clinical diagnosis of “high risk of CP” from the CPA, the infant must have essential criteria for motor dysfunction and one of the following:

- Motor dysfunction where the quality of movement is reduced (abnormal GMs) or suboptimal HINE and/or the infant's motor activities are substantially below that expected for his/her chronological age
- Abnormal neuroimaging: Abnormal MRI and/or cranial ultrasound in preterm infants indicating neuro anatomical abnormalities
- Clinical history indicating risk of cerebral palsy

**Further information about clinical criteria for early diagnosis of cerebral palsy can be found in the Clinical Practice Guidelines written by Professors Nadia Badawi and Iona Novak together with parents in the Practitioner e-Learning Resources at [www.cerebralpalsy.org.au](http://www.cerebralpalsy.org.au)**

## **Clinic cases**

### **Baby 1**

Female, 8 months corrected age, born at 36 weeks by C section due to breech position, in SCBU for 4 days. Developmental newborn screen was “fine”, but at 3-4 months mum noticed that felt that the baby was “a little stiff” in her legs so referred by her GP to local community physiotherapist who told mum that baby had mild CP. (A CP diagnosis can only be given by a neonatologist/neurologist/paediatrician following a sequence of diagnostic tests). As a result, mum, who was highly anxious, self-referred to this clinic for a more in-depth assessment.

Baby able to clap, weight bear in standing with support and just starting to cruise, vocalise, smile and eat finger food.

Assessment process:

Consultation was led by the neonatologist

- Parental history
- Pregnancy history
- Birth history
- General development – (feedback from Mum) feeding, nutrition, sleep, play, communication
- Physical examination of baby; weight, head circumference, length, reflexes, muscle tone
- Assessment – Peabody Developmental Motor Scales (2<sup>nd</sup> Edition)  
<sup>12</sup>(PEDI) carried out by OT and physiotherapist

The therapists work together, one observing and recording and one working with baby.

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<sup>12</sup> Rhonda, M, Fewell R, 2000

Following the assessment and the analysis of the scores, the neonatologist provided feedback to the parents. Whilst the baby's developmental skills were developing well overall, the scores on the motor scales were suboptimal and some stiffness in her upper and lower limbs was detected – her reflexes were “brisk”. This suggested that the baby could be “at risk” of CP, but a firm diagnosis was not possible at this point. Mum was anxious about the future and the social worker explained how it was important to enjoy the baby and family time together.

Next steps;

- Report from this consultation will be sent to parents within 2 weeks
- Referral for MRI scan which will provide more information on the reasons for the symptoms
- Blood and genetic tests will be carried out
- If the neuroimaging is fine but the stiffness continues, then therapy will continue with the community physiotherapist. There will be no cost to the family at present for therapy as this will be provided free of charge by the CPA until Government funding is in place.
- Family will return at 18 months for a follow-up assessment at Prairiewood.

Following the consultation, after the family had left, the team explained to me that this case was an example of a family whose baby had not shown any obvious problems at birth and had therefore not come through the Grace Centre pathway. Referral for follow up assessment had been made by parents as a result of concerns raised by a community therapist, after mum (a teacher) had consulted with her GP about her anxieties about her baby. As a moderately pre-term baby, at 36 week's gestation, she falls into a category which a body of research shows is “at risk” of cerebral palsy /neurodevelopmental disorders due to the critical timing of in utero development. If mum had not raised her concerns with her GP, it is unclear to me whether the baby would have received any further assessment until more obvious signs of developmental delay became apparent. I believe that the same scenario would be the case in most areas in the UK.

**This underlines the need for increased education for families, clinicians and allied health professionals so that they can be better informed about the risk**

**factors and signs associated with CP, and for protocols for screening to be put in place should these factors exist.**

## **Baby 2**

Male, 14 months, born at term, diagnosis of primary microcephaly and global developmental delay, diagnosed with CP by the CPA neonatologist following assessment at the Early Detection Clinic at 10 months. Mum had experienced a bleed in the third trimester of pregnancy.

After the diagnosis at 10 months, a meeting with parents was held with the CPA neonatologist at which CP was explained; its definition, causes and associated complications. Baby was referred for an MRI, to audiology and eye clinic, for blood/genetic tests, for hip x-ray and for physiotherapy, OT and speech pathology provided by the CPA.

At this follow up session, the following consultation took place with the neonatologist, physiotherapist, and social worker:

- General update on appointments and development; MRI due in two months, attended rehab clinic and referred for orthotics
- Physical examination as above including visual (squint)
- Physio “plays” with baby on floor whilst observing him while neonatologist talks to parents. Baby can roll back to front, clap with clenched fists, say 3-4 words. He shows stereotypical movements in upper limbs which are “stiff”
- Neonatologist explained to parents that the genetic tests showed some abnormality. This is common, but further tests will take place on parents which will help to indicate if there are any specific factors which may affect the baby. The MRI will also provide further information about the causes of the baby’s condition
- Mum asked about the GMFS level given (3-4) following diagnosis. The physiotherapist explained the level saying that it’s hard to be accurate until age 2, but as baby isn’t sitting at 14 months it is likely that he will require support for his mobility as he gets older, for example, a walking frame and wheelchair for long distances. Early intervention will help, but it is important to plan now for any potential support which he will need to help him explore his environment

- The physiotherapist discussed postural management and activities to carry out at home
- The social worker explained how funding for special equipment would come through the NDIS (National Disability Insurance Scheme) and that baby would be eligible for the Early Childhood Early Intervention programme. She would support the family with access to these schemes. She also explained the role of different therapists that the family will encounter and types of equipment available

Next steps:

- Team will see family again after the scan and the neonatologist will go through the results with family and discuss any further investigations.

### **Baby 3**

Male, 12 months corrected age, born premature at 26 week's gestation. Developmental delay.

Follow-up assessment as above. Referred for MRI and awaiting date.

Neonatologist explained that the HINE assessment previously carried out showed slightly subnormal scores for lower limb function which causes slight concern, but they are not at the level which would indicate CP at this point. More information will be available after the MRI.

Next steps: Meeting following MRI scan.

### **Discussion**

Once again, I was impressed with the obvious high level of methodology and planning which underpinned this early detection assessment clinic.

In discussions with CPA clinical leaders, it was clear that huge importance was placed in increasing individual and collective understanding of cerebral palsy at the highest level. Nearly every clinician I met had PhDs in their field or were working towards one and this level of personal development was actively encouraged and supported by the leadership. There was a collective undertaking to be "the best we can be".

This commitment to research and personal development naturally resulted in ensuring that current research, if applicable, was put into clinical practice in

both the detection and treatment of cerebral palsy and the clinics I observed were examples of this principle.

I was also impressed with the openness and transparency of information which was shared with the family. I was told that it was a matter of clinical judgement as to how much information was given about prognosis and outcome for the child, but I sensed that the clinicians respected the family's need for full and clear explanations and opinions about the future. This is in line with the family centred approach adopted by the CPA in which families are viewed as equal partners in the diagnostic and intervention process.

The inclusion of a social worker in the multi-disciplinary assessment team supported the emotional and practical needs of the family during and after the consultation. The immediate question of "what happens now?" in terms of community support, therapy and equipment needs could be answered and the family left the consultation knowing that there was a professional available to them who would be able to act as an advisor and advocate for ongoing support needs. This is a model of holistic support that so many families with children with cerebral palsy need and deserve but is often difficult to find.

There was much discussion during the visit to Prairiewood of the newly introduced state system of funding for disability, the National Disability Insurance Scheme known as NDIS, and the pros and cons of this system (discussed further in section 7). As in the UK, there are gaps in funding for intervention for very young babies. Currently, whilst the Cerebral Palsy Alliance is eligible to receive some income from fees for client services via the NDIS, most of their work on research and clinical practice is funded via philanthropic fundraising.





With Dr Prue Gollard (Churchill Fellow) at Prairiewood Centre

### 3. ***CP Check-Up*** screening for “at risk” infants and children with CP

#### **Dr Petra Karlsson**

Dr Petra Karlsson is an occupational therapist from Sweden who started a surveillance project collecting information on hips, knees and upper limb function. On her arrival in Australia, Dr Karlsson collaborated with senior colleagues at the CPA to develop the *CP Check-up* as a resource for the cerebral palsy register. The project took a year to develop and then operated as a pilot for the first 12 months of operation.

The *CP Check-up*, which is exclusive to the CPA, is a comprehensive and holistic surveillance assessment for children “at risk of CP” or with a diagnosis of cerebral palsy from birth to 12 years of age. It is offered every 6 months to children under the age of 6 years and every 12 months for older children. It is free of charge to parents.

The aim of the surveillance assessment for the child is to ensure that the best intervention can be given at the right time, proactively intervening to, for example, reduce deterioration, prevent pain and improve nutrition.

Families can self-refer or be introduced by a therapist or hospital staff. The surveillance for at risk infants will continue until the risk is eliminated. The two-hour session has four areas of focus; Assess, Monitor, Identify and Report, Plan and Provide.

At present the *CP Check-up* is only offered in NSW but the CPA would like to roll it out to other regions when funds permit. Currently, 1200 families are being actively monitored, with 10 new families joining the programme each month

All clinicians who carry out the assessment receive induction training to ensure that assessments are carried out correctly and data input is accurate.

The Assessment has seven areas of surveillance:

1. General information
  - Clinical details
  - Pain
  - Skin integrity
  - Sleep
  
2. Muscle tone type and topography
  - Using Cerebral Palsy Description Form and Australian Assessment Scale (ASAS)<sup>13</sup> which includes details of ranking on the GMFS (Gross Motor Classification System)<sup>14</sup> and MACS (Manual Ability Classification System)<sup>15</sup> (If GMFS ranking is 4-5, child will be seen 6 monthly)
  - Orthoses and interventions
  - What has been done to support mobility?
  - What has been done to support pain (casting/splint/strength training)?
  
3. Upper limb
  - PEDI
  - Interventions
  
4. Swallowing, Nutrition and Communication
  - Enteral feeding

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<sup>13</sup> Love S, Gibson N, Smith N, et al. Interobserver reliability of the Australian Spasticity Assessment Scale (ASAS). *Dev Med Child Neurol*. 2016;58 Suppl 2:18-24

<sup>14</sup> GMFS – E and R Palisano, Rosenbaum et al, 2007, *CanChild* Centre for Childhood Disability Research, McMaster University. *Ref Dev Med Child Neurology* 1997; 39:214-223

<sup>15</sup> Eliasson et al, 2006, *Dev Med Child Neurology*, Vol 48:7;549-554

- Saliva management
  - Ear, nose and throat
  - Hearing assessments
  - Primary mode of communication using classification scale
  - Fluency and stuttering
  - Augmentative and Alternative communication
  - Interventions for dysphagia and communication
5. Developmental assessment and parental feedback
- Standardised developmental assessments
  - What interventions are in place for developmental support?
6. General well-being of child and parents
- Relationship index (optional) and not applicable for parents of a child at GMFS level 4-5
  - Depression, anxiety, stress level (optional)

The therapist will use his/her clinical judgement to decide which areas to assess during the session and may invite the family back for more detail if required. The therapist must interpret the data obtained and explain this in a covering letter/report to the child's parents. This can be done at the time of the consultation or usually after consultation with colleagues.

When recording a child's results into the data base system, data can be shown graphically, leading to an infographic "traffic light" system which would highlight the need for referral. Early referral is vital to prevent or manage secondary issues such as contractures.

**All babies who are diagnosed with cerebral palsy or at risk of cerebral palsy are automatically invited to enrol on programmes of early intervention (see below).**

## **Discussion**

The *CP Check-Up* is another innovative CPA strategic initiative which has benefitted children with or at risk of CP and their families whilst also adding to

the body of data about the condition, treatments, interventions and outcomes for children.

Whilst monitoring and check-up consultations take place for children diagnosed with CP in the UK, the CPA's *CP Check-Up* scheme could provide a helpful tried and tested, evidence-based tool for UK practitioners who wish to carry out holistic and comprehensive monitoring for their patients and for babies who are candidates for the "heightened surveillance" category, in line with the *NICE Guidelines for the Assessment Management of Cerebral Palsy in under 25s*.

**Cerebral Palsy Alliance's protocol for the detection, screening and diagnosis, including an algorithm for early diagnosis of cerebral palsy or high risk of cerebral palsy, is described in Novak et al's important paper *Early, accurate diagnosis and early intervention in cerebral palsy: Advances in diagnosis and treatment*.<sup>16</sup> This paper provides clear evidence-based guidance and protocols for the diagnosis of cerebral palsy which could be used as a robust international standard protocol. It was a privilege to see this protocol put into action so effectively by the clinicians at the CPA.**

**The key purpose of all activities carried out by the CPA on the early detection and diagnosis of cerebral palsy or at risk of cerebral palsy is to provide a diagnosis for families as quickly as possible and thus enable the baby to receive intensive expert early intervention at the very earliest opportunity in infancy which is the optimum time for brain development.**

**The programmes of early intervention offered to families are outlined below.**

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<sup>16</sup> Iona Novak, Cathy Morgan, Lars Adde, *Early, accurate diagnosis and early intervention in cerebral palsy: Advances in diagnosis and treatment*, 2017, *JAMA Pediatrics*, 171 (9)

# INTERVENE

## Research to Practice

Allambie Heights, Cerebral Palsy Alliance Headquarters, Sydney.

Professor Iona Novak



Allambie Heights Reception

Allambie Heights is a spacious, bright and welcoming community Centre for people of all ages with cerebral palsy. The Centre provides a broad range of services and facilities which are listed in the table in section 5. Within the Centre, a long, illustrated time line provides a history of the Cerebral Palsy Alliance since its early days as the Spastics Centre in the 1940s. There are many visual reminders about the strong values and ethos of the organisation which all point to the sense of a shared purpose with people with cerebral palsy and all those who work for the organisation many different capacities.



Identify Intervene Impact – An  
Australian model of best  
practice for cerebral palsy

Professor Iona Novak is a renowned paediatric occupational therapist who manages the strategic development of research into the prevention and cure of CP. She has written and co-written highly influential scholarly papers on the importance of early diagnosis and intervention for cerebral palsy. Professor Novak conducted a tour of the Centre and explained the services offered and the current focus for best practice early intervention.



Professor Iona Novak at CPA Headquarters, Allambie Heights, Sydney

The facilities, which were co-designed by clients (users of the facility), were impressive. The large gymnasium was well used by people of all ages, including those training for elite athlete competitions. Sports activities offered in the gymnasium are adapted for maximum participation by people with CP and families. There was a workshop where engineers produce adapted custom-made equipment to specific orders and impressively, a dental surgery run by volunteer dentists. An equipment store held an extensive range of toys, furniture and equipment. A community run café and family spaces and play areas made the centre truly family friendly. Well-appointed meeting rooms

provide income generating training spaces for national and international gatherings and areas for corporates who are encouraged to engage with the CPA for fundraising and information sharing activities.

### **Research Priorities and Programmes for Intervention**

Professor Novak explained that many research priorities are set by clients, and focus on the four areas of cause, prevention, treatments and cure.

Current work is underway as follows;

**Cause** – using data on register to build a better understanding of the causes of cerebral palsy, for example, the genome consortium and congenital cytomegalovirus (a common virus which can be transmitted to the foetus during pregnancy) study

**Prevention** – for example, looking at the efficacy of magnesium sulphate to prevent cerebral palsy as a result of early onset of labour (MAGENTA and SuPreme studies)

**Treatment** – focussed on early identification and diagnosis followed by timely and effective early intervention (see interventions below).

**Cure** – for example, stem cell studies and the use of erythropoietin (EPO) for neuro protection and repair in neonates

A detailed list of current and completed CPA research projects on cerebral palsy can be viewed at <https://research.cerebralpalsy.org.au/our-work/our-researcher-programme/researchpriorities/>

## **Intervention programmes provided by the Cerebral Palsy Alliance**

### **Infants**

Professor Novak described current programmes of very early intervention being trialled by the CPA. She, together with Professor Nadia Badawi and Dr Cathy Morgan have personally steered some of these programmes and the research underpinning them. The programmes are all intensive in their delivery, focus on active motor learning and are family centred.

## 1. GAME (Goals, Activity, Motor Enrichment)<sup>17</sup>

This programme has been developed by CPA researcher Dr Cathy Morgan and Professor Novak and has been designed for infants from three months of age who are at high risk of cerebral palsy. The activities take advantage of the increased neuroplasticity of early infancy to improve longer term fine and gross motor skills, daily function and adaptive behaviour.

The programme is based on best available research evidence which suggests that intensive, task specific intervention should commence early during the critical period of neural development. Parents are educated and supported to carry out the programme with their baby in the home environment. The programme has been subject to two pilot studies and results and feedback from these have been positive.

Families are actively recruited from the surveillance programmes and from referrals.

## 2. REACH

This is a randomised comparison trial which compares Modified Constraint Induced Movement Therapy (mCIMT) with Bimanual Therapy (CIM).

Recruitment for the programme is for infants between 3 to 6 months of age who have had perinatal stroke or assymetric MRI, absent fidgety GMs and/or asymmetric upper limb movements. 70 - 90 hours of therapy prior to 12 months of age is provided depending on age and time of recruitment.

Therapy is provided according to a strict protocol through monthly home visits by a highly trained therapist with daily input from the parent. There are 50 clients currently on the programme in NSW. The programme starts with the family's goals for their child at a "just right" level of challenge

## 3. PACT (Parenting, Acceptance and Commitment Therapy) for families of newly diagnosed babies.

This is a random controlled trial, being carried out by Koa Wittingham, J. Sheffield and CI Boyd with funding from the CPA. 66 parents of children with a cerebral palsy diagnosis are currently involved. The aim is to empower families

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<sup>17</sup> Morgan c, Novak I, Dale RC, Guzzetta A, Badawi N. GAME (Goals-Activity-Motor Enrichment): protocol of a single blind randomised controlled trial of motor training, parent education and environmental enrichment for infants at high risk of cerebral palsy. BMC Neurology. 2014;14 (1):203



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through an on-line parenting course grounded in Acceptance and Commitment Therapy including videos, online activities and Skype sessions. If it is shown to be effective, it can be made freely available to parents as a web-based programme.

### 4. VISIBLE (Vision Intervention for Seeing Impaired Babies through Learning and Enrichment)

This is a collaborative project in which infants with a severe cerebral visual impairment and at high risk of cerebral palsy at 3–6 months are enrolled into an intervention programme up to the age of 12 months. This programme is home based and supported by a multi-disciplinary team who provide fortnightly parent training in goal directed vision awareness and environmental enrichment to be carried out daily by parents. Vision, motor and general developmental function are monitored using behavioural assessments.

## Early Childhood Intervention programmes

**A recognised global leader**

A recognised global leader in early childhood intervention and development programs, CPA supports babies and children with cerebral palsy, autism, global developmental delay, muscular dystrophy, genetic syndromes and acquired brain injury.

Mind, Body, Best, is an approach informed by Cerebral Palsy Alliance Research Institute. It ensures that through our multidisciplinary evidence-based practice your child will have access to a team of therapy and learning experts who work together to address needs holistically.

**Making the most of the formative years**

We know the first 12 years of life are critical in laying the foundations for all areas of learning, development and participation.

Research shows that for children with a disability or developmental delay accessing the right therapies and interventions as early as possible makes a big difference to their future.

Cerebral Palsy Alliance gives you a choice of more than 50 therapy and learning options which are tailored to the unique goals and needs of your child.

By the time your child reaches school age, their world is expanding. Our goal is to help them develop strong physical, behavioural and social skills so they can participate at school and in their community.

Your child deserves all the opportunities that all other children enjoy – and we are here to make that happen.

**Early Childhood Intervention**

Make the most of your child's early years as their brain rapidly develops to form new neural pathways. Research-backed activities and learning experiences are the building blocks for your child's future and early childhood intervention is key.

You will have access to a diverse range of multi-disciplinary therapists and early childhood educators who are committed to your child and their progress. Together, we will find the best combination of therapies and small groups to meet your child's goals and maximise results.

Our early childhood intervention program is comprehensive, catering to children with a range of physical and neurological needs. Parent support and coaching is a feature of the program, giving you the support, skills and confidence to continue the learning at home.

"We were worried when we found out Oliver has learning problems. CPA has early childhood teachers, psychologists and occupational therapists. They worked together to get him ready for school."

Rachel, parent of Oliver, aged 5 years

**Intensive therapy programs**

We offer individualised and group based intensive therapy programs that typically include 30–70 hours of one-on-one therapy over a two-three week period. Based on the principles of neuroplasticity and using international research our intensive programs enable children to accelerate learning and skill development across a range of life areas.

Our intensive group programs include INAD-ILE, for school age children, and MIND-IT skills for preschool children, who experience challenges with fine and gross motor function. Using playful and engaging methods that will motivate your child these programs deliver results fast.

"It's definitely worth it. I think this two week intensive is a good head ramp. The quantum leap of increasing their capabilities. It's a must do." Richard, parent of Aaron, aged 8 years

**Holiday programs**

School holidays are a time of fun and friends, so why not try a school holiday program? There is a huge range of activities to help your child learn or practice a new skill.

From technology to bike riding, the experiences are designed for maximum fun. Your child won't even realise they are receiving the latest interventions to build independence.

They'll also meet new playmates and develop skills for other areas of life. From one to five days, programs are held in school holidays. Sign up for news on our website to be alerted to events in your area.

"Saurav attended a week long gym program for kids. She did yoga, sports and had lots of fun. Perfect way for her to make friends and build her skills." Saurav, parent of Saurav, aged 11 years

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practice for cerebral palsy



The CPA offers holistic play-based intervention programmes in which parent support and coaching is a key principle so that learning for the child and family is a continuum. All programmes are based on the latest evidence-based research and best practice. Parents take a key part in the planning of goals based on their knowledge of their child. Seventeen CPA Centres offer Early Childhood Intervention Programmes.

The two-hour intervention programmes at the purpose built and well-equipped CPA Centres are small-group based and are delivered weekly by a transdisciplinary team of:

- Physiotherapists
- Occupational therapists
- Speech pathologists
- Early intervention teachers
- Psychologists

- Therapy and allied health assistants
- Social workers

The sessions are age and ability appropriate and are designed to maximise the following early skills:

- Understanding and communicating messages
- Thinking, learning and solving problems
- Self-help skills, for example, eating and drinking, dressing
- Social and emotional development
- Movement and mobility

Hydrotherapy and powered mobility group sessions are also offered.

Individual intervention programmes can also be delivered in the home, pre-school or community centre.

Parents can self-refer to a CPA Early Intervention Programme and use their NDIS (National Disability Insurance Scheme) Early Childhood Intervention funding to cover the costs. These schemes are discussed in detail below.

## **Federal systems for Early Childhood Early Intervention Early Services (ECEI) (0-6) and National Disability Insurance Scheme (NDIS)**

Christine McClelland, Director, ECEI,

Di Strachan, Assistant Director, ECEI

Kate Agus, Director Advisory Team, Technical Advisory and Complaints Branch  
NDIS Canberra.



NDIS Headquarters, Canberra

### **The NDIS**

The NDIS scheme introduced a shift away from a welfare-based system of support to an insurance approach that invests in participants to improve their long-term outcomes. It takes a lifelong approach and promotes early intervention for people with disability. The scheme links “participants” with “providers” and other broader systems of support within universal services and the community to create a holistic package of care and support centred around the individual and their unique needs. It is *“a vision agreed by all (state)”*

*governments for an inclusive Australia that enables people with disability to be equal members of society”<sup>18</sup>*

The remit of the NDIS for children with disabilities is that:

*“The NDIS will be responsible for personalised supports, specific to a child’s disability (or developmental delay) which are additional to the needs of children of a similar age and beyond the reasonable adjustment requirements of early childhood development service providers”<sup>19</sup>*

The Cerebral Palsy Alliance have been selected as the NDIS “Partner in the Community” for ECEI services in the Northern Sydney area.

Ms McClelland and her colleagues outlined the background and key components of the ECEI scheme which is now four years into implementation:

- The ECEI programme, instigated by the NDIS, worked with a range of leading Australian early childhood intervention practitioners (including the Cerebral Palsy Alliance) and researchers to design a best practice, family-centred approach<sup>20</sup> which could identify the type and level of support required to achieve the best outcome for the child and their family.
- The Federal scheme supports children aged 0-6 who have a developmental delay or disability across Australia.
- Families are key partners who co-plan support based on their own goals for their child. These focus on developing the holistic skills they need to take a full part in the daily activities of life and achieve the best possible outcomes in later life.
- A child can be referred to the ECEI scheme by their family or any other practitioner or stakeholder.
- The scheme provides a family supporter (partner) who will assist the family in developing an individualised support plan and will provide information and advice to the family, stakeholders and universal services such as community health or nurseries to ensure that the child is able to fully engage in the community.

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<sup>18</sup> *Improving the NDIS Participant and Provider Experience*, February 2016, [ndis.gov.au](http://ndis.gov.au), p.7

<sup>19</sup> NDIS Operational Guidelines, 10.8.3, Rule 7.8, The Supports for Participants, [www.ndis.gov.au](http://www.ndis.gov.au)

<sup>20</sup> Dunst CJ et al, *Family orientated early intervention policies and practices: Family Centred or not? 1991* *Exceptional Children* 58 (2) 115-126

The plan will consider:

- What support is already there (informal family support)?
- What is the family already accessing?
- What extra is needed?
- How much therapy?
- Assistive technology/mobility equipment/assistance
- Home modifications
- Respite care needs
- ECEI support must be “reasonable and necessary”, but is not specific and quantified.
- Families can choose the providers of reports for recommendations for support/therapy and for the provision of intervention. Providers must register with the ECEI/NDIS in order to be available to families/participants.
- If a therapy package is put in place, this will be co-ordinated by a key worker who is different from the partner and is knowledgeable about the specific needs of the child.
- Assessments on the child can take place anywhere that the family wish (home/community centre, etc.) The PEDI-CAT (Paediatric Evaluation of Disability Inventory Computer Adaptive Test) assessment to assess the child’s needs and to understand how any developmental delay will impact on his/her ability to participate in activities of daily life compared with children of their age. Other functional assessments may be used by allied health professionals who work with the family to provide a fuller understanding of the child’s needs.
- The partner is a professional, for example, an allied health professional with skills and qualifications in early childhood development.
- If it is apparent that the child is likely to require long term or a significantly higher level of support that ECEI can provide, the partner will work with the family/child/community to co-ordinate planning for NDIS funding if the child is eligible.
- Criteria for NDIS funding requires that the child has one or more identified intellectual, cognitive, neurological, sensory or physical



impairments that are or are likely to be permanent or has developmental delay.<sup>21</sup>

- ECEI/NDIS plans are reviewed every 12 months by the partner and family to see if goals and outcomes are being achieved.
- Therapy for older school aged children is co-ordinated via the Ministry for Education.

Ms McClelland and her colleagues explained that as the ECEI/NDIS scheme is still relatively new, implementation is stronger in some states than others, but that there is a high level of commitment to the scheme and collaboration between states. Five trial states around the country are working through the new approach with ACT (Australian Commonwealth Territory) currently leading the delivery of the NDIS.

Overall, I was told that families have been positive and appreciate having a greater degree of control and “one bucket of funding”. There have been some teething problems in the application process which were identified by a review of the NDIS Pathways in February 2018<sup>22</sup>. The review was a result of a consultation with participants, providers, partners and state officials. The review identified lower levels of satisfaction from families and carers of children with more complex needs who expressed that the scheme resulted in an increased administrative burden for families. Families also cited less choice over providers and a lack of sufficiently skilled allied health professionals and Partners. Key areas identified by the NDIS for development are greater transparency and for participants to be better supported throughout their interactions with face-to-face engagement with the NDIS and for clear, easy-to-understand communications.

The previous system used a “block” funding arrangement for therapy, but this caused confusion over roles and responsibilities. The new system has created a “marketplace” for providers and families who are now able to make their own decisions based on their knowledge of their child as to where to source therapy, intervention and support services. Therapists and other providers are required to be more accountable to both families and to the NDIS for the quality of their services.

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<sup>21</sup> [www.ndis.gov.au/operational-guideline/access/early-intervention-requirements.html](http://www.ndis.gov.au/operational-guideline/access/early-intervention-requirements.html)

<sup>22</sup> *Improving the NDIS Participant and Provider Experience*, February 2016, [ndis.gov.au](http://ndis.gov.au)

## **Funding and Cost Benefit of the ECEI and NDIS**

Currently funds for the schemes come equally from State and Commonwealth Governments. The scheme is estimated to have a cost of A\$22 billion at its fullest capacity with 400,000 participants.

We discussed the cost benefit of the ECEI and NDIS. Ms McClelland said that actuaries are “watching this space” and are looking at family and child outcomes, however, it is expected that there will be cost savings for family support systems which have had a high rate of family breakdown, mental health and sibling wellbeing issues. The new systems of ECEI and NDIS allow for earlier and better control of these challenges. Ultimately, the aim of the new system is to enable more people to enter the workforce (and therefore to add to national revenue) and be fully functioning and include members of society.

Evidence-based studies have been commissioned to give a clearer picture of cost benefit.



## **Government overview of health provision for children with cerebral palsy**

**Richard Temperly, Advisor to Greg Hunt, Minister for Health, Parliament House, Canberra, ACT**



Outside Parliament House, Canberra

Richard Temperly was kind enough to explain the Government systems in place for health care and its funding. The Commonwealth (Federal Government) has overall responsibility for universal services, such as: health, Medicare and NDIS, but at state level, regional governments will have their own systems for the allocation of funds. Therefore, when Federal Government develops new programmes such as the ECEI and NDIS, the States and Territories will have autonomy over the way in which programmes are delivered.

Healthcare is funded through two channels; Medicare (a national insurance scheme) and optional private health insurance. The public is encouraged to take out private health insurance and the cost of this cover is subsidised for low income families. If a person decides not to have private cover, a surcharge is placed on their Medicare cover.

Prior to the start of the NDIS (2013), disability services were managed by states which led to national variation of health policy and practice. As a result of lobbying by disability groups, there was all-party support across Federal Government for a national scheme. The productivity commission produced a report in 2011/12 which looked at taxation options to fund a national scheme.

This recommended that a one-off levy of 2% on the public's Medicare payments should cover the additional cost of the NDIS.

*Some key elements of the insurance approach within the context of the NDIS are:*

- *The NDIS provides universal coverage by pooling risk across all Australians and takes the risk of disability support costs away from individuals.*
- *The NDIS creates an innovative and competitive market for disability support, through which participants can exercise choice and control over the planning and delivery of their support.*
- *The NDIS takes a long-term view of the total future social cost of disability for all people who are insured, or yet to be insured.*
- *The NDIA – in its role as the social insurance manager – will actively manage down the total cost of disability over a participant's lifetime, incentivising short-term investment in participants to reduce long-term costs.<sup>23</sup>*

### **Cerebral palsy statistics**

Mr Temperly reported that there are approximately 34,000 individuals with cerebral palsy in Australia. Costs for treatment are covered by Medicare and the pharmaceutical benefits scheme which subsidises the costs of drugs, so there is a maximum charge of A\$37 to individuals for any drug. When receiving a medical consultation or treatment, an individual uses their Medicare card at the surgery and the doctor will charge Medicare.

### **Research commitments**

The National Health Medical Research Council (NHMRC) is Government funded but has an independent panel, administers grants, and has invested A\$1 billion into medical research.

A\$60 million has been allocated for cerebral palsy research with A\$2 million recently granted to the Cerebral Palsy Research Foundation for research on prevention (Genome research).

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<sup>23</sup> ndis.gov.au March 2017 | NDIA Submission to Productivity Commission 23

Data from sources such as the Australian Cerebral Palsy Register is used by the Australian Institute of Health and Welfare to produce reports to inform health strategy and policy work.

There is currently a policy focus on developing consistency of approach for health conditions across the Commonwealth. I asked about a national policy for screening for cerebral palsy. Mr Temperly suggested that, if the CPA were to put proposals for a national screening programme for cerebral palsy to the National Standing Committee on Screening and their analysis showed an economic benefit, it is possible that the States would take up their recommendations.

## **How do the Federal/State systems of Education work for children with disabilities?**

**Dr Gabrielle Phillips, Branch Manager, Schools Data Reform Branch**

**Dept of Education and Training, Canberra, ACT**



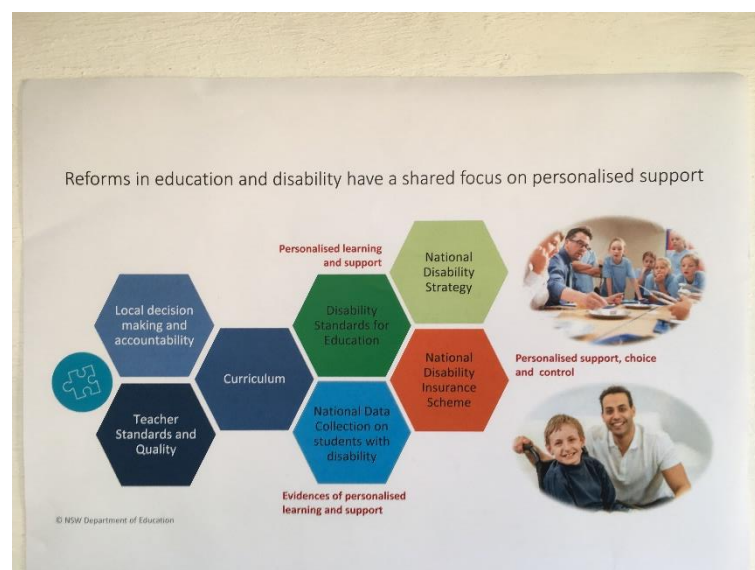
Outside the Department of Education, Canberra.

Dr Philips explained how educational policy is developed and implemented at Commonwealth and State level.

- The Commonwealth (Federal Government) has no function in the direct running of schools.
- A Minister of State for Education is responsible for education policy in each state.

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- The Education Council, a joint council made up from senior officials from each State and Territory, is responsible for setting policy on: early childhood education, disability, assessment and schools' policy. The Education Council regulates all schools in terms of regulations but not curriculum.
- 66% of Australian children attend state schools which are funded by each State and 33% attend Catholic or private schools which receive funding from the Commonwealth.
- The Schools' Curriculum is agreed at State level.
- Parents can choose which type of school they want for their child.
- Schools receive base line funding with extra funding allocated on the basis of: location, scale of school, students with disability, indigenous population, disadvantaged students and those with low economic status.
- Each State has its own formula for funding.



Up until 2005, there were no clear standards of practice for students with disabilities. This was addressed in the *Disability Standards for Education*<sup>24</sup>, which came into effect in August 2005. The Standards were a collaborative effort involving stakeholders from the Human Rights and Equal Opportunity

<sup>24</sup> *Disability Standards for Education 2005*, Commonwealth of Australia, 2006

Commission, State and Territory Governments, the disability sector and non-Government education and training providers.

The Standards set out criteria for “reasonable adjustments” that must be made for access, specialist support and curriculum participation for students with disabilities and for the prevention of harassment and discrimination. The new system moved away from funding for disability specific adjustment to funding for specific needs according to the adjustment required.

The Standards led to a need for increased and more specific data on students with disabilities, and in 2014, the *Nationally Consistent Collection of Data on School Students with Disability* (NCCD)<sup>25</sup> was introduced for all schools to complete in August annually.

Data is collected from State schools, Catholic and Independent Schools, is processed by the State Government and then by the Australian Government. This data informs schools funding.

Each school is required to collect data on students with needs in the following areas:

- Cognitive, social and emotional
- Disability
- Sensory

and at the following levels of need:

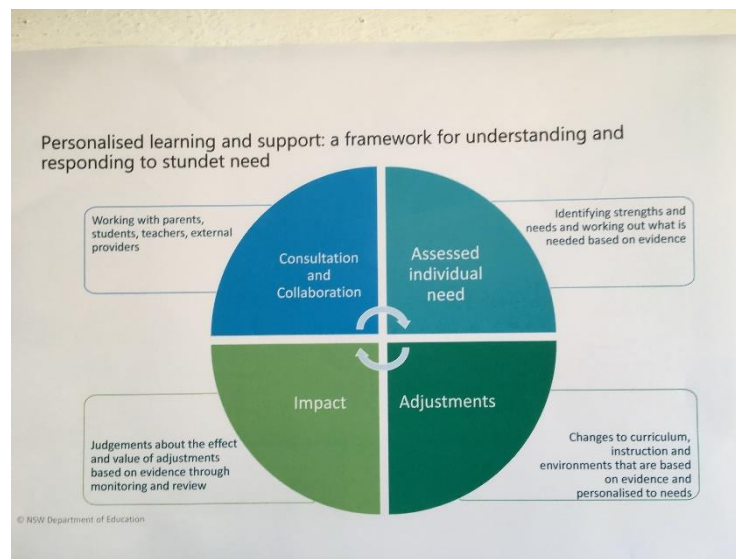
- Supplementary (teacher-differentiated)
- Substantial
- Extensive

These categories identify the threshold for receiving a funded adjustment, and additional evidence from families about medical diagnosis and functional issues is required to trigger input. Any additional need must have been apparent for a minimum of 10 weeks before adjustments are put in place.

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<sup>25</sup> <http://www.schooldisabilitydatapl.edu.au>

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As a result of the more detailed data, State and Federal Government are now more aware of the numbers of children requiring intervention. The data provides an evidence base which informs planning for teacher training and changes in legislation and disability standards. The data also shows where schools are supporting students with disabilities well, the progress they are making and also where schools are struggling to support students with additional needs. If this is the case, state advisors will be sent to schools to support improvement.

Individual states may use funding devolved from the Federal Government to states to allocate according to need within the state to support adjustments required in schools. Currently Federal Government funds 14% and States 86% of Schools' disability funding.

As in the ECEI and NDIS schemes, focus has shifted to a family partnership approach through which school staff work closely with families to achieve the best outcomes for a child's full participation in school and community. The Government Department of Education and Training has produced a Factsheet on how to improve outcomes for students with disability through a partnership approach to parental engagement.<sup>26</sup>

<sup>26</sup> Fact Sheet 3: Parental Engagement, Department of Education and Training, <https://docs.education.gov.au>

Dr Phillips commented that the Federal Government is aware that further input is required to ensure that teachers are equipped to manage the learning of children with disabilities.

**Melissa Clements, Director, Disability, Learning and Support - Department of Education, Sydney, NSW**

**Arrangements for Special Educational Needs and Disability support in Education**



Melissa Clements, Director, Disability, Learning and Support

Ms Clements was kind enough to talk to me about the Education Department's approach to early intervention and identification in schools and pre-schools.

She explained that the current early intervention strategy and policy have developed as a result of "stakeholder engineering" whereby workshops which included parents, providers, non-government agencies and experts developed a parent enabling model which aimed to improve "school readiness" in the under-five population.

We discussed the reality of the ECEI/NDIS schemes and how they impact on young children with disabilities such as cerebral palsy in pre-schools or in early

years education. Currently, most pre-school settings are in the community sector.

Children with disabilities may attend:

- A school with a specific purpose, for example, a school for the visually impaired
- A support unit in mixed schools
- A mainstream school

Ms Clements described a situation whereby, with increased choice of providers and style of delivery in the hands of parents, settings are expecting a higher level of requests for access to individual children in a setting by therapists who are commissioned by the family. Settings are saying that they would prefer therapy expertise to be embedded into disability planning and resources for the school generally, and into education plans for the individual child with a disability or learning need. School principals are concerned that support is not always being targeted appropriately and that there is an imbalance in dynamics between the family, settings and providers. Ms Clements suggested that the relationships between all stakeholders responsible for delivering an early intervention plan should be more openly discussed and factored into conversations with parents and ECEI partners.

The introduction of the role of “Special Support Teacher” in every school has provided a single point of contact for children with disabilities and their family and school staff. The purpose of the special support teacher is to support teachers in their practice by modelling, profiling the child’s needs and working on adjustments for learning. Where there is a range of expertise between Special Support Teachers in an area, this can be pooled across several schools, and this approach appears to be working well.

This raised the question of training for teachers in how to properly support children with disabilities that required specific interventions to enable learning and curriculum access. Ms Clements commented that there is more to do in teacher training at both undergraduate and postgraduate level to improve inclusion. Most states will have aspects of special education included in teacher training courses. Also, the Department of Education sponsors in-service special education courses for serving teachers, however feedback from



teachers has suggested that balancing the study required and their workload is too demanding.

## **Discussion**

The key impression that my research into the Australian Government's policy for early childhood intervention and provision has left me with is the positive dynamic between families, decision-makers and service providers. From the outset, strategy and policy making in this area has been a dialogue between the key players with a desire for families to be not just involved, but truly central to the planning for their children. Discussions with Government officials and documentation produced by Government agencies reinforce the importance of the role of families and working in partnership. In all discussions with officials, I felt that there was a true respect for families and a commitment to maximising their participation in the planning and provision, coupled with the belief that with this respectful partnership working would come better and more effective inclusive practice.

A concern that is shared with the Cerebral Palsy Alliance is who is responsible for funding community therapy input for very young children (0-2) who are not yet in the NDIS application system, but who need intensive early intervention as a result of their diagnosis of "at risk of" or with cerebral palsy, for example, the children seen at the Prairiewood Clinic. Currently, the CPA provides a bridging arrangement for therapy free of charge for families who are in this position who live in their region from their charitable resources, but the fact remains that there is a potential delay for families to swift access to funded intensive early intervention at a time when the infant most requires it.

Officials recognise that the ECEI and NDIS is still a work in progress and are open about the recognised current weaknesses identified in the review reports of the systems. They appear to be as passionate about the changes and the improvements they will make in outcomes for children with developmental delay or disability. The ECEI and NDIS schemes have the potential to be highly effective, family-centred schemes which can deliver very positive outcomes for children with developmental delay and disabilities. They provide a sound model for Government strategy and policy on early intervention. It is clear that the Australian Government has considered the cost benefit case for the schemes and have proceeded with them on the basis of longer term financial

and societal benefits to be gained by the shift to early intervention and greater personal responsibility for achieving community inclusion.

With regard to children with cerebral palsy, it was hard to identify any specific government strategy for this group of children, and indeed there is a clear move away from condition specific pathways or approach to educational practice, although specialist teachers for visually or hearing-impaired children are employed by state's education departments. The focus is on function and community inclusion, which is admirable in principle, but without specialist knowledge and expertise about how this is achieved within an educational setting, the concern is that children with cerebral palsy will not be as included as they could be.

There is concern that this lack of expertise also exists within the ECEI/NDIS system. The principle of placing choice of provider in the hands of families, whilst admirably family-centred, could result in families not being able to make informed decisions about the suitability of providers for clinical services, and “partners” may have inadequate knowledge or expertise to advise appropriately, and therefore potentially do more harm than good. These issues could result in inappropriate clinical intervention which may need to be subsequently rectified. These concerns were raised in a recent report by the Royal Australasian College of Physicians (RACP), *Provision of Services under the NDIS Early Intervention Approach*<sup>27</sup>. The recommendation in the report is that paediatricians and/or accredited professionals play a more prominent role in advising parents about clinical services obtained through the ECEI/NDIS.

It was also apparent from the discussions and reviews of the schemes that the new system works less well for children with very complex needs and their families (many children with cerebral palsy would be in this category) and that further work is needed to ensure that the additional administrative input required of families does not become an oppressive burden for those who already have the challenge of caring for a child with very complex needs.

The solution may lie in ensuring that an appropriate skill base in cerebral palsy, possibly acquired through an accredited qualification, exists in the “partners” charged with supporting families in their planning for their child, the community “providers” of intervention and services commissioned by families

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<sup>27</sup> Royal Australasian College of Physicians written submission to Provision of services under NDIS Early Childhood Early Intervention Approach, August 2017

in their ECEI or NDIS package, the practitioners working with children with cerebral palsy in early years settings and schools. Parents themselves, who of course know their child better than anyone, but may not know about the details of child development in general or cerebral palsy specifically, need specific not generic expertise in order to support their child's development appropriately.

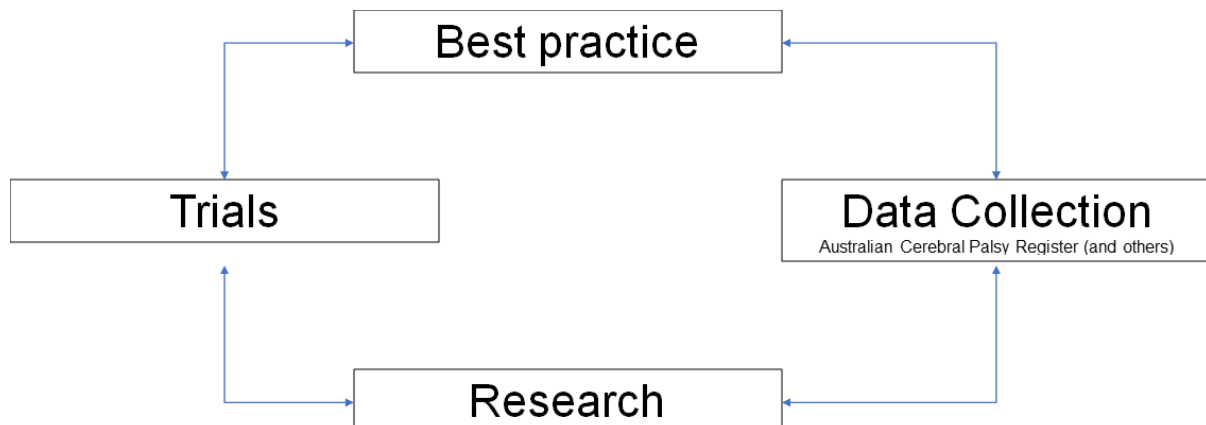
This need applies equally in the UK, and some aspects of the UK's Children and Family's Act reflect the aspirations of the ECEI and NDIS, but Australia has the advantage of having an embedded system which is family/child-centred in its approach and a developing market place of providers (such as the Cerebral Palsy Alliance) which can deliver the quality and frequency of intensive early intervention that young children with cerebral palsy need and deserve.

# IMPACT

## Data Collection, the Australian Cerebral Palsy Register, Research and Practice

The systematic, strategic and robust approach to research priorities and the collection of data to inform research which is adopted by the Cerebral Palsy Alliance provides a continuum of evidence on which to base clinical practice. The CPA must be convinced by the research that the clinical practice they adopt will work for children and families and promote the best possible outcomes before implementing these pathways of care. The outcomes of the trials and pilots they run provide the rationale for continuation and further funding.

Data obtained by the CPA through the ACP register is used to show trends, and as the data base progresses, the CPA hope to show a downward trend in the incidence of CP in Australia and worldwide. It is to be hoped that this positive trend can continue as the result of the adoption of evidence-based prevention strategies, treatments and intervention so admirably modelled by the CPA.



## **Impact of Early Identification and Intervention via CPA and ECEI**

### **The ECEI/NDIS**

It is still too early to draw firm conclusions as to the impact of the ECEI/NDIS system on children with cerebral palsy and their families. What I learnt from my research was that the system enabled families to access the services that they believed would make the most impact on their child's development, quickly and with funds over which they had control. The existence of the Cerebral Palsy Alliance, who are expert "partners" is a hugely valuable resource for families in NSW and ACT. The expert early intensive intervention programmes they provide for children has been shown to achieve positive results and improve outcomes for both children and their parents.

### **Impact on Families**



### **Susan and Molly**

I was fortunate to have the opportunity to meet Susan Hoffman, the mother of Molly aged 10 who has cerebral palsy (and severe epilepsy in her early years) and attends a mainstream school. From the very beginning, Susan wanted Molly, the middle of three sisters, to have an "ordinary" life as possible.

The professionals involved with the family in Molly's early life were not able to give Susan a straightforward answer to how Molly's life would work out. Susan was in a quandary because she wasn't sure about what was the key developmental area to be focusing on – there was no clear pathway. It was very difficult to balance the need for intense physical and medical support that Molly required with therapeutic intervention and a family life.

The CPA provided blocks of therapy input, support with equipment and wheelchair, feeding and transitions into nursery and school. At the time, funding came from the Federal "Better Start" programme and from the family's own resources. The "Better Start" system is now incorporated into the ECEI/NDIS system. Molly has been accessing NDIS for two years and Susan sees the NDIS as still a work in progress. She is frustrated by the distinction between the services; Health – NDIS – Education, which are run as separate agencies, but for Molly, as a child with CP, needs within these services are intrinsically linked. For example, Molly needs a new wheelchair which is applied for through the NDIS, however, as her main form of mobility, the wheelchair needs to be used in school, but Susan told me that the NDIS are not interested in supporting the additional requirements of the wheelchair provision as a result of the school/educational aspects. This "falling between the cracks" of different agencies is also a common challenge faced by families of children with cerebral palsy in the UK.

Susan is also not convinced that the NDIS are as family centred as they could be. She said, "it is up to families like us pushing up against bureaucracies where structures limit people leading the lives they need – policies are ideals, but families have to return to the principles (behind them)". Susan also felt that some partners, therapists and providers are not ready for family centred practice and that families are not the drivers of service provision. She asked, "being able to choose a service is one thing, but will the service be available in the area?"

**Molly's education.** Susan reported that the management at Molly's pre-school was welcoming and their positive attitude enabled the sourcing of funding and resources to make it work with input from therapists and early educators. Susan commented that children with CP are often judged by their appearance and entry to mainstream school was more problematic.

She said that in her experience, the Department of Education had good intentions and there are supportive structures in place, such as the Disability Standards. Molly is one of a minority of children with complex disabilities who attend a mainstream school. It was very difficult for Susan to persuade the school to take Molly, and she had to use her knowledge of legal entitlement to advocate on Molly's behalf. The resistance came from the school management, but the Department of Education, the Cerebral Palsy Alliance and her hospital case manager were supportive. The main issue for the school was the toilet arrangements.

Susan felt that, as Molly was medically fragile at the time, "the resistance came from fear", and once she had worked hard to overcome these anxieties and major surgery in year one alleviated the seizures, Molly became fully integrated into the school. She now moves around freely in her powered chair and has 1:1 support for classroom support and personal care. Overall, inclusion in her local mainstream school has been a success for Molly. The highlight for Molly and her family was when, as a result of a joint effort, she joined her class in her powered wheelchair on the stage of the Sydney Opera House. "It was magnificent. Molly was able to be with the other students and she didn't stand out!"

Susan is pleased with Molly's outcomes so far but is exhausted at having to be the main co-ordinator for all her needs. A medical review is held annually, but there is never a time when all the agencies – medical, school, therapies, come together. This can cause frustrations and time wasting for all concerned but most importantly leads to a disjointed rather than holistic provision for Molly and challenges in communication between Susan and the agencies which support her daughter.

Susan is a very articulate, well informed and educated mother. She worries about what happens for children whose parents who are less confident.

### **Marjorie Logan, Special Needs Teacher.**

Marjorie is a Specialist Teacher for visual impairment and works with children with cerebral palsy. She provides condition specific support directly into the mainstream classroom or individually with the student for 12 hours a week. (This level of support is unprecedented in the UK). Her post is funded by State Government. There is no equivalent post for children with cerebral palsy (the

same is true in the UK). Marjorie explained that physiotherapy, occupational therapy and speech therapy is provided via a student's NDIS plan and is usually delivered out of school. With the NDIS scheme, it is becoming more common for therapy from private providers to take place in school if parents wish and the school principal agrees.

All students with disabilities have 1:1 support. Teachers are used to having disabled students in the classroom, but they rely heavily on specialist teachers such as Marjorie and the 1:1s for support.

## **Discussion**

These accounts from people who receive services or work daily with children and families with cerebral palsy underline the challenges that come with the reality of living with cerebral palsy. As in the UK, there is a sense from a parent of always being the one who “holds it together” as the key co-ordinator for the child. I was disappointed to hear this as I had hoped and understood that the role of “Partner” within the NDIS system would be a valued source of support and facilitation for families as it was clearly designed to be - akin to a “case manager” who would co-ordinate a package of care for a family in receipt of medical negligence funds in the UK.

I hope that others' experience is more positive than Susan's, but I sense that suitably qualified personnel as “partners”, a key resource to make the new system work, may not always be as available or as effective as they should be, and this perhaps should be a key area of development for the NDIS scheme. It is therefore reassuring that the highly skilled professionals at the Cerebral Palsy Alliance are available to families of young children with CP living in NSW, so that they can be assured of the best advice and intervention possible.

Despite the challenges, the ECEI/NDIS is grounded in best practice principles and it clearly provides a sound and embedded system of early support for children with disabilities and their families which is somewhat lacking in the UK. There is a strong desire by officials and staff within the ECEI/NDIS to make the system work as well as it can for families, and also sufficient financial resources have been committed in order to deliver it.



## Summary and Recommendations

### Key differences between Australian and UK models of provision for children with cerebral palsy

Australia	UK
<p><b>Strong stakeholder representation.</b> Australia has the benefit of a dynamic, influential voluntary organisation, the Cerebral Palsy Alliance, dedicated to the advancement of knowledge and best practice for people with cerebral palsy. The CPA are strong advocates on behalf of the cerebral palsy community and have influence at State and Federal level.</p>	<p><b>There are very few organisations which specifically represent people with cerebral palsy, and therefore this is an under represented group in the UK.</b> Action Cerebral Palsy, a very small campaigning charity, is a voice for children with CP and their families. SCOPE, which previously represented people with CP is now a pan disability charity.</p>
<p><b>Strong data and research base for cerebral palsy practice.</b> The breadth and amount of data from the Australian Cerebral Palsy Register and subsequent research findings on cerebral palsy from the Cerebral Palsy Research Alliance have led to robust models of evidence based early detection and intervention driven by the CPA, to be embedded in practice in NSW/ACT. These practice pathways are promoted through the CPA's on-line training portal so that other providers across Australia and beyond can implement high quality practice in their region. Robust data on cerebral palsy has informed Federal and State strategy in health, education and social care</p>	<p><b>There is no central cerebral palsy register in the UK and no standard pathways of care.</b> There is an inadequate data base for clinicians, researchers, strategists and policy makers to use for information on the incidence, aetiology, presentations and outcomes and for planning for people with cerebral palsy. There is no standard pathway or model of care for babies and children with or at risk of cerebral palsy. The NICE Guidelines and Quality Standards, which drew heavily on research from the CPA Research Institute, provide guidance on the management of CP, but lack detail and specificity in screening and early intervention processes. There are some emerging cerebral palsy specific training courses</p>

	(offered under neuro developmental disorders) in the UK, but no on-line training specifically in clinical practice for CP akin to the CPA e-learning portal.
<p><b>Parents have easy access to early intensive intervention programmes specifically designed</b> for children with or at risk of cerebral palsy which provide latest evidence-based input and support for babies and very young children and their families at a time when it can achieve the best outcomes</p>	<p><b>Some specialist Centres in the UK offer programmes specifically designed for children with CP</b> and their families, for example, university hospitals, or centres offering Conductive Education or transdisciplinary programmes for children with CP (these are mainly in the charity/voluntary sector and parents are not routinely referred to them). It is very rare to find programmes offering evidence based intensive early intervention for infants under 2 years of age at risk of or with CP. (Pace in Aylesbury is one such Centre <a href="http://www.thepacecentre.org">www.thepacecentre.org</a>).</p>
<p><b>A national approach to early childhood intervention supported by appropriate levels of funding.</b> (Early Childhood Early Intervention/National Disability Insurance Scheme)</p> <ul style="list-style-type: none"> <li>• Driven by participants needs and child/family centred in approach</li> <li>• Families have a single point of contact (“Partner”) to support them through the process of identifying needs and accessing early support</li> <li>• Families have control of funds and choice over providers of services</li> </ul>	<p><b>There is no nationally co-ordinated approach to early childhood early intervention in the UK.</b> Despite the Sure start initiative, there is no statutory requirement to provide this across the UK and each area will have its own level of services. The Sure Start Centres are generic services for all children.</p> <ul style="list-style-type: none"> <li>• Screening services for babies focus on hearing, hips and weight gain. There is no standard screening model for motor delay or signs of CP for babies at risk of CP</li> <li>• Once babies are discharged from hospital and from the</li> </ul>

Identify Intervene Impact – An  
Australian model of best  
practice for cerebral palsy

<ul style="list-style-type: none"> <li>• This results in a more diverse and responsive market place of providers from across the private, voluntary and state sectors</li> <li>• Skills and expertise of providers is influenced by the market and requirements of families</li> <li>• Level of funding is based on child's needs and is not formulaic. Whilst value for money must be demonstrated, there is no threshold of funding</li> </ul>	<p>health visiting service, the onus is on parents to observe signs of developmental delay until the two-year screening check.</p> <ul style="list-style-type: none"> <li>• If referred to NHS community health teams, provision may be intermittent and non-intensive due to shortages of therapy staff in the community.</li> <li>• There is no single point of contact to co-ordinate support for the family.</li> <li>• Despite the principles underlying the Children and Family's Act, parents of children with cerebral palsy have little real choice or say over the type of provision their child receives and there is often a persistent patriarchal attitude to the allocation of provision from professionals.</li> <li>• Families will not receive funding for specialist intervention from the private or voluntary sector</li> <li>• Community therapists may not be experts in cerebral palsy</li> <li>• Planning for education, health and care needs through the Education, Health and Care Plans is co-ordinated by officials from the local authority who also allocate funding only to services normally provided by the local authority or clinical commissioning group. This limits choice for parents and</li> </ul>
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	<p>inhibits the growth of a diverse range of expert providers from across the sectors.</p> <ul style="list-style-type: none"><li>• Parents are rarely informed by local authorities of their right to a personal budget to access specialist services from private or voluntary providers on the local authority’s “local offer”.</li></ul>
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## Recommendations

There are many dedicated clinicians, researchers and practitioners who work in the field of cerebral palsy in the UK who are constantly pushing the frontiers of knowledge and practice. However, many professionals and families that I have met in my working life and connected to this research believe that we can do much better for children with cerebral palsy and their families here in the UK. I hope that the following recommendations will be well received by my colleagues working in the field of cerebral palsy and that there will be support for their development at local and national level.

- To revisit the development of a national cerebral palsy register with the aim of collecting a minimum data set which will provide information for research, outcomes of clinical practice and policy development
- To further develop and define clinical pathways for very young babies who require heightened surveillance as a result of their birth history or as a result of surgery as neonates. These pathways to include routine screening at 3 months of age in line with the model adopted by the Cerebral Palsy Alliance, and subsequent follow up checks if they are diagnosed as “at risk of cerebral palsy”
- To push for improved training and awareness of the risk factors and signs of cerebral palsy in babies and young children for clinical and care practitioners and parents of young babies, and specifically for more specialist health visitors to be trained and employed in the community health workforce

- To push for a more family centred approach to early childhood early intervention whereby families with children with or at risk of cerebral palsy have a more central role in determining vital early intervention provision for their child. This may take the form of the right of referral to specialist providers in the community/private or voluntary sector who are qualified and able to provide appropriate levels of intensive intervention or for funds to be released directly to parents for them to access these specialist services, possibly via the personal budget option of the Education Health and Care Plan (EHCP) system.
- To consider the introduction of an appropriately qualified and independent key point of contact and supporter (akin to the “Partner” in the Australian ECEI/NDIS scheme) for families going through EHCP planning and implementation to ensure that the child and family’s needs are kept at the centre of the planning process
- To push for improved training in cerebral palsy and its impact on learning and development for teachers, pre-school practitioners and learning support assistants who work with children with, or at risk of, cerebral palsy

## **Conclusion**

It has been a pleasure and privilege to carry out research on cerebral palsy practice in Australia. I have observed outstanding clinical practice and met inspirational professionals and officials who are united in their wish to improve life chances for children with cerebral palsy. I hope that the learning gained from my Churchill Fellowship will inform the ongoing work of Action Cerebral Palsy and other stakeholders in the field of cerebral palsy, leading to ever increasing knowledge and practice for the benefit of all children in the UK with cerebral palsy.

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