

## Physiotherapy for children with cerebral palsy: why we do what we do.

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In this climate of evidence based intervention physiotherapists need to either fulfil that demand, or alternatively offer a rational theoretically based explanation and framework for their interventions. Given that research into intervention for CP is in its infancy (Rosenbaum & Rosenbloom, 2012), it is not surprising that there is no robust research evidence base available currently. The usual conclusion of any systematic review of interventions is that more research is needed. What can therapists do given this situation? This presentation offers a reflection on evidence based practice, considers what evidence is available, suggests possible alternative explanations in lieu of the lack of a robust evidence base and offers some signposts for the future. But firstly a short review on what physiotherapists do before the question of 'why we do what we do' can be discussed.

### The Goal of Intervention

There are many approaches and treatments for CP, but the key objective is to work in collaboration with children and young people and their families with two broad aims; firstly to optimize participation in daily life, and secondly to minimize residual disabilities such as musculoskeletal impairment. These two elements, optimization of participation and minimization of residual disability results in happy children and families. In order to define relevant meaningful goals and decide on the appropriate intervention strategies a systematic assessment of the child's skills needs to be undertaken.

A good starting place is the International Classification of Functioning Disability and Health (ICF; WHO 200; 2007), which is an essential clinical

framework for all therapists. The focus of the ICF is on the child's participation in daily life, the activities required for this, and the elements of body structure and function which impact on what the child can do or finds challenging. This means exploring what the child can do, wants to do and is capable of doing now and in the future, and additionally using the functional classification levels for mobility, hand function, communication and eating and drinking skills. Exploration of what the child can do requires a systematic observation, analysis and interpretation of the child's activities. From this, key impairments may be identified, which if addressed will enable improved **practice** of activities for optimizing participation.

Impairment based treatment alone will not achieve the goal of optimal participation. For this reason it is often useful to arrange the ICF with activity and participation on the left hand side and then to link key areas of impairment to identify specific treatment needs. For example, a common impairment is atypical muscle tone, and an understanding of its influence on activity is important. If spasticity is a limiting factor then a pharmacological approach such as botulinum toxin or baclofen may be needed to enable practice of activities. Alternatively, if there is primarily an alteration of viscoelastic properties of muscle causing the atypical tone, then orthotics/casting are the appropriate choices. However therapists should be aware that there are some children who actually need their spastic hypertonia for functioning and this also needs to be recognized, for to reduce it or abolish it would make the child less functional or not functional at all. Another example of how the ICF can guide clinical reasoning is when therapists identify a goal such as an isolated activity of gaining midline head control. Achievement of this alone will never achieve optimal participation unless it is linked to an activity goal such as accessing a communication system using

eye-gaze, as one example. Figure 1 shows how the ICF can be used in the clinic to summarize the child's activity and associated impairments, reminding all, that participation is key. For the physiotherapist, the Gross Motor Function Classification System (GMFCS; Palisano et al 1997) offers a guide to future mobility potential, is an essential component in goal setting and discussion with children and their families, and should be a key part of the intervention decision

making process. If the child will not be a functional walker then standing transfers should be maintained if feasible and realistic, and discussions about walking practice and equipment can be more usefully undertaken and that difficult question of 'will my child walk?' rationally discussed on the basis of objective evidence.

Child's age and classification: Activity and participation/limitations & restrictions What the child can and cannot do: How and why	GMFCS/MACS/CFCS/EDACS level: Body structure and function /impairments
	Neuromuscular system Tone Patterns Balance Co-ordination
	Musculoskeletal system Strength ROM
	Somatosensory and perceptual
	Cognitive
	Cardiovascular/respiratory
	Gastrointestinal
Contextual	Personal
Environmental	

Fig 1. ICF for the therapist: the focus is on activity and participation.

Once the assessment and baseline outcome measures have been completed and target areas identified, then the intervention strategies can be chosen and implemented, remembering to set a regular review schedule in place. Intervention requires a team approach, with the physiotherapy focus on the physical aspects of intervention such as mobility and independent transfers, self-care, and musculoskeletal integrity, while also addressing the complementary activities of hand function, cognition, sensory/perceptual functioning, communication and eating/drinking. The three therapy disciplines should share basic intervention skills in order to address the child and young person with CP (CYPwCP) holistically. Opportunities to enhance basic communication skills or to improve hand function and self-care activities should be a part of physiotherapy intervention.

For the physiotherapist musculoskeletal integrity is one of the main challenges as the child grows and muscle growth does not increase in parallel with bone growth. With the added component of asymmetry

which usually exists, problems of hip location, muscular and ligamentous contracture, plus the potential for scoliosis, present management challenges for all. Combinations of physical conservative measures need to be considered and balanced with the need for more active and invasive treatments such as pharmacology and surgery. The options will vary according to age, severity, and the care environment to name a few, and need to be reviewed on an individual basis, as for all interventions. There is a need to be cognisant of the principles of growth and development- in particular the nature/nurture debate (Hadders-Algra, 2000a,b), and to maintain a balanced approach to the interaction of neurology and biomechanics in order to achieve the two broad objectives of optimizing participation in daily life and minimizing residual disabilities.

It may be that the term therapy needs to be reinterpreted (Mayston, 2014; 2012) and parents need to be re-educated as to what it really means. Therapy is not about having as much contact time as possible with therapy sessions as many parents (and

therapists) think, but about working with the family to enable their child, and them, to live as fully and as functionally as possible. CP cannot be cured or changed though it can be modified, and all need to be aware of what might be possible and what might not, so that a realistic approach to intervention is undertaken.

### The Tools of Physiotherapy Intervention

Physiotherapy interventions are many and various and options continue to expand, which might be categorized into the traditional and new, those which can be helpful and those which make unrealistic claims. In previous publications I have suggested that rather than using a named approach, that physiotherapists after making an assessment of the needs of the child and family, can consult their tool box and select what might be appropriate for the person at that age and stage of their development (Mayston, 2014; 2007). The general rule is to select tools which can easily be used by the child and family so that intervention can be part of the child's life, not a set of exercises to practice at certain times of the day for a specific length of time, or for a number of repetitions, except of course in the case of a specific progressive resistance exercise regime. Activities may vary from those which enhance play activities, enable safer and easier mealtimes, to those which support participation in daily life. But on what basis are the tools to be used decided? On evidence, experience, other therapist's recommendations, ideas from courses? Why do we do what we do? Is it based on evidence?

### A Reflection on Evidence Based Intervention

The immediate thought when evidence based intervention is mentioned, (here referred to as evidence based practice; EBP), is that it is dependent on the results of experimental studies which have investigated certain interventions such as muscle strengthening or treadmill training, or even therapy systems such as Neurodevelopmental Therapy. EBP is also based on the conclusions reached by systematic

reviews of intervention. But Sackett's model expands the idea of EBP to include client preference - in this case the child and family- as well as clinical expertise. The fact is that there is currently no robust experimental evidence base for the management of CYPwCP, thus physiotherapists and all health professionals in this field need to refer to the Sackett model (1996) and analyze, synthesize and evaluate the best available evidence and integrate it with individual expertise and service users' needs (Frontline, 05.10.11). What does this mean in practice? Physiotherapists need to be able to do just that. They need to critically analyse the relevant literature, have basic management skills for CYPwCP and take the lead from the children and their families in setting goals, all of which also require regular review.

As mentioned earlier EBP comprises three main arms indicated as experimental evidence, client preference and clinical expertise (i.e. empirical evidence), as shown in Fig 2, based on Sackett 1996. I have adapted this figure to include an expanded view of the arm of systematic research which takes into account the value of theoretical knowledge, practice frameworks clinical guidelines.

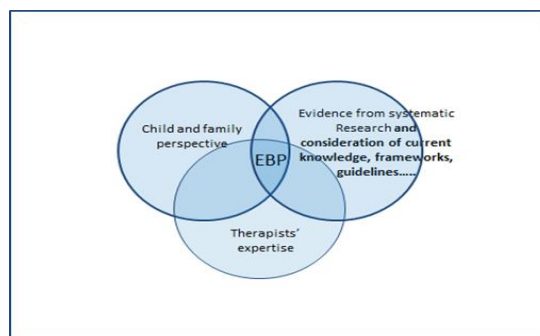


Fig 2. Scheme of evidence based practice based on Sackett, 1996, with an expanded view of experimental evidence to include theoretical knowledge and practice frameworks and guidelines.

### 1.1: Experimental evidence:

Firstly it might be helpful to give some consideration to the role of experimental evidence in EBP. Is the first question you ask yourself when deciding what to do when confronted by the child and their family, "what is the evidence to support intervention for this child"? Perhaps you ask yourself: 'What experimental evidence is available to address this child's lack of muscle power? 'or, 'What is the best way to reduce this child's spasticity which is interfering with their participation so that I can more effectively enable the child to practice participation activities' or 'What evidence is there to support treadmill training in order to work on improving independent transfers?' Or do you consider the Gross Motor Function Classification levels (GMFCS) as a starting point: 'this child is at Gross Motor Classification System level III, this means that he/she can walk independently but may require a walking aid at least for long distances, and as the physiotherapist I must be mindful of growth spurts to ensure optimal musculoskeletal integrity' (whether that be via the application of a stretching regime, Botulinum Toxin A (BoNTA), orthotic use, surgery or a combination of all). Despite the increasing number of studies, reliable robust research evidence is hard to find, and it seems that most of the current research evidence arises from studies of children at GMFCS levels I-III, mostly with unilateral spastic CP, and mostly on upper limb functioning and hand use. So it would be understandable if the questions regarding scientific experimental evidence do not enter our minds.

There is no doubt that research in the field of CP intervention is an enormous challenge, the influence of age, growth and development, functional capability, environment and the presence of a range of comorbidities are just a few of the variables. Another issue is the question of how well the condition of CP is understood? It seems that there is also a need to undertake parallel research into the nature and underlying mechanisms of the various signs and symptoms of children with CP. It is not simply a matter of knowing what works, but how it works, why it works, for whom it works, at what stage of development it works and how long it is needed. For physiotherapy intervention the evidence is probably required at various levels (the ingredients of

therapy) as shown in Fig 3, which indicates that there are three main categories of physiotherapy intervention.

- i. Therapy specific actions: these are actions of the physiotherapist e.g. parent training, task practice, hands on guidance of task practice, muscle stretching;
- ii. Particular physical interventions such as treadmill training, or muscle strengthening,
- iii. Management interventions, i.e. overall outcomes for activity and participation. This might be the evaluation of a range of offered interventions i.e. a treatment package which utilizes various interventions, or a system of therapy such as Bobath/NDT, or Conductive Education, on the child's activity and participation.

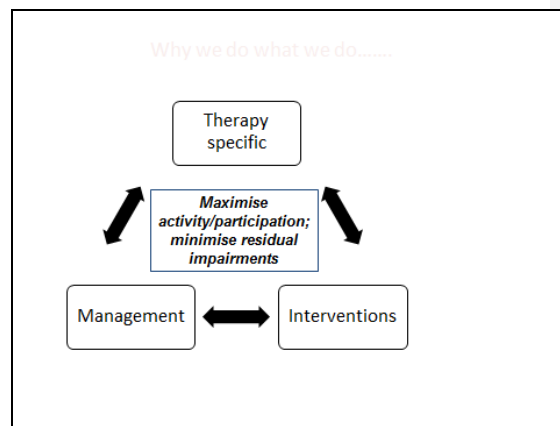


Fig 3: Physiotherapy intervention for CP comprises different levels of application from the specific to the overall treatment programme.

It is a fact that a consideration of the research evidence alone will not provide a treatment guide for the physiotherapist or health professional working in the field of CP, nor will the outcomes of systematic reviews, which offer a summary of research evidence. There have been several published in recent years which have attempted to offer such a summary of the current literature supporting evidence based practice (Morgan et al 2016; Novak et al 2013; Franki et al 2012, Antilla et al 2008). Much has been said about the Novak et al review (Novak 2013) and it has been cited frequently, but it has many limitations, including over simplification of a complex issue, using mixed type of evidence, it reviewed some interventions that are not

interventions (e.g. hip surveillance), compared systems to single treatment types and did not address key issues such as GMFCS level and age. Like the various experimental studies, none of these reviews provide a useful, robust evidence base to guide clinical practice, and simply offer a summary of the evidence at a moment in time. Guides to intervention need to address the issues of age, GMFCS level, environment and probably cognitive functioning too as many interventions require the co-operation and motivation of the child. Constraint Induced Movement Therapy and Task Specific training are two examples. Clearly to rely on a research experimental evidence base for intervention for CP is to walk on very thin ice. How can physiotherapists respond to this? Novak et al (2013) in their response to the many letters sent in reaction to their systematic review stated that "systematic reviews can aid, but never replace sound clinical reasoning." It would seem that clinical reasoning is key to determine what the child might be able to achieve and what might work to help them to achieve their goals. But what can be considered as 'sound clinical reasoning' and how is it done? What other factors might enable the application of sound clinical reasoning?

## **1.2: The relevance of current theoretical knowledge, frameworks and clinical guidelines:**

I have spent much time reflecting on the issues of sound clinical reasoning and a rational basis for therapy for CP. It is my opinion that there are several bodies of useful theoretical knowledge and available guidelines, which can underpin clinical reasoning for clinical practice in CP.

### **1.2.1: There are some basic areas of theoretical knowledge which are useful to the physiotherapist and which are described in detail in Mayston 2012; 2014, but will be briefly reviewed here.**

i. Typical Development (TD): An application of the knowledge area of typical development is not about using it to follow the usual sequence of development, nor is it an ideal to aim for (Rosenbaum & Gorter, 2011). The relevance of TD is in understanding the inter-relationship between its many aspects of cognitive, motor, sensory, perceptual, behavioural and social functioning. It provides a reference point for understanding any deviation from TD and what a child has the potential to do in the

future. To do this requires an understanding of the essential elements of TD, those critical elements that progress a child to the next stage, and the stated interactions of the different aspects of TD, within the three main areas of mobility, communication and manipulation /arm support, which all combine to enable optimal participation. TD is also rich in ideas for intervention activities, and demonstrates that all children are individual in their developmental trajectory, despite there being general trends in skill attainment, supporting the need for a tailor-made interventional approach (Mayston, 2011).

ii. Motor control/learning: For many years I have used the Information Processing Model (Schmidt & Wrisberg, 2008; Mayston, 2014, 2007) to explain the principles of motor control and motor learning in healthy individuals and for those with sensorimotor impairments. This simple representation stresses the importance of motivation, sensorimotor planning, motor execution and the importance of the sensory consequences of action on fine tuning of activities and learning for the future. As McCloskey and Prochazka stated in their 1994 paper: "...one can only control what one senses", highlighting the importance of sensory perception and processing for effective motor performance and learning.

iii. Muscle physiology and Biomechanics: Within the Information Processing framework, muscle physiology and biomechanics are an important element- muscles make actions happen and are also important for proprioception and thus motor learning. Muscles act optimally at mid-range, and yet for children with CP muscle weakness, imbalance and altered length are commonly encountered (Gough & Shortland, 2012; Lieber & Bodine-Fowler, 1993). Not only that, it is becoming increasingly clear that muscle structure is atypical and displays alterations in its extracellular matrix and contractile properties in children with CP, has less potential for growth and there is a suggested relationship with GMFCS levels (Dayanidhi & Lieber, 2014; Smith et al 2011; Frieden & Lieber, 2003).

iv. Neuroplasticity: The neuroscience of neuroplasticity has made rapid progress in the last 20 years, and though present throughout life is thought to be most prolific in the first two years of life. This fact has been seized as important evidence to support

early intervention. Despite that, studies have not been able to show that exploitation of neuroplasticity in early life has clear advantages. Theoretically it should, and no doubt time and further work will elucidate the best way to achieve this (Kolb & Gibb, 2014). It seems to be well accepted that activity and novelty are the two key requirements in driving neuroplasticity processes, and that adaptations can be positive and negative depending on the experiences, or lack of them that a person experiences (Kolb & Gibb, 2014; Martin, 2005).

Knowledge changes constantly, and therapists need to continually update their knowledge base through regular journal reading, journal clubs, attendance on short courses, undertaking MSc programmes, carrying out research in collaboration with experienced researchers and becoming researchers themselves via PhD studies.

### **1.2.2: Practice framework: ICF and Family Centred Service.**

Sound clinical reasoning also requires an understanding of the main practice frameworks which are the basis of intervention and research, and in the last 10 years emphasis has shifted to the International Classification of Functioning Disability and Health (ICF; World Health Organization, 2001, 2007) and the importance of offering a Family Centred Service (Rosenbaum, 2011).

i: ICF. A survey of therapists at the APCP conference (November 2016, Brighton, UK) revealed that only 49% of those in that clinical reasoning workshop based their practice on the ICF. Most of those present were working in the area of neurodisability in the UK thus this low percentage of users was surprising. Aspiration is that 100% of therapists and health professionals base their practice on this framework which stresses the importance of participation, and also makes for clear communication between professionals worldwide. Some have used the ICF as an argument against body structure/impairment based intervention. I would agree. If intervention only addresses the impairments then it will not influence function, but if treatment at an impairment level is done with the intention of making practice of activity and participation more effective it is highly relevant. Furthermore, the ICF also includes the important Contextual factors of environment and personal factors, which if addressed in the context of the whole

person may be the solution which enables optimal participation. As indicated at the start of this paper, the ICF offers a clinical tool which achieves many goals such as clinical reasoning, outcome measure use, communication and education as well as research question formulation. To use the ICF effectively for clinical reasoning and intervention, the physiotherapist needs to make a detailed study at all levels of the framework, starting with participation and then working backwards to the possible impairments which may be interfering with the achievement of a task or activity. This can then guide the process of selection from the intervention tool box, and also keep the therapist on track to achieve the participation goal(s). It also provides a guide for the use of appropriate outcome measures (Thomason et al 2014; Majnemer, 2012 ).

ii: FCS: Research is beginning to show that a service which engages in partnerships with families results in better outcomes (Perrin et al 2007; King et al 2004; 1999; 1996). There is no better explanation of FCS than that given by CanChild (2003). "Family-centred service is made up of a set of values, attitudes, and approaches to services for children with special needs and their families. Family-centred service recognizes that each family is unique; that the family is the constant in the child's life; and that they are the experts on the child's abilities and needs. The family works with service providers to make informed decisions about the services and supports the child and family receive. In family-centred service, the strengths and needs of all family members are considered." This means that the goals and pace of intervention are set by the child/parents with the treatment team providing the expertise on achieving those goals. This is very different from the health professional led process that has been the norm up until recent years.

iii: Functional classifications: In the last 20 years, functional classification systems have emerged to focus on what the child is capable of rather than focusing on their impairments. A recent article describes these, reports their validity and reliability, and the possibility of their use by all including parents (Paulson & Vargus-Adams, 2017). The first one to emerge was the GMFCS, which is now well established as a classification of a child's mobility and postural capacity. As mentioned earlier in this paper, it can also be used to predict mobility and is a useful

tool for discussing walking potential in children with CP (Hanna et al 2008 Rosenbaum et al 2002). This was followed by the Manual Ability Classification System (Eliasson et al, 2005), and now the Mini-MACS (Eliasson et al 2017), and there is ongoing work for the MACS to be used as a predictor for hand use at least for children with unilateral CP (Holmefur et al 2016; 2010). More recently the CFCS for children aged 4-18 years (Hidecker et al 2011) and the EDACS for children older than 3 years (Sellers et al 2014) have emerged to classify communication and eating/drinking skills. There was also a parallel development of a communication classification system called the FCCS for children aged between 4 and 6 years (Barty et al, 2016).

iv: Clinical guidelines: There is a range of clinical guidelines and systematic reviews by various professional bodies which offer guidelines for CP intervention. These include the National Institute for Health and Care Excellence (NICE) who have published several guidelines for cerebral palsy management. The American Academy for Cerebral Palsy and Developmental Medicine (AAPDM) has published many systematic reviews, and the Royal College of Paediatrics and Child Health (RCPCH) also offer guidelines. All of these publications have been produced by teams of professionals with significant expertise in the field of CP.

## 2. The child/family perspective:

The previous discussion on FCS should highlight the importance of the family perspective on EBP. In line with the ICF, the family is seen as the essential 'environment' of the child and as the parents are the central contextual factor in their children's lives, know their children best and want the best for them (King et al 2004). The focus on the parents has also been identified in the Early Intervention (EI) sector where it has been suggested that EI should focus on supporting a reliable and responsive parent-infant relationship in consideration of the next developmental steps (Van Wassenaur-Leemhuis et al 2016). Without the family as an integral part of the intervention process, success will be limited. It is about living for life, not living for therapy.

## 3. Clinical expertise:

When considering the therapists' clinical expertise, I am reminded of the many components of

physiotherapy intervention, shown as three broad areas in Fig. 3. Much of what physiotherapists do has traditionally been at the body structure and functional level, but always with a caveat that this should be pre-requisite to or applied as part of an activity, with the goal of optimization of participation in daily life always uppermost. For example, if a progressive resistance exercise programme is used to address specific muscle weakness, then the activity which it is intended to improve has to be practised and progressed concurrently. If an activity level intervention such as treadmill training is used then its purpose needs to be identified- is it to improve over-ground walking, fitness, mobility, transfers or all of these? Some activity level interventions can address all ICF levels simultaneously. Systems of therapy such as the Bobath approach or NDT are multifaceted and proponents of these systems need to address the components of intervention according to the ICF. Therapists who focus on hands-on therapy will never achieve the important goal of activity and participation. The GMFCS may also provide a 'Rough Guide' for the use of hands-on versus hands off (Mayston, 2014).

## Signposts for the future.

It is the intention of all professionals to deliver best practice for the benefit of the child and family, but somehow in practice it is not easy to do that. Constraints of time, context and experience can block that outcome. Adherence to old comfortable ideas is often difficult to shake off, misinterpretation and misunderstanding of some approaches is prevalent. Perhaps it is time to take a step back, wipe the slate clean and start again.

"What would it be like if the 'neurophysiotherapy treatment strategies memory' was erased and we all had to design a therapy contribution to habilitation/neurorehabilitation from scratch? I think it is an exciting idea and one that should be taken seriously.....We all want to deliver best practice- what is the best way to design that? It might mean that we need to take a blank sheet, then draw on our knowledge, experimental evidence, clinical expertise, client preference and goals, work out what financial and human resources we have, and design a service which takes all of these into account. Rather than being concerned about what approach we might use, we will continue to focus on the client and their needs

and goals.” (Mayston, ACPIN, Synapse, autumn, 2009). The therapy ‘app’ as I suggested in Dan et al, 2014, is still a long way off.

### Conclusion:

It will take a very long time before there is a data base of the signs and symptoms of the different types of CP, and a sound experimental evidence base for the many interventions current and emerging. In the long interim, physiotherapists, and in fact all health professional involved in the management of CP, need to follow some basic guidelines to enable the goal of achieving optimal participation in daily life and minimization of residual disabilities. These are summarized in Fig 4. The absolute bedrock of clinical practice has to be the ICF, now an internationally accepted clinical framework for assessment, intervention and research. The next element is that clinical practice needs to be rooted in Family Centred Practice, depicted in the figure as rich soil. The soil is not always rich- it may be rocky, barren and difficult to negotiate; it might be based in clay with unsound foundation, or on shifting sands where ideas on ‘best intervention’ change frequently. We all know how families vary in their aspirations and approach to their child with disability.

The essence of intervention has to be sound clinical reasoning as shown by the trunk of the tree. This gives rise to a range of branches which all give the tree its shape, structure and balanced appearance. In order for the tree to grow and develop it needs to be fed and watered and generally cared for. The sun enables the

photosynthesis of the leaves and growth, the soil provides basic nutrients and the rain helps the tree to survive and grow. For the physiotherapist, this means continual review of practice, continual attention to keeping up to date with current literature and knowledge, and advances in clinical practice. Only then can a rational theoretical physical intervention be provided.

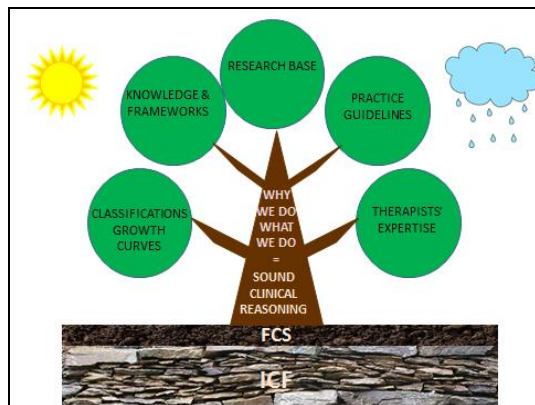


Fig 4. The Clinical Reasoning tree. The ICF forms the bedrock of clinical reasoning.



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