Report by Prue Golland 2015 Churchill Fellow

To investigate evidence-based interventions for maximising gross motor outcomes in children with cerebral palsy

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Signed PRUE GOLLAND Dated 6/10/2016
Introduction

Cerebral palsy is the most common cause of childhood physical disability and arises from multiple and varied aetiologies, resulting in multiple and varied presentations. In Australia, a child is born with cerebral palsy every 15 hours (ACPR, 2013). All children with cerebral palsy will have some degree of motor impairment. The motor impairment can be relatively mild and present in the form of a limp through to a severe motor impairment which significantly limits functional movement.

The heterogeneity of presentations amongst children with cerebral palsy poses a challenge to both families and clinicians with respect to choosing the ‘right’ interventions. With such variability in presentations, no one intervention will address all the needs of all children.

Over the past 15 years, the evidence base relating to interventions for cerebral palsy has grown at a rapid pace making it hard for individuals with cerebral palsy, their families and clinicians to keep abreast of changes and new developments (Novak et al., 2013; Novak, 2014). As researchers and clinicians supporting individuals with cerebral palsy and their families, we have a responsibility to not only provide the most effective interventions, but also to provide individuals and their families with clear and easy to understand information to help empower them to make decisions about which interventions are right for them.

A new intervention approach - HABIT-ILE - is showing great promise for improving both upper and lower extremity motor outcomes in children with cerebral palsy. HABIT-ILE has been developed in Belgium to expand upon an established effective upper extremity therapy HABIT (hand arm bimanual intensive training) that was developed in the USA.

This 2015 Churchill Fellowship has enabled me connect with and learn from professionals from the international cerebral palsy community. I have been able to explore the ways in which intensive interventions are provided with the aim of maximising the gross motor outcomes of children with cerebral palsy across the GMFCS levels. Interventions falling under the three approaches - child-active rehabilitation, compensatory & environmental adaptation, and health and secondary prevention - were explored.

I would like to acknowledge the generous support from the Winston Churchill Memorial Trust for this Fellowship and for enabling me to learn from other passionate and skilled clinicians from around the world.

I would like to thank Cerebral Palsy Alliance for their support in pursuing this Fellowship and for their unwavering commitment to individuals with cerebral palsy and their families.

To all the clinicians and researchers who so graciously shared their time, experience and wisdom, thank you. We truely have a global community working towards improving the lives of people living with cerebral palsy. I look forward to any ongoing collaborations.

Thanks must also go to all the children and families who have allowed me to hear their stories and observe their therapy so that I may learn and continue to support families in Australia.
A special thank you to Margaret Wallen whose encouragement and support to undertake this Fellowship will never be forgotten. Thank you for your friendship.

Finally, to my family, through all that we have faced and that which is yet to come, your love and support shines to guide us all home.
Executive Summary

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Highlights
Connecting with so many national and international colleagues in Stockholm and beyond and being inspired by a shared passion for supporting people with cerebral palsy (CP). Seeing the contribution that Australia and Cerebral Palsy Alliance makes to the international community through research and leadership. Discovering race running and the potential opportunity this offers for Australians with disability. Having an opportunity to attend the HABIT-ILE camp with Yannick Bleyenheuft and her amazing team - watching the progress made by a little girl who had never had access to functional, goal directed therapy before and the difference the camp made to her function.

Major lessons
Intensive motor learning based approaches such as HABIT-ILE result in significant motor outcomes for children with CP and ongoing research is required to determine the optimal dosage. Children with CP require support from a number of rehabilitation approaches to ensure their health and function are maximised and supported as they grow. Musculoskeletal growth and development cannot be ignored in preference for functional outcomes as the two are closely linked and prevention of secondary musculoskeletal deformities should be considered an equal priority.

Conclusions
Australia is a lucky country where the utilisation of evidence based, functional, goal directed therapy is considered the norm for children with CP and where a culture of innovation which welcomes new ways of delivering services, thrives. HABIT-ILE is an intervention approach that is grounded within contemporary understanding of neuroscience and rehabilitation for children with CP and offers many possibilities for Australian children. Ongoing efforts are required to ensure evidence based interventions are translated from the research space into clinical practice and become ‘usual care’ for the benefit of all.

Proposal of dissemination and implementation
Learnings from this Fellowship will be disseminated through Cerebral Palsy Alliance, the Australian Physiotherapy Association NSW Paediatric Special Interest Group and the Australasian Academy of Cerebral Palsy and Developmental Medicine conference 2018. Accessible information for parents will be made available through Cerebral Palsy Alliance. Implementation of a pilot intensive programme based around HABIT-ILE for children with cerebral palsy will be carried out following consumer engagement and establishment of suitable partnerships. An evaluation of the pilot will be undertaken to establish its efficacy and suitability for the Australian context. RaceRunning as an option for fun, fitness and social participation will be further explored and opportunities for children with CP to try RaceRunning in Australia will be developed.
## Programme

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Background

Cerebral palsy is a complex disability. The term cerebral palsy, is in fact an umbrella term that describes 'a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy and by secondary musculoskeletal problems.' (Rosenbaum et al., 2007).

In Australia, a child is born with cerebral palsy every 15 hours (ACPR, 2013).

Cerebral palsy is the most common cause of childhood physical disability and arises from multiple and varied aetiologies, resulting in multiple and varied presentations. Variable characteristics of cerebral palsy include the distribution of motor impairments, the type of movements seen, the severity of the motor disorder (and therefore functional abilities) and the presence of secondary impairments.

Describing cerebral palsy

By distribution

The first way of describing cerebral palsy is to describe the distribution of the motor impairments.

i) hemiplegia - refers to one half of the body affected
ii) diplegia - refers to both legs affected
iii) quadriplegia - refers to all four limbs affected with head and trunk also affected

Hemiplegia is also referred to as unilateral (one side) whilst diplegia and quadriplegia are also referred to as bilateral (both sides) cerebral palsy.

Figure 1 outlines the prevalence of each distribution of cerebral palsy according to the Australian Cerebral Palsy Register report (2013).
By movement type

The second way of describing cerebral palsy is to describe the type of movement disorder. This is closely associated with the area of the brain that is damaged.

i) spasticity - spasticity is a form of hypertonia or high muscle tone in which there is increased resistance to passive movement which results in stiffer and tighter muscles

ii) dyskinesia - dyskinesia refers to involuntary movement. People with dyskinesia experience involuntary movements that may be twirling and repetitive (dystonia), slow and stormy (athetosis) or dance-like and irregular (chorea) in nature

iii) ataxia - ataxia means ‘without order’ or ‘incoordination’. Ataxia is characterised by shaky movements and balance and coordination are impaired.

These movement types may be present in isolation or as mixed presentations. With improved understanding and availability of new assessment tools, there is growing recognition of the co-occurrence of spasticity and dyskinesia in individuals previously identified as having spastic cerebral palsy.

By severity

The third way of describing cerebral palsy is to classify the severity of the motor impairment. Two classification systems of motor function are internationally recognised and relate to how an individual with cerebral palsy mobilises and how they use their hands.

i) Gross Motor Function Classification System - Expanded and Revised (GMFCS-E&R) ‘is a 5-level classification system that describes the gross motor function of children and youth with cerebral palsy on the basis of their self-initiated movement with particular emphasis on sitting, walking, and wheeled mobility’ (Palisano et al., 2007).

In Australia, the distribution of children across GMFCS levels is as follows:

- GMFCS I 35.5% - these individuals walk at home, school, outdoors and in the community, climb stairs without a rail. Speed, balance and coordination of gross motor skills is impaired.
- GMFCS II 24.5% - these individuals walk in most settings and climb stairs using a rail, often experience difficulties walking distances and in crowded environments/uneven surfaces. Gross motor skills such as running and jumping are increasingly more difficult.
- GMFCS III 10.7% - these individuals walk with a hand-held mobility device and use a wheelchair for longer distances.
- GMFCS IV 12.2% - these individuals rely on wheeled mobility (manual or powered) as their main form of mobility however they may walk at home with significant physical assistance.
- GMFCS V 14.1% - these individuals rely on a manual wheelchair in all settings and have significant limitations in head and trunk control and voluntary arm/leg control.
Further information can be found in Appendix A.

ii) Manual Ability Classification System (MACS) is a 5-level classification system that describes how children with cerebral palsy use their hands to handle objects in daily activities (MACS, 2005).

The 5 levels are similar to the GMFCS levels. Individuals classified as MACS I able to handle objects easily while individuals at MACS V are unable to handle objects and require total assistance.

Further information can be found in Appendix B.

Secondary impairments

The motor impairments of cerebral palsy are almost always accompanied by one or more secondary impairments (Rosenbaum, et al., 2007). For many children, these secondary impairments are more disabling than their physical impairment, for instance

- 3 in 4 will experience chronic pain
- 1 in 2 will have an intellectual impairment
- 1 in 3 will be unable to walk
- 1 in 3 will experience hip displacement
- 1 in 4 will be unable to talk
- 1 in 4 will have epilepsy
- 1 in 4 will have a behaviour disorder
- 1 in 4 will have bladder incontinence
- 1 in 5 will have a sleep disorder
- 1 in 10 will have a vision impairment
- 1 in 15 will be unable to eat orally
- 1 in 25 will have a hearing impairment.

(Novak et al., 2012)

Which intervention?

The heterogeneity of presentations amongst children with cerebral palsy poses a challenge to both families and clinicians with respect to choosing the ‘right’ interventions. With such variability in presentations, no one intervention will address all the needs of all children. When choosing appropriate interventions, it is useful to consider the International Classification of Functioning, Disability and Health (ICF) framework and the evidence-based practice (EBP) framework to help guide decisions.

The ICF framework represents a biopsychosocial model of health and disability in which there are dynamic relationships between the health condition or disability, the individual and environmental factors within society (Rosenbaum & Stewart, 2004; WHO, 2002). It highlights that health outcomes can be at the level of the body in terms of its physiological functioning or anatomical structure, at the activity level in terms of how a person performs a task or activity, or at the participation level in terms of the impact on a person’s involvement in everyday life situations (WHO, 2002).
For decades, the focus of interventions for people with cerebral palsy predominantly sat in the body functions and structure domain as clinicians worked to remediate the physical impairments. Following the introduction of the first iterations of the ICF in the early 1980s, greater attention has been paid to increasing the ability of people with disability to be more independent in functional tasks and activities of daily life.

Over recent years, there has been a gradual shift internationally towards a focus on participation outcomes for people with disability. Consequently, the body of work looking at interventions to encourage and improve participation has also increased. Participation is defined by the ICF as ‘involvement in a life situation’ and participation restriction is defined as ‘problems an individual may experience in involvement in life situations’.

Imms and colleagues (2016) recently published a systematic review into the language and definitions used in intervention research with children with disabilities. This review highlighted the inconsistencies in how ‘participation’ is defined within the literature and the challenges this presents in terms of identifying appropriate methods of measuring participation outcomes. They did however identify common themes that describe the participation and related concepts. Attendance and involvement are the key elements to participation while related elements include activity competence, sense of self and preferences. These concepts are related as depicted below (Figure 3) and exist within an environmental dimension.
The participation concept:
Attendance: defined as 'being there' and measured as frequency of attending, and/or the range or diversity of activities in which an individual takes part.
Involvement: the experience of participation while attending, including elements of motivation, persistence, social connection, and affect.

Related concepts:
Activity competence: the ability to execute the activity being undertaken according to an expected standard.
Preferences: the opportunity to choose and to be able to undertake activities that are meaningful or valued.

Environmental dimensions:
Availability: objective provision of activities or services.
Accessibility: ability (or perceived ability) to access the activity or situation.
Affordability: financial, time, energy, and other resource constraints to attending.
Accommodability: the ability of the situation to be adapted or modified.
Acceptability: the person's acceptance of the situation, and other people's acceptance of the individual in the activity setting.

Figure 3. A family of participation and participation-related constructs situated within an environmental context including the five dimensions of the environment.
(From Imms et al., 2016, page 36)

The second framework for helping make decisions around interventions is the evidence-based practice (EBP) framework. Evidence-based decision making involves the integration of best available clinical evidence from systematic research, the proficiency and judgment clinicians acquire through clinical experience and client values and preferences in making clinical decisions about their care (Sackett et al., 1996). Decision making is also made with consideration to the organisational context (for example local policies, procedures and beliefs around approaches) (Figure 4).

Figure 4. EBP Framework

Over the past 15 years, the evidence base relating to interventions for cerebral palsy has grown at a rapid pace making it hard for individuals with cerebral palsy, their families and clinicians to keep abreast of changes and new developments (Novak et al., 2013; Novak, 2014). At the same time, it is also acknowledged that effective interventions are only effective at one level of the ICF (that is, interventions that target the body structure/function level will have a body structure/function outcome and not an activity or participation outcome) (Novak et al., 2013). Several studies have shown that 10-40% of children with cerebral are not provided with evidence-based interventions and at
least 20% of children receive harmful or ineffective interventions (Flores-Mateo, 2007; Rodger, 2005; Saleh, 2008).

Maximising gross motor outcomes in children with cerebral palsy will most often require a combination of therapy approaches targeting different levels of the ICF. Novak (2014) summarises contemporary management of cerebral palsy into three main approaches - child-active rehabilitation, compensatory & environmental adaptation, and health and secondary prevention. The relative contribution of each of these approaches will vary according to each individual child’s presentation and identified needs and goals. As such, an integrated care approach should be promoted to enable children to receive appropriate interventions in a timely and efficient manner.

The changing disability environment in Australia

The disability sector within Australia is currently undergoing the single biggest reform seen since the introduction of Medicare in 1975. The National Disability Insurance Scheme (NDIS) was launched in July 2013 and aims to ‘support people with a permanent and significant disability that affects their ability to take part in everyday activities’ (NDIS, 2016). It does this by working with individuals and their families/carers to identify the supports needed to live their lives and achieve goals across many life domains (independence, community participation, education, employment and health and well-being). It has at its core, the concepts of choice and control - enabling individuals to choose how, when and where supports are provided as well as who provides the supports. (NDIS, 2016)

These changes have significantly changed the way in which services and supports for people with disability are funded. Disability organisations were, by and large, previously funded through state government ‘block funding’ arrangements. This block funding enabled organisations to deliver services to clients ‘free of charge’ however individuals with disability had limited choice over who would provide their service as most organisations had specific eligibility criteria (often based around age, diagnosis or home address). The NDIS has flipped the funding direction, providing a specified funding package to each eligible individual, that can be spent on purchasing services from providers of their choosing to meet their identified goals. This creates a ‘fee for service’ marketplace in which we see growth in the number of providers offering services to people with disability and increasing competition for customers.

Increasing market competition is a good thing for people seeking greater choice over their services. There is a risk however that some service providers, eager for a market share, will offer outdated or ineffective interventions due to the knowledge-to-practice gap that exists in translating new research findings into clinical practice.

As researchers and clinicians supporting individuals with cerebral palsy and their families, we have a responsibility to not only provide the most effective interventions, but also to provide individuals and their families with clear and easy to understand information to help empower them to make decisions about which interventions are right for them.
This 2015 Churchill Fellowship has enabled me connect with and learn from professionals from the international cerebral palsy community. I have been able to explore the ways in which intensive interventions are provided with the aim of maximising the gross motor outcomes of children with cerebral palsy across the GMFCS levels. Interventions falling under the three approaches - child-active rehabilitation, compensatory and environmental adaptation, and health and secondary prevention - were explored.

Fellowship Activities

International Conference on Cerebral Palsy and other Childhood-onset Disabilities, Stockholm, Sweden

The 2016 meeting in Stockholm was the 5th International Conference of Cerebral Palsy (ICCP) and the 28th Annual Meeting of the European Academy of Childhood Disability (EACD). It also marked the inaugural meeting of the International Alliance of Academies of Childhood Disability (IAACD) which brings together members of the American Academy of Cerebral Palsy and Developmental Medicine (AACPDM), the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) and the European Academy of Childhood Disability. Over 1500 participants were present from 66 countries across 6 continents, making this a truly international conference and exemplifies the commitment of clinicians, researchers and academics to making a difference in the world of CP.

The theme for the conference was “Challenging Boundaries” with the scientific committee and organisers aiming to inspire participants to break through the ‘many boundaries that exist in society due to cultural and political traditions, economic constraints and national borders as well as those that are due to limitations of body function and activity’ (ICCP, 2016a, page 5). The many and varied key note speakers were able to speak to many of these issues and provide ample food for thought.

With an extensive conference programme on offer, I chose to focus on five key areas of interest:

1. Epidemiology, aetiology and genetics
2. Spasticity and dystonia
3. Maximising motor outcomes
4. Increasing participation in physical activity
5. Innovative technologies

1. Epidemiology, aetiology and genetics

Knowledge and understanding regarding the incidence and causes of cerebral palsy around the world has continued to evolve over the years, largely due to the establishment and maintenance of various regional and national cerebral palsy registers such as those in Ireland, Sweden, Denmark, Norway, France, the United Kingdom, Germany, the Netherlands (which along with others, contribute to the European Network of Cerebral Palsy Registers), Australia, Canada and the United States of America. There are nearly 40 functioning registers/surveillance programmes worldwide (Goldsmith et
New registers have recently been established in New Zealand and Bangladesh, with more countries (particularly developing countries looking to establish registers in the near future.

The purpose of cerebral palsy registers is to
- monitor the incidence and prevalence of cerebral palsy
- improve understanding about the causes of cerebral palsy
- evaluate preventive strategies
- assist in planning present and future services for children and adults with cerebral palsy (CPA, 2016)
- provide information about cerebral palsy (Goldsmith et al., 2016)

Internationally recognised epidemiologist Professor Eve Blair led a mini-symposium with Kate Himmelman (Sweden), Elodie Sellier (France), Veronka Horber (Germany) and Sarah McIntyre (Australia) on ‘Epidemiology, risk factors and neuroimaging in cerebral palsy - current knowledge and news. Can we predict the future?’

Aetiological research into cerebral palsy has diversified through technological developments in informatics and computer science, genetics, immunology and infectious diseases, perinatal medicine, cerebral imaging and stem cell manipulation. (Eve Blair presentation) These developments bring with them greater opportunities to understand the causes of cerebral palsy and the development of preventive strategies however they also highlight the need for a common language around descriptions and diagnoses.

Trends in the prevalence of cerebral palsy in Europe were presented by Elodie Sellier using data from the Surveillance of Cerebral Palsy in Europe (SCPE) database. The SCPE database now comprises 24 registers in 20 countries and data from birth years 1980 - 2006 were presented. Prevalence rates were presented according to birth weight - normal (>2499g), moderately low (1500 to 2499g), very low (1000 to 1499g) and extremely low birth weight (<1000g).

For children with normal birth weight there is a trend to decreasing prevalence however this is not significant (a change from 1.17 per 1000 live births down to 0.89 per 1000). There is a decrease in the rate of bilateral CP with a slight increase in unilateral CP. There is no significant change in the prevalence of dyskinetic forms of cerebral palsy among children born with normal birth weight. Multiple aetiologies are identified in children with cerebral palsy who are born with normal birth weight including maldevelopment of the brain, white matter lesions and hypoxic ischaemic encephalopathy.

For children born with moderately low birth weight and very low birth weight a significant decrease in prevalence has been noted (8.5 to 6.2 per 1000 live births and 70.9 to 35.9 per 1000 live births respectively) with a decrease in bilateral cerebral palsy only.

For children born with extremely low birth, prevalence is stable at 42.4 per 1000 live births and there has not been a change in any of the cerebral palsy subtypes.

Overall, Europe has experienced a decrease in prevalence of cerebral palsy from 1.9 to 1.77 per 1000 live births over the period 1980 to 2003. This represents a 15% reduction in prevalence over 24 years which is a significant change. There has been an overall decrease in the prevalence of bilateral cerebral palsy (due to a decrease in cystic
periventricular leukomalacia - PVL) however a slight increase in unilateral cerebral palsy has been noted (there has not been a decrease in prevalence of intraventricular haemorrhage or hemorrhagic infarction causing stroke). The trends seen in Europe are comparable to those seen in Australia however Australia sees a declining prevalence among children born with extremely low birth weight.

The prevalence rates and changes seen over the last 2 decades in Europe clearly show that there are differences in prevalence amongst different aetiologies. As discussed earlier in this report, the multiple and varied aetiologies responsible for cerebral palsy result in many different presentations and pose particular challenges with identifying appropriate treatments - treatments for individuals with cerebral palsy as well as treatments or interventions to minimise the risk of brain injury during pregnancy or labour (i.e. preventative measures). Understanding aetiology may also assist in supporting parents with prognostic information particularly with respect to future function.

Abnormal MRI findings are present in 80-87% of children with cerebral palsy and there is now a growing tendency to report on MRI findings in cerebral palsy registers (Veronka Horber conference proceedings). With the growing number of cerebral palsy registers worldwide and greater international collaboration leading to an increased ability to compare data between counties, countries and regions, there is a need to establish a consensus on the language around neuroimaging.

Neuroimaging findings are closely related to the timing of brain development during pregnancy and the timing of an insult/injury to the brain. Maldevelopments of the brain are thought to generally occur during early pregnancy, infants born preterm are more likely to experience white matter injury while infants born at or post term are more likely to experience grey matter injury.

SCPE recommend classifying neuroimaging at age 2 due to developing myelination in the first two years of life. If neuroimaging is assessed before 2 years of age, patterns such as mild PVL and basal ganglia injury might be missed.

Additional work by SCPE has looked at the correlation between neuroimaging findings and functional profiles in 1970 children with CP born between 1995-2006 and for whom MRI was available. This work was presented by Kate Himmelmann.

Post neonatal MRI were conducted over the age of 2 for 907 children, under the age of 2 for 820 children and 243 children had an MRI at age unknown.

When the MRI findings of children presenting with unilateral CP were reviewed, 68% showed unilateral findings with left-sided findings dominating. Bilateral findings were seen in 22% of children and 9% of children had unknown neuroimaging findings. For children with unilateral spastic cerebral palsy (n=276) 85% showed white matter injury and 15% showed grey matter injury. Of those children with grey matter injury, approximately 30% had active epilepsy.

For children presenting with bilateral cerebral palsy, bilateral findings were evident in 77% of children, unilateral in 10% with unknown findings in 13%.

With regards to timing of brain injury, this work demonstrated that gestational age affects MRI pattern. In children born less than 32 weeks gestational age, the
predominant patterns were white matter injury and unknown. Grey matter injury and white matter injury patterns were equally represented in children born greater than 36 weeks gestational age. In children born at term, maldevelopment (mostly GMFCS III-V) and normal (50% bilateral spastic CP) neuroimaging findings were predominant.

The work also shows that three MRI categories (maldevelopment, predominant white matter injury and predominant grey matter injury) describe timing and most of the pathology seen in CP. CP subtypes may be associated with specific MRI patterns (e.g. dyskinetic CP appears to be associated with predominant grey matter injury with bilateral findings).

Michael Kruer from the US gave a keynote presentation on ‘The genomic landscape of cerebral palsy’ and posed the question - do single gene defects causing cerebral palsy exist?. Significant advances have been made in next-generation sequencing technologies (Moreno-De-Luca et al., 2012) enabling sequencing of the human genome and the identification of single gene mutations. Research into the genetic contribution to cerebral palsy has been growing over the last decade or so, with an increasing body of evidence supporting a genetic cause (Maclennon et al., 2015; Moreno-De-Luca, 2012) giving rise to the term “cryptogenic cerebral palsy” - that is, CP that is not related to brain malformation, identified genetic syndrome, metabolic disorder or blood clotting disorder (Kruer, conference proceedings).

Genetic mutations disrupt normal biology. There are potentially hundreds of genes involved in cerebral palsy with up to an estimated 31% of cases of CP having a genetic cause (Maclennon et al., 2015). One such genetic mutation has been identified involving the adaptor protein complex-4 (AP4). AP4 plays a crucial role in normal actin filament growth which is required for the development of normal neuron-neuron connections. Abnormal actin filaments may lead to defective neuron-neuron connections leading to abnormal connectivity and may result in spastic cerebral palsy. (Kruer conference proceedings; Moreno-de-luca, 2012)

Preliminary findings from the Cerebral Palsy Genetic Research Network (an international study on the genetic causes of CP) show that approximately 50% of the cohort (individuals with cryptogenic hypotonic, spastic or dystonic CP) had a potential gene mutation causing cerebral palsy. (Kruer conference proceedings) The aim of this study is to identify new genes that cause CP, which in turn, will lay the foundation needed to improve diagnosis and treatment for affected children (UCP flyer http://ucp.org/tag/cp-genetic-research-network/)

In summary, it is anticipated that the genomic contributions to cerebral palsy may be significant, that single gene causes of CP may map to common pathways and provide a window into the condition and that the suite of single gene causes of CP may lead to therapeutic advances in the treatment of cerebral palsy. (Kruer, conference proceedings) This is an exciting space for the field of cerebral palsy and neurodevelopmental disability, opening up new possibilities in diagnosis and treatment.

2. Spasticity and dystonia

Having a good understanding of spasticity and dystonia is essential for the management of children with cerebral palsy. Being able to correctly identify and describe a child’s movement disorder is important for:
• enabling selection of appropriate interventions
• enabling clear communication between clinicians
• providing a common language for cerebral palsy registers around the world.

James Rice (Adelaide), Darcy Feelings (Canada) and Adrienne Harvey (Melbourne) presented a breakfast session - When spasticity and dystonia co-exist: re-thinking CP motor classification, to highlight some of the challenges in the field.

The session commenced with a discussion of the current classification systems. Generally speaking, current classification systems lead to the identification of a ‘dominant’ motor type and aren’t able to accommodate mixed presentations. This leads to a favouring of spasticity as the major motor type with dystonia frequently missed. This is particularly the case with the Surveillance of Cerebral Palsy in Europe (SCPE) classification tree whereby spasticity and dystonia are mutually exclusive. SCPE results in a classification of spastic cerebral palsy when spasticity is present, even if it is not the dominant motor type in a mixed presentation.

There are many potential implications associated with inaccurate classification of motor types. Inaccuracies in classification can give rise to a heterogenous group of patients recruited into research studies which may lead to increased variability in responses to treatment, making efficacy studies difficult to interpret. Clinically, appropriate interventions especially medications may be more targeted to certain motor types and a clear understanding is needed to help guide clinical recommendations.

The Hypertonicity Assessment Tool (HAT) was presented as a useful tool with good psychometric properties for identifying the presence of three different forms of hypertonicity - spasticity, dystonia and rigidity (although rigidity is infrequently seen in cerebral palsy).

Population estimates reported in the literature point to spasticity as the primary motor pattern in 80-90% of individuals with CP, dystonia in 2-15% and ataxia and hypotonia both 0-5%. As mentioned above, the dominant or primary motor pattern is key as this is utilised in research.

SA review of register and compared with Vic and Swedish registers - check DMCN supplement for results

James Rice and colleagues carried out a population-based cross sectional study involving 151 children aged 2-18yrs (mean age 8.8yrs) in South Australia to examine their motor pattern in relation to their stated CP diagnosis. The breakdown of presentations was as follows:

• 5 children were classified as unilateral dyskinetic
• 46 children were classified as unilateral spastic
• 83 children were classified as bilateral spastic
• 16 children were classified as bilateral dyskinetic
• 1 child was classified as ataxic

All children were assessed using the HAT, Barry Albright Dystonia Scale (BAD), Modified Tardieu Scale (MTS), Modified Ashworth Scale (MAS) and the Australian Spasticity Assessment Scale (ASAS). Functional classification using the GMFCS, MACS and Communication Function Classification System (CFCS) was also confirmed.
Findings of the study include:

- children with dyskinesia presented with worse motor and communication function
- HAT results showed predominantly mixed motor patterns in the lower limbs (spasticity and dystonia)
- BAD scale showed a wide spread of dystonia scores in both the spastic and dyskinetic groups
- median BAD score increased with worsening motor function in children with ambulant bilateral spasticity

It was concluded that dystonia is clearly identifiable and quantifiable and poses issues particularly in children diagnosed as having spastic diplegia (bilateral spasticity) GMFCS I-III. Spasticity is harder to quantify and does not appear to increase as motor function worsens. The range of dystonia severity in the children identified as having spastic cerebral palsy is slight to moderate but increases as motor function worsens (to GMFCS IV). Distinct HAT profile similarities were noted between left and right sides however there were differences between upper and lower limbs.

These results demonstrate that dyskinesia is frequently overlooked particularly in children diagnosed with spastic forms of cerebral palsy. Mixed presentations are very common and use of appropriate assessment tools is encouraged to improve identification and management of children with cerebral palsy.

3. Maximising motor outcomes

Cerebral palsy is a physical disability and all children with CP will have some degree of motor impairment. We now have the ability to diagnose cerebral palsy in children as young as three months of age using Prechtl’s Assessment of General Movements. Diagnosing early opens up new avenues to intervene early and provide evidence based early intervention that maximises neuroplasticity and supports the motor skill acquisition of infants and young children as well as their cognitive, social and communication function.

There is no cure for cerebral palsy - it is a lifelong physical disability. The focus of interventions needs to be able to change to meet the changing needs of individuals as they grow. I will present information relating to interventions for maximising gross motor outcomes in two parts - i) early intervention for infants and ii) interventions for school age/older children.

   i) Early intervention for infants - state of the science

A full-day pre-conference workshop focusing on the current state of the science for early intervention was facilitated by Professor Iona Novak and Dr Cathy Morgan (Sydney).

The workshop commenced with an introduction of new international clinical guidelines for early diagnosis and early intervention for infants with cerebral palsy. These guidelines comprise 12 recommendations. With respect to diagnosing, there is a particular emphasis on best practice early diagnosis for children before 5 months of age (using Prechtl’s Assessment of General Movements in combination with MRI) and children after 5 months of age (when the General Movements assessments can no longer be utilised) especially those who are identified by their parents as not developing
‘normally’. The guidelines also cover recommendations for predicting severity of the motor impairment through appropriate tools such as the Hammersmith Infant Neurological Examination (HINE) and assessing for secondary impairments such as vision. Recommendations regarding early intervention point to interventions that require the infant with cerebral palsy to actively engage in repetitive and structured practice of motor and learning tasks.

These guidelines are still under publication review and as such they are not yet available for distribution. It is anticipated that these guidelines will be published in the near future.

Following the introduction of the clinical guidelines, several motor intervention studies were presented. This was followed by a comment on cognitive interventions and an update on interventions for visual impairment.

State of the science on motor interventions:

Multiple presenters from Australia, Sweden, Canada and the Netherlands shared their research findings from studies examining arm & hand function and gross motor function in children under 3 years of age. Results from trials recently completed (Upper Limb Baby Early Action Observation Training - UpBEAT; Baby Constraint Induced Movement Therapy - Baby CIMT; Goal Oriented Activity Based Motor Training - GAME; and Coping with and Caring for infants with special needs - COPCA) were presented alongside preliminary findings (Intensive Motor Training After Perinatal Stroke to Enhance Walking) and the protocol for a study under recruitment (A Small-step Programme for Development of New Treatment Principles for Children With Cerebral Palsy and Other Neurodevelopmental Disorders). These studies demonstrated that improvements in motor function in children under 3 years are seen with interventions that involve active participation and utilise motor and cognitive learning strategies.

State of the science on cognitive interventions and future directions: presented by Gustaf Gredebäck (Sweden).

Professor Gredebäck is a professor of developmental psychology at Uppsala University and Director of Uppsala Child & BabyLab. During his presentation Professor Gredebäck discussed the correlation between motor and cognitive development and the premise that infants develop an understanding of their world through active exploration. He explored a number of key constructs including action prediction (keeping up with other people’s actions and learning from them), executive control (prohibition tasks, working memory, motor planning) and mathematics (approximation). These constructs are influenced by motor ability and active exploration and may be impaired in infants/children with impaired motor abilities. Infants need to experience movement. He highlighted the importance of facilitating active exploration to support cognitive development.

State of the science on vision interventions and future directions: presented by Dr Andrea Guzzzeta (Italy).

Approximately two thirds of the brain is involved in vision. The main domains of early visual function which are frequently impaired in cerebral palsy are primary visual perception (impaired following damage to the primary visual pathways), ocular motility
(impaired following damage to the oculomotor system) and visuocognitive disorders (due to damage to the associative visual areas).

Early assessment of the visual function of term newborns can be achieved using the Ricci scale which is able to predict visual outcome.

There are no CP-specific interventions for infants under 24 months of age (international clinical guidelines for early diagnosis and early intervention for infants with cerebral palsy, conference proceedings).

The main goals of early vision intervention should be to:

- Promote infants’ emotional and relational development by supporting the mother-infant relationship and or preventing the development of stereotyped behaviours
- Promote activity by improving postural-motor coordination, sensory-guided actions and movement of the body in space

The main strategies for early vision intervention are to:

- Address any treatable eye problems to ensure that the child has the best possible refractive correction and to implement all possible preventive measures (e.g. to prevent amblyopia). Children need an early ophthalmology assessment.
- Optimise the child’s visual experience through environmental enhancement such as perceptual adaptation (e.g. lighting and colour contrasts) and organisation of the physical environment (e.g. distances, speed of moving objects etc).
- Integrate vision with the other sensory channels (hearing and touch) in order to amplify visual information and/or to compensate for severely impaired vision.

Vision is important for learning through observation and movement skills, and therefore for cognitive development. Vision strategies should be incorporated into early motor, communication and cognitive interventions rather than isolated.

ii) Interventions for school age children

Interventions for school age children frequently involve training of more advanced gross motor skills such as balance, bike riding and running. During the conference, a number of studies examining different aspects of gross motor skill acquisition in school age children were presented. Two such studies (both carried out in Australia) explored bike riding ability in ambulatory children with CP whilst the second examined the effectiveness of a running group programme in children with a neurological condition. Both studies involved children with GMFCS I and II (equivalent motor function for children without CP). Interventions for more severely impaired children (CMFCS IV and V) are significantly lacking. In addition to these, a short workshop on motor learning was presented. A summary of the motor learning workshop follows here.

Motor learning is the leading approach utilised for motor skill acquisition at Cerebral Palsy Alliance. Motor learning is defined as ‘a set of processes involving practice and exercise leading to a relatively stable change in motor behaviour’ (Schmidt 1988 in Shepherd 2014, page 20). Motor learning requires active participation and incorporates five key principles:
i) practice - intense and repeated, which may be part or whole practice with scaffolding
ii) feedback - involves both intrinsic and extrinsic feedback
iii) guidance - physical guidance that is reduced as performance increases
iv) mental imagery - involves task visualisation and problem solving
v) task specificity and motivation

Andy Gordon (USA), Kathleen Kriel (USA), Yannick Bleyenheuft (Belgium) and Dido Green (UK) co-presented the motor learning workshop. Principles of motor learning, neuroplasticity and interventions targeting motor skill development were discussed.

Intensity of practice matters for motor learning. Infants as they begin to walk take about 14,000 steps, and 100 falls per day and need approximately one million steps to become efficient walkers. ‘Green light’ interventions (those with demonstrated effectiveness) for motor outcomes require intense practice.

Motor learning theory considers the person, the environment and the task. It utilises cognitive strategies to learn and allows compensatory movements. This is a fundamental difference to neurodevelopmental therapy approaches which focus on ‘normalising’ the body structure/function impairment. Motor learning based approaches involve the establishment of a goal/s, setting up the regulatory stimulus conditions and utilise problem solving. For motor learning to be achieved (that is, for new motor skills to be learnt), motor learning approaches need to incorporate the principles of neuroplasticity. These include:

- movement must be self-initiated (not passively done on behalf of the person)
- there must be mental and physical effort involved
- training must be of sufficient intensity
- training requires variability and must not be by rote
- training and the movement must be meaningful to the participant.

Optimal neuroplasticity depends on age, intensity, specificity and salience (Kleim, 2009) (see Appendix C for further background information relating to neuroplasticity).

Structured skill practice matters - repetitive motor activity alone does not produce functional reorganisation of critical motor maps within the brain. Motor skill acquisition/motor learning is required in order to see changes in motor maps. Intensive unimanual or bimanual training using activity-based therapy has been shown to repair/improve the motor control system in unilateral cerebral palsy by strengthening the corticospinal tract.

Hand Arm Bimanual Intensive Training (HABIT) and Constraint Induced Movement Therapy (CIMT) are interventions which have been developed based on motor learning principles. HABIT and CIMT camps have been run by Andy Gordan’s group in the USA since 2002 with 28 camps run to date. Children have ranged in age from 3.5 to 17 years with benefits achieved across all ages. Their results have shown that CIMT and HABIT result in the same clinical improvements however HABIT drives goal performance and movement coordination. Structured and unstructured practice improves dexterity and bimanual hand use, structured skill training drives goal performance and improves movement coordination as measured with kinematics. Repeated camp attendance results in further improvement.
Much of the work to date has been focused on applying these motor learning principles to interventions for the upper limb (CIMT, HABIT). New work is successfully applying motor learning principles to the lower extremity. Hand Arm Bimanual Intensive Training Incorporating the Lower Extremity (HABIT-ILE) was developed to help address a lack of effective interventions for intensive training for the lower extremities. HABIT-ILE continues to provide intensive bimanual upper extremity training whilst incorporating activities for the lower extremities and for postural control. This is an important approach for a number of reasons - lower extremity abilities frequently deteriorate as children with CP grow, interactions between the upper extremities and lower extremities are rarely trained together whilst they are present in everyday life and there is a lack of intensive interventions targeting the lower extremity.

This Churchill Fellowship has enabled me to attend a HABIT-ILE camp in Brussels. As such, HABIT-ILE will be discussed in greater detail towards the end of this report, including results from recent studies.

Summary for maximising motor outcomes from studies in early childhood and school-aged children:
A large number of studies of interventions targeting motor outcomes were presented during the conference. Many interventions demonstrated improvements in motor outcomes however some did not. For those interventions that resulted in improved motor outcomes, some common features can be identified:

- they harness motor learning and the principles of neuroplasticity (see Appendix C)
- they require the children to be actively involved in the therapy
- they are goal-directed
- they are directed at the activity level of the ICF.

4. Increasing participation in physical activity

It is well recognised that children with cerebral palsy are less physically active, participate in fewer preferred activities and experience greater barriers to participating in physical activities than their typically developing peers. A number of papers examining various aspects of participation in children with disability were presented. These included results of a systematic review looking at the efficacy of interventions to increase participation, and studies examining behaviour change amongst physiotherapists, the impact of a goal-directed family intervention on change in physical activity participation, predictors of participating in physical activity and the psychosocial outcomes of participating in a themed activity programme.

Leanne Sakzweski (QLD) presented findings from a systematic review exploring the efficacy and active ingredients of interventions aimed to increase participation in physical activities in children with cerebral palsy aged 5-18 years. Four studies were included in the meta-analysis. Interventions that included progressive resistance training, an online behaviour change intervention programme, context-focused occupational performance coaching, aerobic training, strength training and physiotherapy, and aerobic training and fitness. The authors reported that most interventions targeted either Body Structures and Functions or Activity domains of the ICF and acted to modify physical activity behaviour through the practice of skills (thus implying an increase in participation). There were no significant effects of the intervention on improving participation in physical activity in any study using physical
training. Contextual barriers were less frequently considered in the studies however where context-focused therapy was utilised, participation increased.

All studies involved children with GMFCS levels I, II or III. Children with GMFCS levels IV and V were not represented in the studies.

The authors concluded that therapy and behaviour change interventions have the potential to increase participation in physical activity in children with CP and that participation interventions should ideally be multimodal with a participation focus (rather than a body structures/function impairment or activity limitation focus). To try and address the lack of effective interventions for increasing participation in physical activity, the authors introduced a new study - ParticiPAte CP (a motivational physiotherapy programme to facilitate participation in physical activities for children with cerebral palsy). This study will utilise a participation-focused physiotherapy approach within a strengths-based framework. Recruitment is due to commence in 2016 and we await the results of this study with anticipation.

Several presenters from the Netherlands, Norway, the UK and Australia shared findings from a variety of studies:

- Evaluation of implementing a working method for stimulating physical activity in paediatric physiotherapy (Leontien Van Wely, the Netherlands)
- Enabling physical activity participation for children with disabilities: Goal attainment, performance and satisfaction following intervention (Claire Willis, Norway)
- Participation in physical leisure in children with motor impairments: a child-friendly interview study with 6-8-year-olds (Niina Kolehmainen, the UK)
- Psychosocial changes in children with hemiplegic cerebral palsy following participation in Amazing Magic Clubs (Ashleigh Hines, Australia)

The findings from these studies, whilst diverse, demonstrate the multi-dimensional challenges with interventions targeting the participation domain of the ICF. The first study highlighted that physiotherapists needed support to improve their coaching skills to support physical activity behavioural change in children. Environmental factors were the most common barriers to goal attainment identified in the second study and included climate and access to activities and assistive devices. Results from the study in the UK indicated that young children with disabilities are aware that the social environment influences their leisure participation whilst results in Australia indicate that participating in a magic club can result in increased motivation and engagement, greater awareness of self, and a sense of belonging and specialness.

Summary for increasing participation in physical activity:

The ‘participation’ construct is clearly gaining momentum as a focus for therapy. There is a strong bias by physiotherapists towards participation in physical activity, which is important to try and combat higher levels of inactivity and sedentary behaviour amongst individuals with cerebral palsy compared with typically developing peers. There appears to be fewer studies examining participation in children with cerebral palsy classified as GMFCS IV or V. The studies presented during the conference highlight the complex nature of the participation construct, the challenges in measuring participation, the challenges in identifying effective interventions for increasing participation and the complex interaction between barriers and facilitators to participation across communities.
5. Innovative technologies

Dr Patrice Tamar Weiss (Israel) gave an interesting and thought-provoking presentation on achieving ‘disruptive innovation’ for cerebral palsy.

In the world today, there are in excess of 50,000 medium and high tech assistive devices available however the rate of technology disuse is 50% or more. Some of the reasons why technology is underused include:

- poor design
- high cost
- high cost of maintenance
- limited device awareness
- poor device selection
- not durable
- poor cosmesis
- inadequate training
- inadequate demonstration of efficacy
- incompatibility with environment

Dr Tamar Weiss challenged the audience to explore disruptive innovations that lead to technologies that invigorate an existing paradigm to greatly influence current consensus and practice (that is, finding technologies that will change the way we practice). There are many examples of disruptive technologies that have changed society and behaviour over the years including trains, cars, planes, computers, the internet, mobile phones and social media. The impact of disruptive technologies gets faster and faster and the uptake of technology in the general population is becoming more and more rapid. However disruptive innovations in rehabilitation have been more difficult to achieve. Many advances in rehabilitation technology (e.g. robotics and virtual reality) have not yet been translated into everyday practice.

How do we try to achieve disruptive technology in rehabilitation? One principal approach is that of user-centred, participatory design whereby the end-users of the technology take part in the identification of technology needs, how they are going to be designed and used and in the development and review of the technology through an iterative process. The second approach is to increase the intuitiveness of the design - technology should be easy to use and not require extensive and complex training. Thirdly, there is a need to continue to create and test really novel ideas and have the courage to do so.

For disruptive technologies in rehabilitation to really have an impact, the support structures (social, health, education etc) need to be able to support the use of the technology in the individual’s environment. If it isn’t available, it doesn’t matter how good the technology is.

Disruptive technologies in rehabilitation will require the breaking of previous boundaries and constraints, financial support and collaboration if the true potential impact is to be realised.

Two examples of innovative technologies that I encountered during the conference are Petra RaceRunner running bikes and the Innowalk.
Petra RaceRunner running bikes:

Designed in Denmark by Connie Hansen in 1989, a RaceRunner is a three-wheeled running bike which provides people who use wheelchairs for mobility with an opportunity to walk and run. RaceRunners can be used recreationally or competitively on the track, road or off-road. The racerunner can be used in therapy, as sport and in daily life, to enhance an active lifestyle.

RaceRunning clubs are established in around 15 countries. RaceRunning has been featured at the International Wheelchair & Amputee Sports Federation Games since 2011, as well as a host of other international athletics events. RaceRunning has the potential to be included at paralympic level.

RaceRunning is not yet active in Australia and there is an opportunity to introduce this innovative, inclusive and fun option to benefit Australians with CP and other disabilities.
Innowalk:

The Innowalk is a sit-to-stand standing frame which is motorised to allow gentle leg movements to occur in an upright position. There are anecdotal reports of improved comfort in the Innowalk compared with a regular standing frame.

At this stage there is limited high quality evidence comparing the use of the Innowalk with regular standing frames however I am aware of a number of people who are interested in looking at this. I will follow this work with interest.

Conference summary:

The 5th International Conference on Cerebral Palsy and the 28th Annual Meeting of the European Academy of Childhood Disability delivered on its theme of “Challenging Boundaries”. It brought together passionate professionals from around the world who shared their knowledge and experiences in supporting people with cerebral palsy and other childhood disabilities.

There is a growing body of work focussing on motor learning interventions across the lifespan however with the exception of HABIT-ILE, there remains a gap in interventions to maximise motor outcomes in children at GMFCS levels IV and V. Attention on participation as a focus area for intervention continues to grow and despite advances in technology across our lives, advances in rehabilitation technology lags behind.

Conference abstracts are available from [http://eacd2016.org/program/](http://eacd2016.org/program/)

Keynote presentations are available on YouTube [https://www.youtube.com/playlist?list=PLnqQJI0EhuwyyntnPeFhohbB9Vv6EFp4N](https://www.youtube.com/playlist?list=PLnqQJI0EhuwyyntnPeFhohbB9Vv6EFp4N)
CPUP, University of Lund, Lund, Sweden

Uppföljningsprogram för cerebral pares or CPUP, is a follow-up surveillance programme for people with cerebral palsy in Sweden that commenced in 1994 (CPUP). The programme started in southern Sweden and was developed following the identification of high rates of hip dislocation and severe joint contractures in children with CP. The initial programme was a joint project between the paediatric orthopaedic departments and the child habilitation centres (CPUP). CPUP is now operating in all regions in Sweden and has expanded to Norway, Denmark, Iceland, Scotland and Australia (with regional adaptations) (CPUP).

CPUP offers an organised and systematic way of monitoring children with cerebral palsy as they grow. The aims of CPUP are to (CPUP):

• prevent the occurrence of hip dislocation and severe deformities by means of continuous and standardised surveillance, if necessary combined with treatment at an early stage, thereby optimising the functional ability and quality of life of those with CP
• gain knowledge about CP
• improve the cooperation between the various professionals with respect to people with CP

CPUP has reduced the incidence of some of the secondary impairments associated with cerebral palsy including pain, scoliosis, severe contractures, hip dislocation and malnutrition. Hip dislocation has been nearly eradicated (Hagglund et al., 2005a) and the number of children with severe contractures has been reduced by 70% (Hagglund et al., 2005b). The rate of orthopaedic surgery to address severe contractures, rotational deformity, foot deformity and salvage surgery for hip dislocation has also decreased from 40% to 15% (Hagglund et al., 2005a). Management strategies that have contributed to this success include regular surveillance and early detection, appropriate positioning in lying, sitting and standing as well as the use of orthoses (Hagglund et al., 2014).

Active surveillance and monitoring through programmes such as CPUP are now considered best practice in the management of the secondary impairments of cerebral palsy.

In 2011, Cerebral Palsy Alliance (CPA) introduced CPUP into New South Wales where it is now known as CP Check-Up™. In order to optimise the outcomes of children living with cerebral palsy, Cerebral Palsy Alliance has expanded its focus beyond musculoskeletal management of the lower and upper limbs and management of nutrition. It includes monitoring across a range of domains including cognition and learning, communication, sleep, pain, and parent and child well-being. CP Check-Up™ shares its aims with the Swedish CPUP - the prevention of many of the common associated conditions with cerebral palsy by providing timely support and interventions. The results from the assessments are used to help understand each client’s current skills and difficulties in order to plan and provide appropriate and timely interventions now and in the future (CPA, 2016).

Eva Nordmark (who was instrumental in the establishment of CPUP) and Katarina Lauruschkus (who has been actively implementing CPUP since 2009) are two physiotherapists in Skåne County, southern Sweden who have generously shared their
knowledge and experiences around CPUP, particularly regarding the physiotherapy contribution to the outcomes achieved by CPUP to date.

Three key areas of service delivery were of high interest for me to pursue in my Fellowship time at CPUP:

- how services are delivered and how this facilitates the implementation of CPUP
- the role of interventions to enable standing and facilitate hip development and prevent hip displacement
- the role of interventions to increase/encourage participation in physical activity

Service delivery

In Sweden, disability services (habilitation/rehabilitation) including physiotherapy, occupational therapy, speech pathology and assistive devices and medical services for people with cerebral palsy are publicly funded, run by the county councils and overseen by the Ministry of Health and Social Affairs. The Ministry of Health and Social Affairs is responsible for issues concerning the welfare of society - healthcare; financial security in the case of illness, old age and for the family; providing care for people with social difficulties, people with disabilities and the elderly; the rights of the child; rights for people with disabilities; and gender equality) (Government Offices of Sweden).

As such, children with cerebral palsy will generally have their medical and disability needs met by the same provider/funder (i.e., the healthcare system run by the county council). This enables relatively smooth processes for referrals to appropriate interventions such as botulinum toxin for tone management, orthopaedic surgery to manage musculoskeletal issues or assistive devices such as standing frames.

By contrast, in New South Wales, children with cerebral palsy have historically accessed a number of different service providers with different funding in order to have their needs met.

Medical services (such as tone management interventions, orthopaedic surgery and some orthoses) are provided publicly through the Department of Health and are generally provided out of one of the three tertiary children’s hospitals - Sydney Children’s Hospital, The Children’s Hospital at Westmead and John Hunter Children’s Hospital. The tertiary cerebral palsy services have, by and large, offered a consultative service and haven’t been in a position to be an individual’s primary provider of therapy/habilitation services. These services have historically been provided by one of three options - publicly funded through the Department of Ageing, Disability and Home Care (ADHC), through non-government organisations (NGOs) such as CPA, whose funding base has usually been a mix of public government (via block grants) and philanthropic money, or by private services on a fee-for-service basis. Assistive technology devices have historically been funded through either public government funded programmes (whose directive has been to fund assistive technology to support functional activities or reduce care giver burden) or philanthropic funding bodies (who are able to fund items not funded under the government scheme that support health outcomes).

The complex service and funding environment within NSW (which is mirrored across Australia with some state-by-state variations) can result in fragmentation of services for individuals with cerebral palsy.
The National Disability Insurance Scheme (NDIS), as mentioned earlier, is designed to facilitate the inclusion of individuals with disabilities in everyday life. It has a strong emphasis on skill development for carrying out tasks of daily life as well as supports to enable participation in an individual’s community. It specifically does not fund medical services as these are provided at the state level by the Department of Health. This has an impact on the funding of health and surveillance programmes for individuals with cerebral palsy as there is likely to be limited access to CP Check-Up™ through NDIS funding. As yet, the Department of Health has not yet taken surveillance on as core business. As such, much of CP Check-Up™ delivered by CPA, is funded philanthropically.

This poses some unique challenges for New South Wales (and Australia) in comparison with Sweden, particularly with respect to access to timely hip and spinal x-rays, orthopaedic reviews and tone management interventions which are fundamental to surveillance programmes and the prevention of secondary musculoskeletal issues (i.e. those assessments and interventions not directly provided within the disability sector).

Interventions to enable standing and facilitate hip development
The attainment of independent standing and walking skills in children with cerebral palsy is frequently delayed and for some children, independent standing and walking is not possible due to the severity of their motor impairment. Children whose standing and walking abilities are significantly impaired are at high risk of developing secondary musculoskeletal problems such as muscle contractures and abnormalities of skeletal development and alignment (e.g. hip displacement, hip dislocation and scoliosis). If left untreated, skeletal mal-alignments can progress to permanent and painful deformities that impair lying, sitting, standing and motor skills and impact upon an individual’s function, comfort, care needs and quality of life.

Standing programmes, often utilising assistive technology, have been standard clinical practice for physiotherapists for over half a century (Paleg et al., 2013). Standing frames to enable supported standing are frequently prescribed for children with cerebral palsy to achieve a variety of outcomes including: (Common guidelines for standing with standing shell / raising aid in Bou Region Skåne; Paleg et al., 2013)

- increasing range of movement about a joint (namely ankle, knee and hip)
- encouraging hip development and improving hip stability
- minimising postural asymmetry
- improving bone mineral density
- psychosocial outcomes (enabling social participation with peers, general well-being, alertness)
- improving cardiovascular and respiratory function
- improving gastrointestinal function
- enabling achievement of specific functional goals
- reducing sedentary time and increasing physical activity

Supported standing programmes and the use of standing devices have been an integral component of the Swedish CPUP since its inception and contribute to the reduction in rates of hip displacement and dislocation across Sweden. Every child with CP has access to appropriate standing devices throughout childhood through their local habilitation service. The most common standing device in childhood is a custom-made standing shell (below).
These standing shells are made by local orthotists and altered or remade as the child grows. They are used as they are or with a frame to provide additional support. Whilst the standing shells provide a custom-moulded option that fits each child’s individual body shape, challenges are sometimes faced with respect to the rate at which very young children grow and therefore grow out of the shell. There are often times where a child is not able to use their standing shell due to the need to alter or remake it due to growth. Alternative options may need to be utilised.

As children become older, grow taller and get heavier, the standing shells become more difficult and commercial standing frames generally take their place. Commercial options may also need to be considered for children who present with severe contractures to ensure they are appropriately supported.

The primary goal for using standing frames in Sweden is to encourage hip development and hip stability, thereby preventing or limiting the development of hip displacement and dislocation. Secondary goals (as outlined above) may also be relevant to individual children.
There are many questions surrounding the use of standing frames particularly regarding dosage and outcomes. To assist clinicians within Skåne County, clinical recommendations around the dosing of supported standing and use of standing frames have been developed based upon clinical experience and a systematic review by Paleg and colleagues (2013) on dosing of supported standing programmes.

These recommendations are listed here:

- have a clear purpose/goal for all supported standing programmes - the purpose/goal for standing may change with age
- all children and young people who do not have age-appropriate ability achieve standing, active standing or walking should participate in a supported standing programme (this will cover all children at GMFCS levels III-V and some at GMFCS level II)
- in most cases, supported standing programmes should be commenced from as early as 1 year (+/- 2 months)
- selection of the standing shell or alternate standing aid is individual and depends on the purpose/goal of the standing programme
- recommended standing time (dosage) to achieve positive effect is 5 times per week and depending on the on the indication as follows (based on the Paleg systematic review):
  - Joint range of movement/contracture management - 45-60 minutes daily
  - Reduce lower limb spasticity - 45-60 minutes daily
  - Preventing osteoporosis - 60-90 minutes (can be divided into shorter time periods)
  - Improve hip migration (hip stability) (stand in 30-60 degrees bilateral hip abduction) - 60-90 minutes daily
  - Improve gastrointestinal function (no time given in Skåne County recommendations)
  - Increase in general well-being (no time given in Skåne County recommendations)
  - Improved alertness (GMFCS V) (no time given in Skåne County recommendations)
  - Stability for dyskinetic CP (no time given in Skåne County recommendations)
  - Influence psychosocial factors (coming in the same eye level as peers) (no time given in Skåne County recommendations)
  - Further aims for young people include the relief of back and neck discomfort, reducing sedentary and increase physical activity (no time given in Skåne County recommendations)

In addition to supported standing programmes, goal directed training/functional training interventions are also utilised to develop active standing, walking and other gross motor tasks. Goal directed training/functional training is a child-active intervention that involves structured and repetitive practice of gross motor skills that work towards a goal(s) that has been identified by the child/family (Novak, 2014). Goal directed training is an effective intervention for helping individuals develop new motor skills (Novak et al., 2013). In Skåne County, children are generally provided with a six-week block of 1:1 physiotherapy once or twice a year. There is an expectation that children will continue to practice activities at home supported by a home programme.
Interventions to encourage participation in physical activity

Katarina Lauruschokus kindly shared her PhD thesis ‘Participation in physical activities and sedentary behaviour among children with physical disabilities’. Katarina has examined the participation of children with cerebral palsy in physical activities and explored the personal experiences of children and parents to identify facilitators and barriers to participation in physical activity. She also evaluated the feasibility of Physical Activity Referrals as an intervention to increase participation in physical activity.

A Physical Activity Referral (PAR) is an individualised written prescription for physical activity which may be for structured facility-based or community-based activities, with or without support from the prescriber. During her PhD Katarina combined PARs with motivational interviewing techniques to work with children and their families to identify preferred physical activities, support each individual to access, and participate in, self-selected activities and encourage lifestyle behaviour change.

In a feasibility study, Katarina demonstrated that participation in self-selected physical activities increased in frequency and duration and all children involved in the study (14) reported that their abilities in their self-selected activities improved. Children were aged between 7 and 11 years and were equally spread across the GMFCS levels (3, 3, 2, 4, 2 for GMFCS levels I-V respectively). Examples of activities included swimming, cycling, wheelchair hockey, transfers, table tennis, football and using the Innowalk.

Physical Activity Referrals is a multi-modal intervention incorporating therapy and skill development with a behaviour change intervention that is delivered in real-life, everyday environments. It is a promising approach to increasing participation in physical activities.
Oaklands School, Edinburgh, Scotland

Oaklands School is a school for children and young people with disability located in Edinburgh. Students attending Oaklands have high support needs secondary to learning difficulties, significant visual/sensory, health and medical needs which cannot be met within a mainstream setting. Many of the students also have a physical impairment including cerebral palsy. The predominant severity classifications for students with cerebral palsy are GMFCS IV and V (that is, most of the students at Oaklands who have cerebral palsy are unable to walk independently).

The school’s vision is ‘for all children and young people in Oaklands to enjoy their childhood and achieve their potential’. The educational team within the school is supported by an onsite therapy team comprised of occupational therapists, physiotherapists, speech and language therapists and therapy assistants.

One of the school’s aims is to develop transdisciplinary practice which maximises pupil learning. One of the ways the school is working towards achieving this aim, has been to implement the MOVE Programme.

The MOVE Programme (Mobility Opportunities Via Education/Experience) is a goal-directed, activity-based programme that offers a collaborative approach to learning movement skills in an educational setting. It was developed in Bakersfield, USA in the early 1980s by a special education teacher as a way of supporting the mobility skills of children with complex physical disabilities in special schools. It focuses on the functional movement skills of sitting, standing, walking and transferring, places movement at the centre of learning and considers every waking hour to be an opportunity for learning. It is designed around 16 practical life skill movements - sitting, movement in sitting, standing, transitioning from sitting to standing, transitioning from standing to sitting, pivoting while standing, walking forward, transitioning from standing to walking, transitioning from walking to standing, walking backwards, turning while walking, walking up steps, walking down steps, walking on uneven ground, walking up slopes and walking down slopes (MOVE manual).

Varying levels of mastery of each of these movement skills can mean the difference between independent mobility in the community or being dependent on others, the difference between a standing transfer or a hoist transfer or the difference between one or two people being required to assist the individual with completing daily activities including transfers.

There are six steps involved in implementing MOVE:

- assessment of current skills with input from the whole team (family, therapists, educators etc)
- setting with meaningful goals identified by the child and family
- task analysis to determine which skills are needed to achieve the goal
- measuring the prompts/supports currently required to start learning the skills needed to achieve the goal
- reducing the prompts/supports over time as the child progresses
- teaching the skills needed to achieve the goal through integrating strategies into every day activities and routines to enable every possible opportunity to learn

These steps are not necessarily linear.
The MOVE Programme results in an individualised, targeted programme specifically designed around each individual child’s unique circumstances. It provides a structure and a framework for linking movement goals with each child’s individual education plan and thereby providing a common language across families, educational staff and therapists.

At Oaklands School, access to the MOVE Programme is one of the draw cards for parents seeking admission for their children. Unpublished research conducted by Anke Baillie, paediatric physiotherapist and MOVE consultant at Oaklands, shows that in a cohort of 29 children on the MOVE Programme, 75% of students demonstrated a measurable increase in their motor ability (Baillie, 2014).

Anecdotally, there was a positive relationship between increases in motor skill ability and learning outcomes. Whilst these results suggest a positive effect for the MOVE Programme, caution should be taken in interpreting this relationship as the improvements in mobility and cognition occurred across a number of years and the influence of natural development has not been controlled for. Larger studies involving a comparison group of children in schools not involved in the MOVE Programme are recommended to help answer some of these questions.

The framework of the MOVE Programme lends itself to be transferrable across settings such as programmes supporting youth and adults in the community. Individuals with cerebral palsy develop movement skills later than typically developing peers. They are also at risk of losing movement skills from adolescence and experience ‘early onset ageing’ with an associated deterioration in movement skills (Frisch & Msall, 2013; Morgan & McGinley, 2013). A programme that focuses on maintenance of functional movement skills is likely to enable individuals with CP to continue to develop skills in independence and daily living. Further investigation into the programme - its development and current use in the USA - has revealed that the scope of MOVE has in fact broadened and since 2004, it has been used with adults with motor impairment with positive results.

Knowledge about the effectiveness of the MOVE Programme in supporting individuals with cerebral palsy is currently limited. The information available does not distinguish individuals with cerebral palsy from individuals with motor impairments not due to CP. However, the fundamental philosophy and principles of the MOVE Programme are in keeping with current best practice approaches for supporting individuals with cerebral palsy. That is, it is a child/person-active, goal-directed and child/person-centred approach. It utilises a ‘top down’ approach to developing functional movement skills and doesn’t depend on remediation of the motor impairment as is seen in ‘bottom up’ approaches such as neurodevelopment therapy.
Cerebral Palsy Integrated Pathway Scotland (CPIPS), Glasgow, Scotland

Cerebral Palsy Integrated Pathway Scotland (CPIPS) is the Scottish version of the Swedish surveillance programme CPUP. It was rolled out across Scotland in September 2013 following a successful trial in Lothian in early 2013. It comprises a patient management system for children with cerebral palsy aged 2 years and over, which contains the following data set:

- dominant neurological pattern
- GMFCS level
- Functional Mobility Scale
- lower limb range of movement
- spine - visual observation of presence of scoliosis
- spasticity management, surgery, fractures
- Migration Percentage - a measure of hip displacement
- use of aids and orthoses
- action plan following assessment

I had an opportunity to meet with Laura Wiggins, Senior Paediatric Physiotherapist, NHS Greater Glasgow and Clyde, to learn about how CPIPS has been adopted and embedded across Scotland.

The success of the programme in Scotland is grounded in a common understanding and purpose of a group of orthopaedic surgeons and paediatric physiotherapists with an interest in working with children with cerebral palsy. This understanding and purpose stems from the success of the work in Sweden discussed above. The aim of CPIPS is to provide a high quality, standardised follow-up programme for children with CP that will identify musculoskeletal problems by regular physical and radiological examinations to enable effective management of these problems during childhood (Gaston, date unknown).

The orthopaedic surgeons have an agreed-upon protocol for hip radiography for children with CP at risk of hip displacement and a protocol for x-ray technique. The paediatric physiotherapists have an agreed-upon standardised examination and reporting protocol which was developed collaboratively with paediatric physiotherapy representatives from all 14 health boards across Scotland.

To enable the implementation of CPIPS across Scotland, a number of resources were created to support the clinical skills of physiotherapists. These include a manual, assessment forms and protocols for measuring hip migration percentage. In addition to these, training workshops were run to teach physiotherapists about the purpose of CPIPS, how to conduct a CPIPS assessment and how to communicate assessment findings and recommendations to families and other health professionals. A competency document was developed to support the training. All 14 health boards across Scotland have at least one physiotherapist trained in conducting CPIPS assessments and annual competencies in physical examination are carried out. To increase access to training in CPIPS, train the trainer workshops are also conducted.

In 2016, CPIPS is now embedded as part of core physiotherapy management of children with cerebral palsy and has been endorsed by the Association of Paediatric Chartered Physiotherapists. Steps have also been taken towards establishing a similar programme across the UK.

Features enabling the successful implementation of CPIPS include:

- common understanding and agreement between orthopaedic surgeons and paediatric physiotherapists
- implementation of CPIPS within NHS Scotland which provides the vast majority of health and allied health services (including physiotherapy) to children with disabilities - this means that there is one set of organisational policies and procedures and one client management system accessible to all relevant NHS clinicians
- a clear organisational structure within CPIPS
  - Executive - two physiotherapists and two orthopaedic surgeons
  - Steering group that meets twice a year - physiotherapy representative from each health region and Executive
  - Annual meeting - audit and academic content
  - Named contact in the Health Informatics Centre
- commitment to ongoing training and support for clinicians to ensure competencies remain current
- ability of physiotherapists trained in CPIPS to refer directly for x-ray according to the CPIPS x-ray protocol which increases the accessibility of x-rays and minimises the number of appointments a family needs to attend
Wolfson Neurodisability Service, Great Ormond Street Hospital for Sick Children (GOSH), London, England

The Wolfson Neurodisability Service is a specialist service supporting children with complex neurodevelopmental disorders such as cerebral palsy. They operate a number of services and clinics including the Developmental Vision and Botulinum Toxin clinics. During my visit to Great Ormond Street Hospital I had an opportunity to meet with staff from both these clinics and I am grateful to Dr Jenefer Sargent and Dr Neil Wimalasundera for their time during my visit.

The Developmental Vision clinic provides assessment of the functional vision of each child (how they use their vision in everyday life) as well as their development, and provides practical recommendations for home and/or school. There is a significantly elevated risk of visual impairment in children with disability (10.5%) compared with children without disability (0.16%) (Salt and Sargent, 2014). At least 1 in 10 children with CP present with visual impairment (Novak et al., 2012). Visual impairments are seen across all types and severity of CP although there is an increasing risk with increasing motor impairment (Salt and Sargent, 2014).

Visual impairment can adversely impact upon early development. Visual impairment affects the development of

- spatial awareness, posture and movement skills
- use of hands and fine movement coordination
- early concept development, for example, object permanence
- locating sound in space
- understanding of the meaning of words and therefore speech and language development
- social interaction and communication
- self-care skills (Salt and Sargent, 2014).

At the Developmental Vision Clinic, assessments are conducted by a multidisciplinary team and utilise the “Reynell-Zinkin Scales: developmental scales for young visually handicapped children”. This tool gives an indication of development in comparison with both children who are partially sighted as well as those with full vision. Dr Sargent reported that in the UK, this tool is not widely used.

During discussions with Dr Sargent, she shared some of the challenges faced with regards to vision assessments and reporting in children with physical impairments such as cerebral palsy. Her experiences have been that there are significant differences in the reporting of assessment findings and in many cases, the reported results are not able to provide meaningful recommendations for families. Often assessments conducted through eye clinics are more an assessment of eye health rather than vision. Dr Sargent recommends being specific with requests for vision assessments and specify in the referral/request that an assessment of visual acuity, functional vision and eye structure be carried out in addition to an eye health examination.
Recommendations:
1. commence assessment of vision as early as possible in infants with disability
2. when referring/requesting vision assessments, be specific about what information is needed - vision assessment of children with disability should always include an ocular and visual assessment (Salt and Sargent, 2014)
3. early intervention therapy should incorporate all aspects of development in an integrated approach. Vision therapy should not be separated from other therapies and motor exploration can be encouraged as a means of promoting vision.

Botulinum Toxin Clinic is part of the Movement Disorder Service and provides botulinum toxin injections to address specific goals which are impacted upon by spasticity or dystonia. Botulinum toxin is now considered a standard intervention for managing hypertonia (spasticity and dystonia) in children with cerebral palsy. It is directed at the body structures level of the ICF however it is frequently provided to achieve activity level outcomes. It is considered to reduce the hypertonia that is interfering with the activity thereby enabling the activity/skill to be practiced/developed using motor learning approaches.

Children across all GMFCS levels have access to the botulinum toxin programme. During the International Conference on Cerebral Palsy and other Childhood-onset Disabilities in Stockholm, the GOSH team presented data from a retrospective chart review looking at the long term utility of botulinum toxin in children with CP. Amongst their cohort, the most common treatment goals were to improve gait and splint tolerance in GMFCS I-III whilst in GMFCS levels IV and V the goals related to reduction in pain, improved seating tolerance, facilitating personal cares and improving upper limb position. This is consistent with the utilisation of botulinum toxin across Australia.

My interest in attending the Botulinum Toxin Clinic was to learn about GOSH’s approach to botulinum toxin and physiotherapy for maximising gross motor outcomes in children with CP across the GMFCS levels. Unfortunately I was not able to connect with the lead physiotherapist who is commencing a research project into physiotherapy following botulinum toxin injections, due to competing clinic demands. I will continue to follow this work into the future as many questions exist relating to the dosage of physiotherapy required to achieve activity level outcomes following botulinum toxin injections.
Chailey Clinical Services & Chailey Heritage Foundation School, North Chailey, England

Chailey Clinical Services (CCS), part of Sussex Community NHS Trust, is a specialist multidisciplinary service for children and young people with complex neurodisability. They offer medical and allied health support through specialist outpatient clinics (e.g., Movement Assessment Clinic, Eating and Drinking Management Clinic, Orthopaedic Clinic, Posture Clinic, Functional Vision Clinic etc), rehabilitation engineering services to address problems around equipment and a research department.

The Chailey Heritage Foundation School is a special school for children and young people, aged 3 to 19 years, with complex physical disabilities, high health needs, sensory impairments and associated communication and learning difficulties. Each student has a carer that works with them on a 1:1 ratio to support their learning goals. Students with higher health needs, such as students who are ventilated, may have a 2:1 carer:student ratio. Many of the students attending the Chailey Heritage Foundation School who have cerebral palsy are classified as GMFCS IV or V.

Chailey Clinical Services provides medical and therapeutic supports (including physiotherapy) to the Chailey Heritage Foundation School and the two services are co-located in North Chailey in South West England.

My interest in visiting the therapy team at CCS was to learn about how they support gross motor skill development in students with GMFCS IV and V. I had an opportunity to spend time with some of the physiotherapists in the school as well as meet with members of the research team.

Physiotherapy across the UK is strongly influenced by neurodevelopmental therapy approaches including Bobath. These approaches have a strong emphasis on postural alignment and normalisation of movement. The team at CCS has also adopted a more activity-based approach to intervention and incorporate child-active elements into their therapy. The aim of physiotherapy at Chailey Heritage Foundation School is to promote maximal physical functional ability, independence, and health and well-being. They achieve these aims through providing opportunities for students to move and change position, maintain comfort in muscles and joints, enable participation in physical activities, learn new movement and functional skills and provide opportunities for fitness and enjoyment. Therapy and education goals are integrated through student profiles utilising SMART goals (goals that are specific, measurable, achievable, realistic and time-based). This facilitates clear communication between the education team and the clinical team and demonstrates how therapeutic intervention supports each child’s learning and educational outcomes.

Physiotherapy services provided by the CCS team include individual or group based therapy (NDT and/or child-active motor learning approach and/or strengthening), 24 hours positioning and postural management, assistive technology for standing and walking, bike riding, massage, hydrotherapy and orthoses.

The research team has undertaken a number of studies in recent years looking at techniques for increasing physical activity amongst students with CP at GMFCS levels IV and V. The team explored the the use of body weight supported treadmill walking and static bikes as well as the use of Petra RaceRunner running bikes. Liz Bryant, research
physiotherapist kindly shared their experiences. Short term gains in motor function were observed in children participating in body weight supported training and static bike training following a six-week programme. Liz reported that students lost interest and motivation when engaging in these activities over a longer period. She reported that they enjoyed the novelty of the training early on however became bored quickly with the static nature of both options. Following this, the team ran a pilot study around the use of running bikes to encourage and facilitate weight bearing exercise.

The pilot study involved 15 non-ambulant children with CP (GMFCS IV and V) between the ages of 4 and 12 years from two special schools in south east England. They used the running bikes 3 times a week over a 12 week period. All the children learnt to initiate walking in the running bikes with assistance from a their physiotherapist, some children learnt to walk independently in the running bikes and two children learnt to run for the first time. All children who used the running bikes enjoyed the experience and running bikes are now routinely used in both schools.

Ultrasound measurements of the heel bone taken before and after the study showed promising results with 7 of 9 children (for whom measurements were taken) demonstrated an increase in calcaneal bone strength. Small increases in the children’s ability to stand with support were noted following the 12 week programme however results were not statistically significant.

Regular participation in physical activity using Petra RaceRunner running bikes can lead to improvements in motor skills for children with non-ambulant cerebral palsy and provide a fun and enjoyable option for experiencing movement. The clinical experience of the CCS team has been that students using running bikes have demonstrated cardiovascular and bone strength improvements in addition to their motor outcomes. They also feel that secondary outcomes such as improved communication ability (such as the ability to use augmentative devices), improved health and well-being (fewer sick days) and decreased care giver burden (through improved health and motor ability) may be achievable. Anecdotal improvements were reported by school staff however these outcomes were not included in the pilot study. Children with dyskinetic cerebral palsy seem to benefit particularly well.

I also had an opportunity to discuss the use of standing frames with the team at CCS. Standing frames are routinely prescribed for use at school as well as home. They usually form part of a 24 hour postural management programme aimed at maintaining (or improving) postural symmetry of the musculoskeletal system to prevent hip and spinal mal-alignments and deformities. Functional outcomes from 24 hour postural management programmes are usually secondary aims, such as improved sleep through the use of sleep systems or improved arm or leg function through the use of standing frames.
HABIT-ILE camp, Brussels, Belgium

What is HABIT-ILE?
HABIT-ILE (Hand arm bimanual intensive training including the lower extremity) is a functional, activities-based intensive intervention approach designed specifically for children with cerebral palsy. It is based upon the principles of motor learning and neuroplasticity and utilises problem solving and highly structured practice. HABIT-ILE evolved from HABIT (Hand arm bimanual intensive training) in an attempt to address a gap in effective interventions for the lower extremity, and in recognition of the requirement to perform upper and lower extremity tasks simultaneously in activities of everyday living. Examples of such tasks are climbing stairs using a rail, walking carrying an object or standing to brush one’s teeth. Interactions between the upper and lower extremities, whilst present in everyday life, are rarely trained together. HABIT is an intervention aimed solely at improving upper limb function. Children are provided with postural supports to enable them to focus on engaging in upper extremity tasks/activities and no specific postural or lower extremity training is provided. During HABIT-ILE, postural supports are removed requiring the children to activate their postural muscles whilst engaging in upper limb activities. HABIT-ILE also includes activities that engage the lower extremities. HABIT-ILE therefore, encourages the development of control and coordination between upper and lower extremity movements.

HABIT was developed to address the imbalance in bimanual upper extremity use in children with unilateral (hemiplegic) cerebral palsy (encouraging use of the affected arm and hand through activities that require the use of both hands together). As a direct result, HABIT-ILE was initially focused on children with unilateral CP as well. HABIT-ILE has now been trialled with children with bilateral cerebral palsy (both diplegia and quadriplegia) and is showing great promise for improving both upper extremity function as well as postural control and gross motor skills.

The tasks and activities for each child are selected according to age, functional ability, personal interests and the child’s individual goals or objectives for participating in the intervention programme. Practice (part and whole) of tasks/activities is highly structured and the complexity of the tasks/activities is graded to enable children to achieve success and practice increasingly more challenging tasks/activities. Activities incorporated into HABIT-ILE fall into three categories i) tabletop activities, ii) activities of daily living performed in standing and walking, and iii) gross motor, play and physical activities.

Upper extremity bimanual tasks/activities include:
- gross dexterity
- manipulation games and tasks
- functional tasks
- arts and craft
- virtual reality

Lower extremity/postural stimulation tasks/activities that are systematically coupled with upper extremity tasks/activities include:
- ball sitting
- standing
- balance board
- virtual reality
- walking/running
- jumping
- cycling
- scootering

For a more in-depth description of how these tasks/activities are incorporated together, please read Hand-Arm Bimanual Intensive Therapy Including Lower Extremities (HABIT-ILE) for Children with Cerebral Palsy by Yannick Bleyenheuft and Andrew M. Gordon, from which the above information is drawn (available http://thirdworld.nl/hand-arm-bimanual-intensive-therapy-including-lower-extremities-habit-ile-for-children-with-cerebral-palsy).

Evidence for HABIT-ILE

A number of studies have been completed or are underway looking at the effectiveness of HABIT-ILE.

The initial study (Bleyenheuft el al., 2015) was conducted in children with unilateral cerebral palsy (GMFCS I-II; MACS I-III) with the aim of determining the efficacy of HABIT-ILE by comparing HABIT-ILE to an equal dose of usual care. In a randomised, cross over trial with two phases, 24 children were randomised to one of two groups - an immediate HABIT-ILE group and a delayed HABIT-ILE group. Children completed HABIT-ILE during an intensive camp over 10 days for a total of 90 hours. During the usual care phase, children continued with their conventional treatment (for an intended 90 hours). Conventional treatment in Belgium is usually provided using neurodevelopmental therapy approaches (NDT). Following the first phase, children in the delayed HABIT-ILE group (receiving conventional therapy during phase one) participated in a HABIT-ILE camp.

Primary outcome measures were the Assisting Hand Assessment (AHA) and the Six-minute walk test (6MWT). Secondary measures for the upper extremity included ABILHAND-Kids, the Pediatric Evaluation of Disability Inventory (PEDI) and Box and Blocks Test (BBT) for dexterity and pinch strength. Secondary measures for the lower extremity included the ABILOCO-Kids Questionnaire (locomotor ability), mean step length (at self-selected and maximal walking speed) and the difference in body weight distribution over each leg during upright standing (Wii™ Balance Board). Social participation was measured with the Assessment of Life Habits (scored by the parents).

Total engagement time (in activities) during the camp averaged 96% (ranging from 89%-98%). The percentage of time spent across the various upper extremity activities was:
- 27% gross dexterity (including 2% virtual reality)
- 27% manipulative games
- 5% card games
- 5% arts and craft
- 36% ADLs

The percentage of time spent in the various lower extremity positions/activities was:
- 54% sitting on ball
- 24% standing
- 20% walking/jumping/running
- 2% balance board
The AHA and 6MWT scores were significantly improved following HABIT-ILE (but not conventional therapy) and all secondary outcome measures except BBT, step length and bodyweight distribution also showed significant improvement following HABIT-ILE.

Additionally, when a comparison of upper extremity function following HABIT and HABIT-ILE was completed, HABIT-ILE did not result in lower gains than HABIT (i.e. upper extremity improvements were not compromised by the addition of lower extremity activities) and PEDI scores were higher for the HABIT-ILE group.

A second study (presented at the International Conference on Cerebral Palsy and other Childhood-onset Disabilities 2016; awaiting publication) examined the efficacy of HABIT-ILE in children with bilateral CP at GMFCS levels II-IV (ICCP, 2016b, page 107).

Twenty children aged between 6 and 15 years with bilateral CP, GMFCS II-IV and MACS I-III participated in the study. They were assigned to one of two groups in the order in which they enrolled in the study - children assigned to the treatment group participated in a HABIT-ILE camp while children in the control group continued their usual care. HABIT-ILE was delivered in an intensive camp over 13 days for a total of 84 hours (6.5 hours per day).

Primary outcomes measures were the Gross Motor Function Measure (GMFM) and ABILHAND-Kids. Secondary measures included the Pediatric Balance Scale, 6 Minute-Walk Test, ABILOCO-Kids, Pediatric Evaluation of Disability Inventory, Box-and-Blocks (BBT), Jebsen-Taylor Test of Hand Function (JTTHF) and Canadian Occupational Performance Measure. All children were assessed at baseline and at 3 months follow up with the children in the HABIT-ILE group also being assessed immediately after the camp.

Results showed that children in the HABIT-ILE group experienced significant improvements for all measures except the BBT and JTTHF on the more affected hand compared with the control group. They demonstrated improved upper extremity ability, gross motor performance, balance, walking endurance and walking abilities.

The findings from both studies suggest that combined upper and lower extremity training carried out following an intensive protocol is efficacious for improving both upper and lower extremity function in children with unilateral and bilateral cerebral palsy with gains made during the intervention period being maintained at 3 months.

In addition to these completed studies, further studies are currently underway in Brussels and New York.

HABIT-ILE implementation - where and how?

HABIT-ILE was developed in Belgium and since 2011, four HABIT-ILE camps have been run in Brussels. Following the results demonstrated by the Belgian camps, HABIT-ILE camps are now being run by Professor Andrew Gordon and colleagues at Columbia University, New York, USA. In both Brussels and New York, camps are run as part of research studies and have not yet been adopted as standard care.

In Belgium, standard physiotherapy is typically based upon neurodevelopmental principles (either Bobath or LeMétayer) which focuses on promoting typical developmental milestones and the remediation of body structures/functions...
impairments through the correction of motor patterns. Neurodevelopmental therapy (NDT) has been shown to be ineffective for improving motor skills in children with cerebral palsy (Novak et al., 2013).

Despite this, NDT continues to be the prevailing approach in Belgium and France (as well as other European countries) and forms the basis for undergraduate training in paediatric physiotherapy. As such, those responsible for HABIT-ILE experience resistance within Belgium as they challenge the current paradigm. The HABIT-ILE team reported that many treating therapists do not want their patients/clients to come to camp and do not promote the approach amongst their patients’/clients’ families.

HABIT-ILE is implemented in small group camps over a 2-week period — 90 hours over 10 days for children with unilateral CP and 84 hours over 13 days for children with bilateral CP. The early camps (unilateral CP) were conducted as sleep-over camps over 10 consecutive days. Subsequent camps (bilateral and unilateral CP) have been conducted as day camps. Each camp has utilised an interventionist:child ratio of 1:1 or 2:1.

HABIT-ILE camp August 2016

I had the great pleasure of attending a HABIT-ILE camp between 31st July and 13th August 2016. This camp was being run as part of a research study, so to respect the fidelity of the study, I will only be providing a high level overview of how the camp is run as well as my own personal reflections.

This camp was offered to both children with unilateral and bilateral cerebral palsy (GMFCS I-IV and MACS I-III). Children with unilateral cerebral palsy attended camp for 9 hours a day for 10 days over a 12 day period (Monday to Friday for two weeks). In contrast, children with bilateral cerebral palsy attended camp for 6.5 hours a day for 13 days over a 14 day period (Sunday to Saturday and Monday to Saturday). All children attended the same venue however they were separated into two groups (unilateral and bilateral groups) to make the most of the available space. Seven children with bilateral CP and 10 children with unilateral CP were in attendance. Children ranged in age from 5 to 17 years across both groups.

All children with unilateral CP were allocated one interventionist while all except two children with bilateral CP were allocated two interventionists for safety reasons. Twenty-two interventionists were involved in the camp with the addition of 6 supervisors made up of the team from the Institute of Neuroscience at UCL. Interventionists were a mix of final year physiotherapy students, qualified physiotherapists and occupational therapists, a psychologist and a medical doctor. Interventionists came from Belgium, France, Spain, England, Benin and Burundi. Clinicians from Benin and Burundi aim to introduce HABIT-ILE into their respective countries.

Interventionists were provided with one day of training prior to commencing the camp (this occurred the day before on 30th July) and were provided with support during the camp by the supervisors.

Prior to attending the camp, all children underwent a comprehensive assessment to establish baseline levels across all the primary and secondary outcome measures (see the previous evidence section for information relating to the outcome measures used).
In addition to the functional outcome measures, each child/parent identified specific objectives/goals for the camp. Some example goals for this camp included:

- being able to brush own teeth
- putting on shoes and socks
- tying shoelaces
- managing buttons on trousers
- being able to wash oneself
- washing hands
- being able to walk with a walking frame inside
- being able to walk outside and navigate uneven surfaces, around obstacles, in crowded environments
- walking further without fatigue
- riding a two-wheel bike or tricycle
- to be able to carry an object when walking

Whilst I spent some time observing the unilateral group, I chose to focus my attention on the children with bilateral CP as the programme structure is the same however the support needs are higher in the bilateral group.

Children carried out various activities and games with their interventionist, separately from the other participants. At times, children carried out activities/games with another participant, supported by their interventionists. This structure enables the children to achieve a high engagement time and subsequently the desired level of intervention intensity. Lunch time was a common time with the children sharing their meal together as a group. Activities and games were varied and designed to target the areas of both upper and lower extremity function such as gross dexterity, manipulation, postural control, walking etc that are outlined in the introductory section on HABIT-ILE.

Interventionists kept a running record of the activities that each child engaged in, documenting start and finish times, supports or modifications required and any specific notes about their efforts. At the end of each day, the interventionist team held a meeting to discuss each child’s progress and any challenges experienced during the day. Suggestions were provided by the supervisors on how to modify activities for the following day. This team meeting also provided an opportunity for the interventionists to debrief at the end of a long day and helped to maintain motivation levels.

Reflections

The HABIT-ILE camp provided an opportunity for children to participate in intensive, individualised therapy. Therapy was carried out individually rather than as a group however the camp setting brought multiple children together in the same place at the same time. Group time was structured for the last 30 minutes of each day however opportunities for both structured and unstructured child-child interactions were present throughout the day (e.g., lunch time, playing games together supported by the interventionists, watching and encouraging each other).

The individual nature of the intervention required a high interventionist:child ratio (minimum 1:1 with many children with bilateral CP requiring 2:1). This high staff demand poses some challenges in translating this programme beyond the research space and into clinical settings. It would be associated with a high financial cost which may be restrictive - innovative and creative solutions will need to be identified to enable this programme to be delivered effectively and efficiently.
All children in the bilateral group engaged well throughout the duration of the camp. They were happy to be dropped off and settled quickly into the routine of the camp. They engaged quickly with the interventionists and arrived each day ready to commence activities. Most children were dropped off and had commenced activities before the scheduled start time of 9am. The children participated well throughout the day with the activities and had no trouble managing to cope with 6.5 hours of therapy a day. Only the youngest child (who turned 5 at the end of the first week of camp) had a rest after lunch each day.

The first week of the camp for children with bilateral CP went for 7 days straight. I felt this to be a very long time for all involved in the camp. By day 6, energy levels had dropped amongst children, interventionists and supervisors alike with some lapses in concentration which resulted in a couple of minor trips and falls. Children returned after one day off with fatigue still evident for some. The intervention team were very successful with keeping activities at the right level to enable success whilst still providing a challenge. As the camp progressed, it was clear that individual children were making gains with various aspects of their movements (postural control, upper extremity function and lower extremity function). A critical feature of success with therapy was the ability of the interventionists to motivate the children, keep activities fun and keep their own energy levels high.

At the end of each day, the interventionists spent a few moments discussing the progress of the children with their respective parents. Parents are not expected to encourage their children to do activities at home during the camp. At the end of the camp, families are provided with a letter outlining what their child’s achievements and current abilities as well as some strategies to continue with at home. The parents do not have an opportunity to observe their child carrying out the activities during the camp so there is little opportunity for them to model of the interventionists.

**Dosage - what do we know?**

One of the biggest questions surrounding interventions for maximising motor outcomes in children with cerebral palsy is the question of dosage. We know that intensity matters however we don’t yet know what the optimal dose is. Most of what is currently known around intensity stems from research done in the upper extremity, namely HABIT and Constraint Induced Movement Therapy (CIMT). Very little information exists around intensity in the lower extremity. We hypothesise that similar intensities are required.

We see that upper extremity gains are made following either 60 or 90 hours of HABIT however gains appear to be retained for longer following 90 hours of intervention (up to 6 months compared with 1 month) (Gordon, 2011). It should be remembered that these studies examined the effects of HABIT or CIMT on upper extremity function of children with unilateral CP with outcomes relating to increased use of the affected hand/arm. Children with bilateral CP frequently have impairments in the ability to use both hands/arms (as well as impairments with postural control and mobility) and it is currently unknown if the gains from HABIT-ILE are retained beyond 3 months as studies have not yet included a longer follow-up period.

As HABIT-ILE was developed utilising the existing structure of HABIT, 90 hours of intervention over 2 weeks was the established protocol for unilateral CP and 84 hours for bilateral CP. Although HABIT-ILE has demonstrated good efficacy, it is in its research
infancy and as such no studies have been conducted looking at HABIT-ILE delivered over fewer hours. Additionally, no studies have looked at whether providing a shorter initial intervention period with a repeated intervention period results in similar benefits (e.g. 60 hours over 2 weeks followed by 30 hours over 1 week 3-6 months later).

Dosage studies are required to help answer these questions and more. However, the lack of dosage studies should not prevent attempts to translate efficacious interventions into everyday clinical practice. Any proposed protocol should be developed in consultation with clients and their families to marry research findings, clinical expertise and the views of those who will benefit, with consideration to the current disability-sector environment (NDIS). As dosage information becomes clearer, clinical practice needs to be dynamic and responsive to ensure intervention offers continue to be in line with evidence based practice.

HABIT-ILE in Australia

HABIT-ILE is a goal-directed, functional, activities-based therapy grounded in the principles of motor relearning and current understanding of neuroplasticity. It targets both upper and lower extremity function in children with unilateral and bilateral cerebral palsy. It is consistent with contemporary neurorehabilitation approaches for children with CP that are supported and implemented at Cerebral Palsy Alliance, making it a promising approach for the Australian context.

As mentioned earlier, translating the existing HABIT-ILE protocol from the research setting into clinical practice will require innovative and creative solutions to enable the level of intensity to be achieved. This is particularly true if the same interventionist:child ratio is to be achieved.

With the rollout of the NDIS across the disability sector, there is now a greater understanding of the financial cost of service delivery. Families are acutely aware of the cost to purchase therapy and are looking for ways to maximise the financial package available to them whilst at the same time maximising their child’s outcomes across a number of domains. Individual therapy is currently priced at $175.57 per hour (Vic/QLD/NSW/Tas price guide 2016). A programme that delivers 90 hours of therapy and utilises a therapist:child ratio of 1:1 will cost nearly $16,000 (more than the average yearly therapy package), is unlikely to be financially attractive to families or financially viable for service providers.

The team in Brussels utilises physiotherapy and occupational therapy students and trained allied health and medical clinicians on a volunteer basis to deliver the individual therapy. It may be possible to harness existing relationships with universities in order to deliver a programme that utilises students. This approach would likely restrict programme dates to coincide with either existing university placements or university holidays which may not be ideal for families. In addition, a reliance on a volunteer workforce may put the long term sustainability of the programme offer at risk.

Potential solutions may include:

- utilising a different interventionist:child ratio and offering the programme as a group programme with group therapy rates rather than individual therapy rates ($58.53 per hour compared with $175.57)
• minimising the number of clinical therapists involved and utilising allied health assistants (under direction) to decrease the cost (cost per hour for a therapy assistant is $40.92)
• exploring ways in which NDIS support categories may be utilised to support clients’ participation
• offering a programme consisting of fewer hours (e.g. 60 instead of 90)
• mixing group offers with individual support
• seeking corporate support/sponsorship to off-set some of the cost.

Regardless of how a programme offer evolves to match the Australian context, the quality and integrity of the intervention needs to be maintained.

With so many variables to consider, it is not possible to develop a modified programme and present it in this report at this time. A consumer engagement process is strongly recommended to explore some of the ways in which such a programme could be offered that suits the needs of the consumers and the NDIS environment. A more in depth exploration of the financial aspects of delivering an intensive camp programme will also need to be completed. Implementation of a pilot intensive programme for children with cerebral palsy, based around the principles used in HABIT-ILE, is recommended which includes an evaluation to establish its efficacy and suitability for the Australian context.

Some of the aspects to explore during a pilot and subsequent evaluation include: whether or not an intensive camp offer meets the needs of children and their families; do they experience greater satisfaction with therapy outcomes by attending an intensive camp; is an intensive camp offer financially viable within the NDIS environment; and how do we ensure rural and remote families have access to the programme?

Conclusions

This Churchill Fellowship enabled me to explore a number of different perspectives on interventions that play a role in maximising gross motor outcomes in children with cerebral palsy across different levels of ability. International experts in cerebral palsy shared their experiences and knowledge through conference proceedings, meetings, networking and through enabling participation in therapy programmes.

Motor outcomes in children are maximised through child-active interventions that are grounded within motor learning theory such as GAME, early leg training, Baby CIMT and CIMT, HABIT-ILE and goal directed therapy/training. Significantly more is known about how these interventions contribute to gross motor outcomes in children with GMFCS levels I-III than in children with GMFCS IV and V however it is exciting to see more focus being directed towards non-ambulant individuals. The opportunity to explore HABIT-ILE in depth during an intensive camp gave new insight into the possibilities for service delivery in Australia.

Interventions to increase participation in physical activity need to be multi-modal and require strategies to encourage lifestyle behaviour change and address barriers faced within the community. Physical activity referrals may be one approach to support this. For children with cerebral palsy who are classified as GMFCS IV and V, interventions will undoubtedly require the use of assistive technology in order to achieve identified goals - Petra RaceRunner running bikes may offer one such option.
Assistive technology for standing is routinely prescribed across all the services visited with the goal of maintaining postural symmetry and minimising adverse musculoskeletal outcomes. Whilst these outcomes are at the body structures level of the ICF, adverse musculoskeletal outcomes can negatively influence gross motor outcomes through an increase in pain, a decrease in comfort, an increase in care giver burden and a decrease in individual/family well-being. High quality studies examining the outcomes of using standing frames are lacking and the evidence base around using standing frames relies heavily on low level studies and years of clinical experience. The field faces some research challenges given the long term nature of skeletal development in CP and many consider it unethical to withhold standing frames as part of the management of children with CP. As such, it is likely that the evidence base around the use of standing frames will continue to rely on low level studies and clinical experience rather than randomised controlled trials.

Cerebral palsy surveillance programmes have been successfully implemented across a number of countries resulting in decreased rates of secondary musculoskeletal impairments. A common feature across these countries that appears to have enabled successful implementation is that health and therapy services for children with cerebral palsy are overseen by one primary body - Department of Health. Australia's complex health system and separation of health and disability funding poses specific challenges for children with CP. Cerebral palsy results in impairments that are seen across the ICF levels with body functions and structure impairments coupled with activity and participation impairments. Historically the system in NSW (and more broadly across Australia) has resulted in a separation of responsibilities - health have provided support for many (but not all) body functions and structure interventions whilst the disability sector has largely provided interventions aimed at maximising performance of activities and participation in daily life.

Gross motor outcomes for children with cerebral palsy are maximised through a combination of health and disability-related interventions. The relative contribution of child-active rehabilitation, compensatory and environmental adaptation, and health and secondary prevention interventions needs to be considered across the severity levels.

**Recommendations**

1. To ensure people with cerebral palsy have timely access to appropriate services to address their needs across the ICF levels, the health and disability sectors have a responsibility to work together to find solutions and move towards integrated care in the new environment created by the National Disability Insurance Scheme. This includes developing strategies to enable effective implementation of surveillance programmes and recognising the interaction between interventions to minimise body functions and structure impairments and maximise performance of activities and participation.

2. Early access to evidence-based interventions is critical for maximising outcomes across all developmental domains for infants with cerebral palsy and their families. Strategies to support early diagnosis and timely referrals to specialist services as well as support to access the NDIS and funding are required across the health and disability sectors from both a state and federal perspective. Clinicians need access to
appropriate and timely information and training to support infants and their families. Families and carers need access to appropriate and timely information to empower them to make decisions regarding the best supports to meet their needs.

3. HABIT-ILE has demonstrated improved motor outcomes for children with cerebral palsy when offered as an intensive camp. The principles underpinning HABIT-ILE are compatible with therapy approaches offered at Cerebral Palsy Alliance and many of our partner organisations across Australia. The current HABIT-ILE approach will need to be modified to fit the clinical setting within the Australian context with particular consideration to the NDIS. To achieve this, I will engage with consumers to develop preferred models of intensive therapy offers based around the HABIT-ILE approach as well as undertake financial modelling to ensure affordable and viable options can be identified. A pilot of an intensive therapy offer(s) (based around the HABIT-ILE approach) will be carried out at Cerebral Palsy Alliance and an evaluation conducted.

4. RaceRunning provides a unique opportunity for people with disabilities to participate in physical activity that is fun, fast and offers health and well-being benefits. RaceRunning is not yet available in Australia and there are no Australian suppliers of running bikes. I recommend establishing a relationship with Connie Hansen in Denmark (pioneer and developer of the running bikes) and race running clubs worldwide (such as Race Running Denmark, Race Running Scotland and Race Running Sweden - who have successfully established race running nationally) and promoting race running in Australia through information sessions for individuals with disability, their families, physiotherapists and athletics/sporting clubs and bodies.

5. Standing frames continue to play an integral part in managing some of the skeletal and postural mal-alignments frequently seen in children with cerebral palsy, particularly hip displacement. Clearer guidance is required around the impact of using or not using standing frames for children with CP in order to support clinicians and families to identify relevant outcomes and to assist in implementing appropriate supported standing programmes. Those responsible for funding assistive technology for people with disabilities should consider the role that assistive technology plays in supporting musculoskeletal growth and development in children with CP and enable access to appropriate devices with minimal bureaucracy. To assist all interested parties, a review of the current evidence base around standing frames is recommended.

Dissemination of Information

Learnings from this Fellowship will be disseminated through Cerebral Palsy Alliance, the Australian Physiotherapy Association NSW Paediatric Special Interest Group and the Australasian Academy of Cerebral Palsy and Developmental Medicine conference 2018. Accessible information for parents will be made available through Cerebral Palsy Alliance. Implementation of a pilot intensive programme based around HABIT-ILE for children with cerebral palsy will be carried out following consumer engagement and establishment of suitable partnerships. An evaluation of the pilot will be undertaken to establish its efficacy and suitability for the Australian context. RaceRunning as an option for fun, fitness and social participation will be further explored and opportunities to try RaceRunning in Australia will be developed.
References


Common guidelines for standing with standing shell / raising aid in Bou Region Skåne. Date unknown. Provided directly by Katarina Lauruschku.


Appendix A - GMFCS

INTRODUCTION & USER INSTRUCTIONS

The Gross Motor Function Classification System (GMFCS) for cerebral palsy is based on self-initiated movement, with emphasis on sitting, transfers, and mobility. When defining a five-level classification system, our primary criterion has been that the distinctions between levels must be meaningful in daily life. Distinctions are based on functional limitations, the need for hand-held mobility devices (such as walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement. The distinctions between Levels I and II are not as pronounced as the distinctions between the other levels, particularly for infants less than 2 years of age.

The expanded GMFCS (2007) includes an age band for youth 12 to 18 years of age and emphasizes the concepts inherent in the World Health Organization’s International Classification of Functioning, Disability and Health (ICF). We encourage users to be aware of the impact that environmental and personal factors may have on what children and youth are observed or reported to do. The focus of the GMFCS is on determining which level best represents the child's or youth's present abilities and limitations in gross motor function. Emphasis is on usual performance in home, school, and community settings (i.e., what they do), rather than what they are known to be able to do at their best (capability). It is therefore important to classify current performance in gross motor function and not to include judgments about the quality of movement or prognosis for improvement.

The title for each level is the method of mobility that is most characteristic of performance after 6 years of age. The descriptions of functional abilities and limitations for each age band are broad and are not intended to describe all aspects of the function of individual children/youth. For example, an infant with hemiplegia who is unable to crawl on his or her hands and knees, but otherwise fits the description of Level I (i.e., can pull to stand and walk), would be classified in Level I. The scale is ordinal, with no intent that the distances between levels be considered equal or that children and youth with cerebral palsy are equally distributed across the five levels. A summary of the distinctions between each pair of levels is provided to assist in determining the level that most closely resembles a child’s/youth’s current gross motor function.

We recognize that the manifestations of gross motor function are dependent on age, especially during infancy and early childhood. For each level, separate descriptions are provided in several age bands. Children below age 2 should be considered at their corrected age if they were premature. The descriptions for the 6 to 12 year and 12 to 18 year age bands reflect the potential impact of environment factors (e.g., distances in school and community) and personal factors (e.g., energy demands and social preferences) on methods of mobility.

An effort has been made to emphasize abilities rather than limitations. Thus, as a general principle, the gross motor function of children and youth who are able to perform the functions described in any particular level will probably be classified at or above that level of function; in contrast, the gross motor function of children and youth who cannot perform the functions of a particular level should be classified below that level of function.
### OPERATIONAL DEFINITIONS

**Body support walker** – A mobility device that supports the pelvis and trunk. The child/youth is physically positioned in the walker by another person.

**Hand-held mobility device** – Canes, crutches, and anterior and posterior walkers that do not support the trunk during walking.

**Physical assistance** – Another person manually assists the child/youth to move.

**Powered mobility** – The child/youth actively controls the joystick or electrical switch that enables independent mobility. The mobility base may be a wheelchair, scooter or other type of powered mobility device.

**Self-propsel manual wheelchair** – The child/youth actively uses arms and hands or feet to propel the wheels and move.

**Transported** – A person manually pushes a mobility device (e.g., wheelchair, stroller, or pram) to move the child/youth from one place to another.

**Walks** – Unless otherwise specified indicates no physical assistance from another person or any use of a hand-held mobility device. An orthosis (i.e., brace or splint) may be worn.

**Wheeled mobility** – Refers to any type of device with wheels that enables movement (e.g., stroller, manual wheelchair, or powered wheelchair).

### GENERAL HEADINGS FOR EACH LEVEL

<table>
<thead>
<tr>
<th>LEVEL</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>LEVEL I</td>
<td>Walks without Limitations</td>
</tr>
<tr>
<td>LEVEL II</td>
<td>Walks with Limitations</td>
</tr>
<tr>
<td>LEVEL III</td>
<td>Walks Using a Hand-Held Mobility Device</td>
</tr>
<tr>
<td>LEVEL IV</td>
<td>Self-Mobility with Limitations; May Use Powered Mobility</td>
</tr>
<tr>
<td>LEVEL V</td>
<td>Transported in a Manual Wheelchair</td>
</tr>
</tbody>
</table>

### DISTINCTIONS BETWEEN LEVELS

**Distinctions Between Levels I and II** - Compared with children and youth in Level I, children and youth in Level II have limitations walking long distances and balancing; may need a hand-held mobility device when first learning to walk; may use wheeled mobility when traveling long distances outdoors and in the community; require the use of a railing to walk up and down stairs; and are not as capable of running and jumping.

**Distinctions Between Levels II and III** - Children and youth in Level II are capable of walking without a hand-held mobility device after age 4 (although they may choose to use one at times). Children and youth in Level III need a hand-held mobility device to walk indoors and use wheeled mobility outdoors and in the community.

**Distinctions Between Levels III and IV** - Children and youth in Level III sit on their own or require at most limited external support to sit, are more independent in standing transfers, and walk with a hand-held mobility device. Children and youth in Level IV function in sitting (usually supported) but self-mobility is limited. Children and youth in Level IV are more likely to be transported in a manual wheelchair or use powered mobility.

**Distinctions Between Levels IV and V** - Children and youth in Level V have severe limitations in head and trunk control and require extensive assisted technology and physical assistance. Self-mobility is achieved only if the child/youth can learn how to operate a powered wheelchair.
Gross Motor Function Classification System – Expanded and Revised (GMFCS – E & R)

BEFORE 2ND BIRTHDAY

**LEVEL I:** Infants move in and out of sitting and floor sit with both hands free to manipulate objects. Infants crawl on hands and knees, pull to stand and take steps holding on to furniture. Infants walk between 18 months and 2 years of age without the need for any assistive mobility device.

**LEVEL II:** Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding on to furniture.

**LEVEL III:** Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.

**LEVEL IV:** Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone.

**LEVEL V:** Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll.

BETWEEN 2ND AND 4TH BIRTHDAY

**LEVEL I:** Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Children walk as the preferred method of mobility without the need for any assistive mobility device.

**LEVEL II:** Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface. Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.

**LEVEL III:** Children maintain floor sitting often by "W-sitting" (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting. Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using a hand-held mobility device (walker) and adult assistance for steering and turning.

**LEVEL IV:** Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.

**LEVEL V:** Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

BETWEEN 4TH AND 6TH BIRTHDAY

**LEVEL I:** Children get into and out of, and sit in, a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.

**LEVEL II:** Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without the need for a hand-held mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.

**LEVEL III:** Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children move in and out of chair sitting using a stable surface to push on or pull up with their arms. Children walk with a hand-held mobility device on level surfaces and climb stairs with assistance from an adult. Children frequently are transported when traveling for long distances or outdoors on uneven terrain.

**LEVEL IV:** Children sit on a chair but need adaptive seating for trunk control and to maximize hand function. Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a powered wheelchair.

**LEVEL V:** Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.
Level I: Children walk at home, school, outdoors, and in the community. Children are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Children perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Children may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Children walk in most settings. Children may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas, confined spaces or when carrying objects. Children walk up and down stairs holding onto a railing or with physical assistance if there is no railing. Outdoors and in the community, children may walk with physical assistance, a hand-held mobility device, or use wheeled mobility when traveling long distances. Children have at best only minimal ability to perform gross motor skills such as running and jumping. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Children walk using a hand-held mobility device in most indoor settings. When seated, children may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface. When traveling long distances, children use some form of wheeled mobility. Children may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Children use methods of mobility that require physical assistance or powered mobility in most settings. Children require adaptive seating for trunk and pelvic control and physical assistance for most transfers. At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility. When positioned, children may use a body support walker at home or school. At school, outdoors, and in the community, children are transported in a manual wheelchair or use powered mobility. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and/or mobility but limitations are not fully compensated by equipment. Transfers require complete physical assistance of an adult. At home, children may move short distances on the floor or may be carried by an adult. Children may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

Level I: Youth walk at home, school, outdoors, and in the community. Youth are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Youth perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Youth may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Youth walk in most settings. Environmental factors (such as uneven terrain, inclines, long distances, time demands, weather, and peer acceptability) and personal preference influence mobility choices. At school or work, youth may walk using a hand-held mobility device for safety. Outdoors and in the community, youth may use wheeled mobility when traveling long distances. Youth walk up and down stairs holding a railing or with physical assistance if there is no railing. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Youth are capable of walking using a hand-held mobility device. Compared to individuals in other levels, youth in Level III demonstrate more variability in methods of mobility depending on physical ability and environmental and personal factors. When seated, youth may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance from a person or support surface. At school, youth may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community, youth are transported in a wheelchair or use powered mobility. Youth may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Youth use wheeled mobility in most settings. Youth require adaptive seating for pelvic and trunk control. Physical assistance from 1 or 2 persons is required for transfers. Youth may support weight with their legs to assist with standing transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility, or, when positioned, use a body support walker. Youth are physically capable of operating a powered wheelchair. When a powered wheelchair is not feasible or available, youth are transported in a manual wheelchair. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and mobility but limitations are not fully compensated by equipment. Physical assistance from 1 or 2 persons or a mechanical lift is required for transfers. Youth may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

© Palisano, Rosenbaum, Bartlett & Livingston, 2007
GMFCS E & R between 6th and 12th birthday: Descriptors and illustrations

GMFCS Level I
Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.

GMFCS Level II
Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.

GMFCS Level III
Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.

GMFCS Level IV
Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.

GMFCS Level V
Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.
GMFCS Level I
Youth walk at home, school, outdoors and in the community. Youth are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.

GMFCS Level II
Youth walk in most settings but environmental factors and personal choice influence mobility choices. At school or work they may require a hand held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.

GMFCS Level III
Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.

GMFCS Level IV
Youth use wheeled mobility in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.

GMFCS Level V
Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.

CanChild: www.canchild.ca
Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham, The Royal Children’s Hospital Melbourne ERC151050
Appendix B - Manual Ability Classification Scale

**What do you need to know to use MACS?**

The child’s ability to handle objects in important daily activities, for example during play and leisure, eating and dressing.

In which situation is the child independent and to what extent do they need support and adaptation?

I. **Handles objects easily and successfully.** At most, limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities.

II. **Handles most objects but with somewhat reduced quality and/or speed of achievement.** Certain activities may be avoided or be achieved with some difficulty; alternative ways of performance might be used but manual abilities do not usually restrict independence in daily activities.

III. **Handles objects with difficulty; needs help to prepare and/or modify activities.** The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted.

IV. **Handles a limited selection of easily managed objects in adapted situations.** Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.

V. **Does not handle objects and has severely limited ability to perform even simple actions.** Requires total assistance.

**Distinctions between Levels I and II**

Children in Level I may have limitations in handling very small, heavy or fragile objects which demand detailed fine motor control, or efficient coordination between hands. Limitations may also involve performance in new and unfamiliar situations. Children in Level II perform almost the same activities as children in Level I but the quality of performance is decreased, or the performance is slower. Functional differences between hands can limit effectiveness of performance. Children in Level II commonly try to simplify handling of objects, for example by using a surface for support instead of handling objects with both hands.

**Distinctions between Levels II and III**

Children in Level II handle most objects, although slowly or with reduced quality of performance. Children in Level III commonly need help to prepare the activity and/or require adjustments to be made to the environment since their ability to reach or handle objects is limited. They cannot perform certain activities and their degree of independence is related to the supportiveness of the environmental context.

**Distinctions between Levels III and IV**

Children in Level III can perform selected activities if the situation is prearranged and if they get supervision and plenty of time. Children in Level IV need continuous help during the activity and can at best participate meaningfully in only parts of an activity.

**Distinctions between Levels IV and V**

Children in Level IV perform part of an activity, however, they need help continuously. Children in Level V might at best participate with a simple movement in special situations, e.g. by pushing a button or occasionally hold undemanding objects.
Appendix C - What is Neuroplasticity?

Neural plasticity or neuroplasticity can be defined as the changing of the structure, function and organisation of neurons, or nerve cells, in response to new experiences. Neural plasticity is the basis for both learning in the intact brain and relearning in the damaged brain, or in other words, the adaptive capacity of the central nervous system. Neurons have the ability to alter their structure and function in response to a variety of internal and external pressures e.g. motor learning programme (Kleim & Jones, 2008). Therefore neural plasticity is the mechanism by which the brain encodes experience and learns new behaviours.

Kleim & Jones (2008) outline ten principles of experience-dependent neural plasticity and their translation to the damaged brain. A description is provided in the table below:

<table>
<thead>
<tr>
<th>Principle</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Use it or lose it</td>
<td>Functional ability may reduce or be lost if neural circuits are not engaged in task performance</td>
</tr>
<tr>
<td>2. Use it and improve it</td>
<td>Improvements in sensory and motor performance brought about by skill training are accompanied by profound plasticity in the cerebral cortex. This can be observed by MRI representation areas of the brain.</td>
</tr>
<tr>
<td>3. Specificity</td>
<td>In order to produce significant changes in patterns of neural connectivity, learning or skill acquisition needs to take place rather than just ‘use’. This means there needs to be learning of a functional or important skill rather than just learning a new movement.</td>
</tr>
<tr>
<td>4. Repetition Matters</td>
<td>Repeating a learned skill may be required in order for neural changes to last i.e. continued performance of a skill may be needed over time.</td>
</tr>
<tr>
<td>5. Intensity Matters</td>
<td>The intensity of stimulation can affect the induction of neural plasticity e.g. there needs to be a high level of repetitions for learning to occur</td>
</tr>
<tr>
<td>6. Time Matters</td>
<td>Different forms of plasticity occur at different times during skill development or training. Neural plasticity is a process rather than a single measurable event.</td>
</tr>
<tr>
<td>7. Salience Matters</td>
<td>The experience of the activity or skill development must be meaningful to the person in order to induce plasticity</td>
</tr>
<tr>
<td>8. Age Matters</td>
<td>Younger brains are more plastic than older brains. 0 - 2 is the age when the brain is most plastic.</td>
</tr>
<tr>
<td>9. Transference</td>
<td>This means the ability of plasticity within one set of neural circuits to promote concurrent or subsequent plasticity and therefore enhance related behaviours.</td>
</tr>
<tr>
<td>10. Interference</td>
<td>Even though some types of stimulation can enhance plasticity, other types can be disruptive of learning, for example if neural networks are engaged with maladaptive or compensatory behaviours.</td>
</tr>
</tbody>
</table>