

# Evidence update:

# Conductive education in children with cerebral palsy

August 2016

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# **Executive Summary**

# Background

Conductive Education (CE) is an education programme that combines special education and rehabilitation<sup>i</sup>. It was originally developed as an education programme for children with motor disorders who were excluded from mainstream education in Hungary at the time<sup>1</sup>. The premise of CE is to maximise the functional potential through teaching the child how to successfully adapt to their environment, known as "orthofunction" by CE practitioners<sup>2</sup>.

In a previous ACC evidence-based <sup>2</sup> academic literature was reviewed up to August 2003. The conclusions from this previous review showed that the evidence from the academic peer-reviewed literature did not show that CE was more effective than other conventional approaches. From these results <u>it was recommended that ACC do not purchase CE services</u>. This review is intended to update the original evidence-based review produced in 2003 to inform the ACC Serious Injury Unit whether the evidence supporting the <u>previous</u> "do not purchase" recommendation is still relevant in 2016 on the basis of the most up to date academic peer-reviewed literature and relevant grey literature.

#### Methods

A search of multiple databases (Medline, Pre-Medline, AMED, Embase, PsychInfo, Trip, the Cochrane Library, National Guidelines Clearinghouse, GoogleScholar and relevant NZ, Australian and US government agencies was performed. The types of studies included were systematic reviews and primary studies published since September 2003 that specifically reported on the efficacy of CE programmes in children with cerebral palsy (CP).

#### Main results

A structured search revealed a large volume of material related to CE however upon analysis it was found that some of these articles were reviews of systematic reviews that that assessed primary studies already included within the 2003 report, and that some systematic reviews did not critically appraise the primary studies so were deemed literature reviews and did not fit the inclusion criteria (See Appendix 2 for the overview). One systematic review and four primary studies were included for analysis as they had not been previously reported in the original report and fit the inclusion criteria for this review.

Due the low quality of available studies and the variable nature of the topic it is hard to draw conclusions of the effectiveness of CE.

The main findings outlined below were drawn from studies considered low quality due to the study design:

- CE programmes are variable between the centres that provide it, how outcomes are measured and because they are individually tailored to each child;
- There was some improvement in ADLs in the three primary studies that used tools to assess ADLs (Table 3).
- There was an improvement in complex tasks that were practiced as part of the CE programme<sup>3, 4</sup>, however there was no significant change in motor strength or non-practised tasks<sup>3</sup>.
- Better results were seen among the children who had higher motor function

# Conclusion

Overall CE programmes are largely tailored to the individual and differs to other therapy techniques as it is a combination of education and therapy. Different centres across the world appear to adapt their programmes to suit their specific context. The variable nature of CE programmes and the needs of children with CP make it difficult to

http://www.conductive-education.org.nz/whatisconductiveed.htm

determine the efficacy of the programme and this may be a factor as to why the quality of available literature has not changed since 2003.

As in the 2003 report there is still a need for well-designed cohort studies or RCTs with relatively large sample sizes, a clear definition of CE an adequate period of follow-up and standardised outcome measures to determine the efficacy of CE programmes.

#### Recommendation

# To determine the recommendation the following points were taken into consideration the following:

- The current recommendation cannot be changed based on the evidence alone, as it is unlikely, for this
  specific research question, that the quality and consistency of evidence is likely to change in the near
  future
- Both the MoE and the MoH include CE programmes, as part of Disability Support Services Child
  Development Services (MoH), or as part of a network of early intervention and school aged special
  education services which aligns to the NZ national curriculum "Te Whaariki" (MoE)
- Both the MoH and the MoE consider CE as no better or worse than other programmes
- CE includes components of best practice paediatric rehabilitation interventions provided by NZ registered professionals

After consideration by the PGAG and endorsement by the Clinical Governance Committee\* the recommendation for Conductive Education Programmes in children with Cerebral Palsy is to:

# Purchase on a case by case basis

Considerations for case-by-case may include:

- Was the child receiving conductive education services prior to becoming an ACC client?
- Availability of conductive education services in the child's area
- Does the proposed provider have a Child Development Services contract with the MOH?
- Is the proposed provider a registered early education centre or kindergarten?

<sup>\*</sup> This was determined as a pragmatic for a low risk area and endorsed by the CGC on the 26 October 2016

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# **Abbreviations**

CE Conductive Education

CP Cerebral Palsy

GMFCS score<sup>ii</sup> Gross Motor Function Classification System: Clinical classification system consisting of

five levels:

I - Walks without limitations

II - Walks with limitations

III – Walks using a hand held mobility device (e.g. Frame)

IV - Self-mobility with limitations; may use powered mobility

V – transported in a manual wheelchair

# Other definitions

Orthofunction The ability to function in normal social settings without the use of adapted equipment

(Colman et al., 1995, cited in Tuersley-Dixon 2010)

Quasi-experimental Experimental design that attempts to achieve a good match on relevant variables between

affected (eg. with CP) and non-affected (eg no CP) groups

# **Revision History**

Date	Version	Description	Author
10/08/2016			
12/08/2016	V1.1	MS Comments	Melissa Barry
22/08/2016	V1.5	External peer-reviewer suggested amendments made	Melissa Barry

<sup>&</sup>lt;sup>11</sup> Palisano, Rosenbaum, Bartlett and Livingstone, (2007) GMFCS – E & R: CanChild Centre for Childhood Disability Research, McMaster University, www.canchild.ca

# 1 Background and purpose

# 1.1 Background

Conductive Education (CE) is an education programme that combines special education and rehabilitation<sup>iii</sup>. It is designed for children and adults with motor disorders like cerebral palsy (CP) as well as Parkinson's Disease, Multiple Sclerosis, and paraplegia arising from stroke. In a previous ACC evidence-based <sup>2</sup> academic literature was reviewed up to August 2003. The conclusions from this previous review showed that the evidence from the academic peer-reviewed literature did not show that CE was more effective than other conventional approaches. From these results *it was recommended that ACC do not purchase CE services*.

Since 2003 further evidence has been published in academic articles and from non-academic government papers regarding CE. The Ministry of Health in New Zealand currently does fund CE and the Serious Injury unit who receives requests for CE from clients with CP has asked that the 2003 report is updated.

# 1.1.1 Overview of conductive education

Conductive education was designed by Dr Andras Peto in Hungary in the 1940s. It was originally developed as an education programme for children with motor disorders who were excluded from mainstream education in Hungary at the time<sup>1</sup>. The premise of CE is to maximise the functional potential through teaching the child how to successfully adapt to their environment, known as "orthofunction" by CE practitioners<sup>2</sup>. The four components of the program identified use a combination of teaching methods and therapy which is led by a specifically trained 'conductor'<sup>4</sup>:

- Task-orientated learning within highly structured programmes;
- Facilitating motor actions through rhythmic speaking or singing;
- Integrating manual activities into the context of activities of daily life (ADLs); and
- Child oriented group settings to facilitate psychosocial learning to increase participation

The 'Conductor" is defined as the person who plans and delivers the CE programme, they are also the individual who determines whether the individual is fit for the programme or not<sup>5</sup>. The key qualification required to be a Conductor is a Diploma in Conductive Education that is earned from the International Peto Institute in Budapest, University of Wolverhampton<sup>iv</sup>. It is a four year programme described as a 'trans-disciplinary' approach to education and includes a range of techniques: teaching, nursing, physiotherapy and occupational therapy in order to work with the child holistically. Conductors are responsible for organising and co-ordinating other professionals (e.g. speech language therapists, specialist teachers and teacher aides) involvement with the individual. The CE programme is customised towards each individual's needs and can be delivered at home, in a specialised centre or within the child's school.

There are both benefits and concerns around CE programmes. Benefits include improvements in: motor skills, independence, cognitive skills, social and communicative skills<sup>5</sup>. Concerns reported around CE have been around the nature of the physical exercises and that these may cause harm (from two reports in the late nineties reported by Tuersley-Dixon, 2010). One study reported deterioration in hip mobility, however this was not reported in other studies<sup>2</sup>. Parents of children with CP involved in CE programmes appreciate the intense training and believe it is motivating for the child, and have been described as the force behind establishing CE programmes<sup>3</sup>.

# 1.1.2 Conductive education facilities in New Zealand

In New Zealand CE is supported by their national body which was established in 1993. There are a number of centres located across the country - Auckland, Hamilton, Wellington, Christchurch and Invercargill (see Appendix 1

<sup>&</sup>quot; http://www.conductive-education.org.nz/whatisconductiveed.htm

http://www.conductive-education.org.nz/Profile\_of\_the\_conductor.pdf

for list) with over 20 conductors who provide programmes for babies, primary and high school aged children and adults. Participation in programs range from a 1 - 2 of hours a week to 5 - 6 hours a day, five days a week.

# 1.2 Purpose

This review is intended to update the original evidence-based review produced in 2003 to inform the ACC Serious Injury Unit whether the evidence supporting the <u>previous</u> "do not purchase" recommendation is still relevant in 2016 on the basis of the most up to date academic peer-reviewed literature and relevant grey literature.

The <u>purpose</u> of this evidence update is to critically appraise academic literature from September 2003 to July 2016 on the efficacy of Conductive Education in children with cerebral palsy.

# 2 Methods

A search of the following sources was carried out for articles printed after August 2003 up to April 2016 by two ACC Research Advisors:

- Medline, Pre-Medline, AMED, Embase, Psychlnfo, Trip, Cochrane Library databases and National Guidelines Clearinghouse
- Google and Google Scholar
   Guidelines / policies from other agencies: NZ, Australian and US government agencies, Cigna and Aetna (major US health insurers)

Search terms included those used in the original report: Conductive education, conductive learning, conductive therapy, conductive pedagogy, andras peto.

#### 2.1.1 Inclusion criteria

- Types of studies: systematic reviews and primary studies post September 2003
- Types of participant: any human participants with cerebral palsy
- Types of intervention: conductive education programmes as described by study authors

# 2.1.2 Exclusion criteria

- Animal studies
- Articles not in English
- Studies on therapy approaches for cerebral palsy that do not mention conductive education
- Conductive education therapy on populations that are not children with cerebral palsy

# 2.2 Level of Evidence

Studies that met the criteria for inclusion in this report were assessed for their methodological quality using the Centre of Evidence Based Medicine (CEBM) criteria. These criteria were assessed using the CEBM Critical Appraisal Tool (CAT) Manager that is available as a mobile phone application. The questions within the application are based on their appraisal checklists. These cover similar aspects of critical appraisal to other standardised methods like the Scottish Intercollegiate Guideline Network (SIGN) checklists.

The reason why the CEBM tool was used instead of SIGN (which has been conventionally used in previous ACC EBH critical appraisal reports) is that the primary studies were either case-series or before-after quantitative study designs and the SIGN checklists were not suitable. A description of the meaning of each CEBM grade for each study is included in the evidence tables in Appendix 3 and 4.

# 3 Findings

# 3.1 Reasoning behind the included and excluded studies

The articles related to conductive therapy were a mixture of reviews of systematic reviews (SRs) <sup>6</sup> <sup>7</sup>, SRs<sup>8</sup>, literature reviews<sup>5</sup>, evaluative reports<sup>9</sup> and primary studies <sup>4</sup> <sup>10</sup> <sup>3</sup> <sup>11</sup>. There was cross-over in the primary studies reviewed to form the SRs; and a number of these primary studies are already included in the original 2003 report produced by the ACC Evidence-based healthcare group. To see the cross-over across different articles please refer to Appendix 2 of this document.

Only one of the SRs found met the inclusion criteria for this report<sup>8</sup>. One review<sup>5</sup> previously described as an SR<sup>7</sup> did not meet the inclusion criteria for this ACC report because the authors of Tuersley-Dixon (2010)<sup>5</sup> did not publish a critical appraisal process and so was excluded. The primary studies included in Tuesley-Dixon (2010) were checked by hand alongside our search results to ensure no relative studies were missed (further details regarding this SR can be found in Appendix 3 on page 23.

The final studies and SRs appraised for this report were done on the following basis:

- They met the inclusion criteria outlined in the methods section of this document
- They were not included as primary studies in the 2003 review
- They were not included within the systematic reviews in the 2003 review

Taking these criteria into consideration to ensure new information about the efficacy of conductive education programmes is reported, one SR <sup>11</sup> and four primary studies<sup>4</sup> <sup>10</sup> <sup>3</sup> <sup>11</sup> were included in this analysis. Further details about the primary studies that are included in the SR can be found in Appendix 3 on page 32 and studies not included in the analysis were not critically appraised for this report (outlined in Appendix 4).

An overview of two grey literature reports (Carson St Evaluation<sup>9</sup> by Miles Morgan (2010) and the Auckland Uniservices Stocktake<sup>12</sup> by Widdowson, 2016) are also taken into consideration due to the limited literature found and the understanding that these resources have been used by other NZ government agencies to inform decision making with regards to CE programmes.

# 3.2 Guidelines

There were minimal evidence-based guidelines on conductive education in children with cerebral palsy. A search for international guideline recommendations regarding conductive education revealed no findings from: the National Guidelines Clearinghouse (United States; https://www.guideline.gov/), the National Institute of Clinical Excellence (NICE, United Kingdom), and National Health and Medical Research Council (NHMRC, Australia). No results were found when searching other health insurance company sites Cigna and Aetna.

A recent draft guideline regarding cerebral palsy is currently undergoing consultation by NICE<sup>v</sup>. It covers the diagnosis, assessment and management of CP in children and young people from birth up to their 25<sup>th</sup> birthday. Different aspects of care are covered within the draft guideline however conductive education was is not mentioned as a specific programme of management within this guideline.

Conductive education was mentioned as an option in one New Zealand based clinical practice guideline<sup>vi</sup> produced by the Waikato District Health Board (New Zealand) as an option for intervention in young children with cerebral palsy. However the supporting evidence and methodology for how this guideline was formed was not included within this document so no comment can be made regarding whether it is based on evidence or not.

Details regarding the guideline search can be found in Appendix 8 on page 37.

v https://www.nice.org.uk/guidance/GID-CGWAVE0687/documents/draft-guideline-3

www.waikatodhb.health.nz/assets/for-health-professionals/

# 3.3 Systematic review (Franki et al, 2012)

The SR by Franki et al, (2012) was a review of the efficacy of conceptual approaches and additional therapies (e.g. Bobath techniques and constraint induced therapy) used in lower limb therapy of children with CP. Results for CE only are reported here. This SR appraised 10 studies on CE, four of these were already included in the previous ACC EBH report<sup>2</sup>.

The included studies ranged from randomised control trials (level II evidence higher quality) to case series, case-control and cohort without control group study designs (level IV evidence – low quality).

This systematic review, although it was a high quality analysis of the literature, did not report the effect size of CE. It should also be noted that the level of evidence of the studies that the SR reviewed ranged from high to low quality. Further detail of this review can be found in Appendix 3.

# 3.3.1 Main findings of systematic review

Any positive findings on CE from the articles included in the SR were from studies of low quality. This was because the study designs they used are more susceptible to bias (e.g. case series, cohort studies with no control and case control studies); and the number of participants was low. Higher quality studies (the two RCTs) were described as having no evidence to support the effectiveness of CE. Low quality evidence showed that CE programmes showed some effectiveness in body function and structure outcomes, and for gross motor skills and individual motor goals. There was conflicting evidence for its effectiveness on participation, parental coping and stress.

A main conclusion from the SR<sup>8</sup> was that the number of studies was too small and the quality too low to be able to be conclusive about the effectiveness or ineffectiveness of CE programmes. A consideration highlighted in the review is the variable nature of the CP population; the variable effects of therapies; and variability in how outcomes are measured making it difficult to draw any consistent statements or conclusions from the literature.

# 3.4 Primary studies

Four primary studies were found that fit the inclusion criteria<sup>4</sup>. All of these studies were graded as having lower quality of evidence due to their study design. The number of participants included within the studies ranged from n = 9 to n = 64, and they used a range of outcome measures to determine the efficacy of CE programmes. Between the studies participants differed in age; within and between studies there were differences in the type of CP they had. An overview of the methodologies and measures used in the studies are presented below followed by a section on the main findings of these studies.

# 3.4.1 Overview of study design

An overview of the study methodology and participants are included in Table 1 below along with the CEBM grading. All the studies were of low quality design and examined CE on children with a range of disorders as part of their CP condition (i.e. bilateral spastic CP, diplegia, quadriplegia etc). There was variation in how the CE programs were performed, the duration of the programme and how the outcomes were measured. This limited the ability to pool data between studies and difficult to summarise the results of all the studies to determine an overall understanding of CE programmes in children with CP.

Some details regarding the objects and methods for these articles are shown in Table 1 below. Further details regarding these studies can be found in the evidence tables in Appendix 3 at the end of this document.

Table 1. Brief overview of primary studies

Study	Description	Participants	CEBM rating
Blank et al, 2008 <sup>4</sup>	<u>Objective:</u> To study effects of conductive education in children with CP on their hand motor functions and activities of daily living	n = 64 <u>Examined by a child</u> <u>neurologist</u>	C-
Study design: Individual cohort	Study design: B-A-B design B-phase: 4.5 month period of conventional special	n = 59 had bilateral spastic CP n = 3 hemi paretic CP n = 2 dyskinetic CP	
study, B-A-B design	education  A-phase: 9 month period, during which the children	n = 3 cerebellar CP Aged 3 – 6 years, recruited	
	participated in 3 4-week inpatient blocks of CE, outside of this they continued in their individual programmes.	over a four year period  Gross Motor Function  Classification system (GMFCS)	
	Outcomes were measured at the start and end of Phase A and end of Phase B2. Results of the two B phases were averaged to take into account improvements that normally may have come about due to age	score of II (n = 16), III (n = 38) and IV (n = 10)	
	Components of individual CE programme:		
	Standing and walking 14.9%; Hand 16.8%; Cognitive program 6.9%; Movement program: 22.1%; Individual program: 39.3%		
	Motor parts of program 52.6% of time and 28.8% to ADLs, 18.6% to cognitive education		
	Outcome measures:		
	ADLs (in a subgroup of 33 children), preferred and non- preferred hand measured separately. This was introduced during the course of the study so it was only applied to children who entered the study when it entered its second half.		
	Specific measures included: grip force on a small cylindrical 20g object; finger tap; hand tap; pinch grip strength; drawing analysis system; 3D ultrasound based movement analysis systems.		
Dalvand et al, 2009	<u>Objective:</u> To compare the effect of the Bobath technique,	n = 45, aged 4 – 8 years	C-
Study design:	conductive education (CE) and education to parents in activities of daily living (ADLs) in children with cerebral palsy aged 4 – 8 years	n = 15 in each experimental group:	
Quasi-experimental clinical trial with pre/post design	<u>Study design:</u> Sessions were 3 hours long, held four times a week over a period of 3 months.	- CE - Bobath - Education to parents	
pre/post design	Outcome measures: Client Development Evaluation Report (CDER): Assessment of 19 points of 16 ADLs before and after intervention. Scoring performed according to instruction manual	Participants were matched according to sex, age, and IQ	
Effgen et al, 2010 <sup>3</sup>	<u>Objective:</u> To study the frequency of occurrence/practice	n = 9	D-
Study design:	of gross motor behaviours in a CE preschool program and the attainment of individualised gross motor objectives in	n = 6 had spastic diplegia n = 2 had spastic quadriplegia	
Case series.	preschoolers with CP	n = 1 had ataxia	
Described by study as a systematic	<u>Study design:</u> Children participated in a full day CE 5 days a week for 11 months. The CE curriculum was tailored to	Aged 42 – 72 months (3.5 – 6	

observational and exploratory study	the needs of the participant  Program provided by staff of teachers, OTs, PTs, and SLTs supported by parents, (although no 'conductors' were used the programme was closely modelled on the Peto Institute's CE principles).  Outcome measures: Four gross motor objectives around Mobility, stability and transfer activities that were integrated throughout the day into the child's activities. These measures were designed to cater towards a particular child's ability and were measured by reporting the month of when that objective was achieved, or labelled as 'not achieved' if the child did not achieve that objective.	Average GMFCS score was Level III (walks with assistive devices; limitation walking outdoors and in the community), all the preschool aged children were learning how to walk.	
Liberty et al, 2004 <sup>10</sup> Study design: Case series	Objective: To investigate an early intervention programme based on the principles of CE by measuring the functional skills of young children with CP in natural contexts over a 12-month period.  Study design: Programme of systematic task routines incorporating functional skill training guided by parents under the supervision of a conductor. Sessions 3 hour in duration, 1 – 5 times a week (Average of 7.4 hours per week)  Outcome measures: Uniform Performance Assessment System (UPAS) a standardised measure for measuring the development of a range of skills in a child's progress up to age 6	n = 29 (10 girls)  n = 26 had cerebral palsy, n = 17 of these had spastic quadriplegia, n = 4 had other types of quadriplegia, n = 3 had hemiplegia, n = 1 had diplegia, n = 1 had an unspecified form of CP. n = 3 others had motor disorders. Aged 16 – 95 months (~8 years)	C-

# 3.4.2 Findings 1. Activities of daily living

Three out of the four primary studies included a measure for ADLs. None of them used the same assessment tool however all showed some improvement in ADLs after the CE intervention. Only one study<sup>11</sup> reported on individual aspects of the ADLs that were measured in the assessment tools, the other two<sup>4, 10</sup> reported overall scores.

Table 2. Overview of ADLs reported in primary studies

Study	Findings
Blank et al, 2008 <sup>4</sup>	Outcome measure
	Measures of Activities of Daily Living (M-ADL) questionnaire.
	The "domains" of the M-ADL questionnaire included: Manual ability, eating and drinking, dressing and washing, bladder and bowel management and mobility. Score is completed by parents.
	<u>Findings</u>
	N = 33 participants (out of 64 as it was only applied to children who entered the study when it entered its second half).
	Conductive education improved ADL competence (corresponding to a 20% increase from baseline) whereas in comparison there was no improvement seen with special education alone. Results on specific domains were not included only global effects are reported.

Dalvand et al, 2009	Outcome measure	
"	Client Development Evaluation Report (CDER) – an assessment of 16 ADLs, although it was not clear	
	who rated the CDER.	
	<u>Findings</u>	
	Significant increases in the general CDER score, CE appeared to have the biggest change compared to	
	the two other comparison groups (Bobath technique and education to parents)	
	ADLs showing significant change: Household chores, eating, toileting, level of bowel control, personal hygiene, bathing, dressing, movement in a familiar setting, community transportation, money handling, ordering food in public	
Liberty et al, 2004	Outcome measure	
10	Uniform Performance Assessment System (UPAS) – A standardised measure of a range of skills in	
	functional contexts. These tasks were tailored to the abilities of the child and included: potty training,	
	social and communicative interaction, plinth based gross motor movement, object use, singing,	
	snack/lunch and play routines and saying goodbye and leaving routines. These were designed to	
	measure progress in children aged up to 6.	
	<u>Findings</u>	
	Significant gains were seen across all the CP groups; however the individual components of the UPAS were not reported so it is unknown how the individuals performed for specific skills.	

# 3.4.3 Findings 2. Changes to motor function

Definitions of gross motor function varied between studies and some of the functions described overlapped with ADLs<sup>3</sup>. Overall outcomes appeared to be better in tasks that were practiced<sup>3</sup> and that actual strength measures did not change after training. Better outcomes were identified in one study with children who had a higher gross motor function score for both hands<sup>4</sup>.

Table 3. Motor function changes reported in primary studies

Study	Findings
Blank et al, 2008 <sup>4</sup>	Outcome measure
	Measures were done on both preferred and non-preferred hands and each task was repeated 3 times, the mean was reported. Specific upper limb tasks were measured including: pincer and grip forces, finger and hand taps, 3D ultrasound based movement analysis of complex movements like drawing.
	<u>Findings</u>
	The better outcomes were among children who had higher GMFC scores (Level III) for both hands. Grip strength did not change. Parents verbally described improved manipulative skills and there was an improvement in coordinative hand functions (up to 25% compared to baseline) compared to special education alone)
Effgen et al, 2010 <sup>3</sup>	Outcome measure
	These were based on the individual child's abilities and were grouped into four main areas: Classroom activity (including fine motor and gross motor, tea time, potty, transitions); Stability behaviours (including lying, assisted sit, kneeling, standing, squatting); transfer behaviours (including: in / out of a chair, rolling, independent/dependant); Mobility behaviours (Rolling, knee walking, assisted / independent walking and other behaviours).
	Results were collected by observing the child through the day and scores were only collected for the 'achieved' tasks as number of incidences of that objective occurring per hour and then grouped by

month. Incidents were observed by two independent viewers during four data collection periods.

#### Findings:

By the end of the first term, 83% of the gross motor objectives had been achieved. Children did not achieve objectives that were not practiced, suggesting a relationship between practice, achievement and gross motor objectives. Once achieved the number of incidences per hour between each month did not increase or decrease significantly for the gross motor objectives.

# 3.5 Overview of the Carson St Evaluation<sup>9</sup>, and Stocktake report<sup>12</sup>

Two pieces of grey literature regarding CE that are included are an evaluation conducted in Australia from 2007 to 2009 on CE as an early intervention (children aged 0-4)<sup>9</sup>; and a report that assess services delivery of CE services in New Zealand<sup>12</sup>. These reports have been used to inform decision making regarding CE programmes in New Zealand which is why they are outlined here, however it should be noted that these reports included an analysis of primary data of users of CE and perceptions of CE and have a very different focus to the evidence-based report.

Both reports included literature reviews (not critical appraisals of the literature) that came to similar conclusions – namely that published articles were inconsistent in both how they investigated and reported CE, and that CE programmes themselves are variable making it difficult to make conclusions on the effectiveness of the programme based on literature. These literature reviews also concluded paucity in good, high quality evidence-based research on the effectiveness of CE.

Outcomes from the grey literature show that CE is associated with improvements in individual student plans, and that parental feedback from thematic analysis of parent interviews and forums was largely positive and any negativity was associated with the operational side of the service rather than the treatment itself. Both the evaluation<sup>9</sup> and the stocktake<sup>12</sup> report suggest that an integrative approach for parental involvement is beneficial as reported by the parents themselves.

It should be noted that the included analyses are performed on small sample sizes (n = 18 and n = 4) for the analytical components of their reports also that both of these reports have not undergone the robust peer-review process that the academic peer-reviewed articles have.

Further summary of these documents are available in Appendix 7.

**Table 4. Grey literature overview** 

Title	Objectives	Findings
Miles Morgan, 2010. 9 Orchestrating Lives: an Evaluation of the early intervention conductive education trial at Carson St	-This was an evaluation of an early intervention CE trial conducted between 2007 and 2009. It was intended to provide recommendations for ongoing program design and deliver to meet early education needs of students with CP and other motor disorders.  -Data analysis included a consultation with key stakeholders,	Literature review summary:  There is inconsistency in data as the CE program and how it is measured making it difficult to determine if it is more beneficial than other therapy techniques.  There is variety in settings, staffing, age, professional roles, funding mechanisms and how the program is run with the educational curriculum across different studies. It is difficult to ascertain specific criteria when defining and comparing CE programmes
School.	including parents, and observation	<u>Evaluation</u>
	of children and CE in early intervention and primary school	There is evidence of student's making satisfactory progress, high levels of parental satisfaction, and improved levels of

classes.

- -N = 18 parents were involved, 5 participated in one on one semi-structured interviews, the other 13 in a 3 hour forum
- -Carson St staff were interviewed, including teaching staff, specialists on the CE team and administrative staff.
- -Evaluation team observed CE in action in the classroom to gain a sense of how the program enabled students to progress into CE programmes in primary school from the early intervention phase.
- -The document includes a literature review that discusses the literature but does not critically appraise it. There is no clear search strategy as to how articles were included or excluded.
- -Cost of programme for 32 children aged 0 4 to attend two half-day sessions per week required an additional allocation of AUS \$205,435 (equating to a cost of \$6,419 per child excluding all facility overheads)

parental coping outcomes.

Measures of students' progress was shown from data collected from their individual education (ICE) plans and used as evidence to show effectiveness of the CE programme which was assessed by Carson St senior staff.

ICE targets included: lying/sitting/sit-to-stand; standing/walking/transfers; communication; and hand function / self-care and play skills. Five children showed various ranges of improvements (from "some progress" to "mastered" the skill) in these tasks.

Gross motor function results were not included in this evaluation.

The early intervention plan itself was highly regarded by parents, who report high levels of satisfaction with children's achievements and improved levels of parental coping and family functioning. Parents were asked about satisfaction at a parent forum (n = 13 participants) and parent interviews (n = 5) where they were asked a series of questions. Positive outcomes were summarised from thematic analysis of quotes taken from the forum and parent interviews, these are reported in the evaluation as:

- Improved mental health and physical health for themselves and the child
- Improved communication with their child
- Opportunity for child to socialise
- Enhanced motor skills, and
- Behavioural changes.

Negative experience due to school's inability to locate suitable staff, or staff not being available to assist children / families transition to mainstream schools.

Elements of effective early intervention programs reported to include:

- Continuity of care
- Intensity of the programme
- Active involvement of parents in the design and delivery
- Use of group activities in addition to individual program planning

Widdowson, 2016.

Final report: A stocktake and needs analysis of Child Development Services This stocktake appears to be an analysis of the process and operations of Childhood Development Services (CDS) and CE services rather an analysis of the effectiveness of either programme towards an individual child's progress.

The stocktake includes a literature review, however this is not a critical

Aims of this documents were:

- To create a baseline of quality and diversity of CDS and CE provision with which the Ministry can measure future progress
- Develop a self-assessment and reporting instrument in collaboration with the Ministry, CDS/CE providers and service user groups to extend this baseline and assess progress towards improving outcomes for children

Literature review conclusion:

The studies that investigate the effectiveness of CE are largely

appraisal, and there is no clear search strategy.

The literature review component heavily refers to the Carson St Evaluation.

A mixed-methods approach was adopted to discuss service quality and delivery models using surveys (n = 4 CE related replies) and case studies.

small scale (small numbers of participants with variable function) with indicative results only.

Despite the rapid growth of CE worldwide and perceived benefits, the research literature highlights the paucity of, and need for, good quality evidence-based research on the effectiveness of practice and outcomes for CE.

#### Survey results

Team composition and ratings of services reported here, not relevant for this review.

#### Case study results

Two CE sties were reported, both described the level of need of their clients as complex, the age range was 0-4 and 0-5, and the team members were from a range of disciplines from allied health disciplines and administrative staff. Both were centre based.

Of some interest for this review referrals to the CE programme were from an Early Intervention Coordination service for one centre, the other was from parents via the phone or internet, or a neurologist.

CE did not generally receive referrals from CDS or developmental paediatricians and this is stated in the report as due to CE not being considered by this service and group of health professionals as a valid method of intervention.

# 4 Summary

Although there appears to be a large volume of articles on conductive education within the peer-reviewed literature, there was cross-over between the primary studies reported by the systematic reviews, literature reviews and the reviews of the systematic reviews (this cross-over is outlined in a table presented in Appendix 2). No further evidence was reported in the included studies about adverse effects. A large proportion of this information has already been reported in the original 2003 ACC evidence based review.

# 4.1 Evidence statement

The final studies included in this review were one systematic review<sup>8</sup> and four primary studies<sup>3, 4, 11</sup>.

The SR provided a high quality analysis of 10 high to low quality primary studies based on study design and small numbers of participants. The main findings from the SR was that the number of studies, quality of these studies and the variable nature of how CE is measured and used makes it difficult to draw any conclusive understanding of the efficacy of CE. Evidence from the two included RCTs showed no evidence to support effectiveness of CE due to the variable nature of the topic, with information on effectiveness mainly being drawn from study designs deemed of lower quality – case studies; before and after studies; and case control studies<sup>13</sup>.

Similar findings were seen in the four primary studies. As all the studies were either of case series (n = 2) or before / after intervention (n = 2) study design, the quality was deemed to be low across the studies. This was due to the low numbers of participants in two of the studies, and differences in the level of CP and motor skill between different participants. How outcomes were measured across the studies differed due to the different focus each of the primary studies had. Two studies used comparison groups however no studies looked at the long term outcomes of CE programmes.

Although the grey literature shows results that support the use of CE programmes, it should be noted that these are from small sample sizes and methodologies that are susceptible to bias. Also that these results have less weight than evidence presented by the academic literature has it has not gone through a robust peer-review process.

# 4.2 Main findings

Main findings from these studies were:

- CE programmes are variable between the centres that provide it, how outcomes are measured and because they are individually tailored to each child;
- there was improvement in ADLs in the three primary studies that used tools to assess ADLs (Table 3). Only one primary study<sup>11</sup> reported individual ADLs, the other two only reported a global score for the outcome measure they used;
- There was an improvement in complex tasks that were practiced as part of the CE programme<sup>3, 4</sup>, however there was no significant change in motor strength or non-practised tasks<sup>3</sup>.
- Better results were seen among the children who had higher motor function

In the grey literature semi-structured interviews and workshops with parents (n = 18) were used to assess CE programmes<sup>9</sup>. Feedback was largely positive, and both the evaluation and stocktake report suggested that an integrative approach with parental involvement is beneficial, and this result was reported by parents themselves. Both of the grey literature articles included a literature review however the search strategies for these were not clear and they were not critical appraised, although the conclusions were similar – that CE programmes and outcomes are variable and that there is a paucity of high quality studies available.

# 4.3 External peer-review

An impartial external peer-review was conducted by a reviewer with an allied health background and research expertise in the efficacy of participation-focused paediatric interventions. The reviewer stated a number of points (truncated) to be taken into consideration when interpreting the evidence from this report that are outlined below, (the full interpretation of subject and conclusions section provided by the reviewer can be found in Appendix 9):

- While the evidence for CE is negative or untrustworthy in these studies, <u>several of the studies describe</u> <u>components of best practice paediatric rehabilitation (or therapy)</u>, namely child/parent education and tailored, context and task specific intervention.
- The greatest barrier to advancing research into CE is the absence of a clear description of it.
- The limited generalisation in CE studies is generally true of most interventions for most children with a wide variety of impairments to body structures and body functions.
- Generally interventions for children with cerebral palsy at best lead to gains in what is trained (i.e. improvement in the ability that was practiced during intervention) with little cross over between improvement in impaired body structures and functions.
- The intensity of CE reported in these studies is very high and sustained compared to other paediatric rehabilitation interventions, thus if significant gains are not evident with this level of intensity then its effectiveness should be questioned.

# 5 Conclusion

Overall there is a paucity of conclusive and consistent high quality peer-reviewed articles regarding the efficacy of CE programmes. This makes it difficult to determine whether the programme is effective or not and indicates that the quality of available literature has not changed much since the 2003 ACC evidence based review <sup>2</sup>.

The most conclusive evidence comes from studies which are of low quality design which use different outcome measures. They mostly report the programme has some positive effect for improvement in some ADLs and complex motor movement however the studies largely report global scores, some studies did not use comparison groups and no studies investigated the long term effects of CE. However given the small size of populations that access CE programmes as seen in the stocktake report<sup>12</sup> and the variability of the programmes as they are tailored to the individual child's needs it may be difficult to cohesively answer the efficacy of CE programmes solely from the basis of academic evidence.

Two of the included studies show that CE appears to have a more positive effect than other techniques (Bobath, or Special Education alone). These comparisons are questionable as these therapies are different in methodologies and intensity compared to CE.

Parental feedback from both the peer-reviewed and grey literatures are positive about CE programmes, the positive effects reported were both for the child's function, and for the parental relationship with the child.

Overall CE programmes are largely tailored to the individual and differs to other therapy techniques as it is a combination of education and therapy. Different centres across the world appear to adapt their programmes to suit their specific context. The variable nature of CE programmes and the needs of children with CP make it difficult to determine the efficacy of the programme and this may be a factor as to why the quality of available literature has not changed since 2003.

If academic evidence is to be used in future to justify purchasing CE programmes well-designed cohort studies or RCTs with relatively large sample sizes; standardised outcome measures; a clear definition of CE and an adequate period of follow-up are required to determine the efficacy of CE programmes. However as stated by the external peer-reviewer this may be difficult to do due adequately due to the variable nature of CP and CE programmes as they have to be designed to meet the children's needs.

# 6 Recommendation

Analysis of the academic peer-reviewed literature does not clearly present a case for or against purchasing CE programmes. There is some low quality evidence that CE may be more beneficial than other therapy techniques, however it should be noted that CE programmes are not standardised between centres in how the programme is delivered, the intensity of the programme delivered, or the staff providing the treatment. Although CE includes components of best practice paediatric rehabilitation interventions as a specific programme itself the evidence for it is poor.

#### **PGAG** discussions

During the meeting it was suggested that a final purchasing recommendation needed to take into account other considerations. It was also suggested that it is unlikely - for this specific research question in this cohort of children with CP - that the quality and consistency of evidence in the peer-reviewed academic literature is likely to change in the near future. PGAG therefore questioned whether it is fair to base the recommendation mostly on academic evidence.

It was considered by the PGAG that while evidence for the programme itself is low quality, the services provided within the program align with the principles of best practice paediatric rehabilitation for children with needs like those with CP.

The PGAG asked for more information in three key areas before a final quorum could be made regarding the final recommendation for this topic. The information is summarised in the table below:

Question	Information
	<ul> <li>The NZ MoH offers CE as part of Disability Support Services - Child Development Services when a child needs therapies to facilitate and enhance development of neurological and motor skills and function, swallowing and feeding skills, respiratory skills and function and speech, language and communication.</li> <li>All DHB's also offer Child Development Services, so for the areas where CE is provided, parents can choose between the DHB model or the CE model.</li> <li>ACC children are actively excluded from accessing Child Development Services.</li> </ul>
How does the Ministry of Health (MoH) justify funding for this service?	- The CE provider is often a registered early education centre or kindergarten. Many parents choose CE because they view it as more intensive and the joint early childhood centre approach means the child is accessing therapies in the preschool setting.
	- CE is not perceived as any better or worse than other programmes.
	- The CE provider has a Child Development Service contract with Ministry of Health and is bulk funded by the Ministry based on the role of the provider.
	- If the child gains an accepted ACC Treatment Injury claim, they transition to becoming an ACC client. They may have already chosen to access the CE programme. However, as CE is currently declined by ACC, ACC often meets resistance and anger from parents when transitioning to contracted therapies to meet the child's needs (Child and Youth Training for Independence Programme). Parents do not want to give up the CE programme.
	- The Ministry of Education (MoE) includes CE as part of a network of Early intervention and school aged special education services in NZ.
What is the Ministry of Education's policy / position on Conductive	-CE is considered to align to the National NZ Curriculum "Te Whaariki"  (http://www.education.govt.nz/early-childhood/teaching-and-learning/ece- curriculum/te-whariki/) as CE is an integrative approach that embeds therapy into learning.
Education?	- The CE programme itself has changed from a purist approach, as it was initially introduced by Peto in Hungary, to a more integrative model that enables it to be made part of an adaptive programme.
	- CE is considered to cause no harm, and is no better or worse than other programmes for children with physical disabilities.
What are the alternatives if a child with CP does not receive funding for this programme?	- The alternative to CE that is offered by ACC is a Child and Youth Training for Independence Programme that consists of occupational therapy, speech language therapy and physiotherapy within a home, preschool/school or community setting. Other health professionals can be accessed on this programme depending on the

child's needs including nursing, dietician, psychology, social work.
Some families will transition to this programme, but many would prefer to stay with the CE programme if they are already accessing it.

# Taking into consideration the following points:

- The current recommendation cannot be changed based on the evidence alone, as it is unlikely, for this
  specific research question, that the quality and consistency of evidence is likely to change in the near
  future
- Both the MoE and the MoH include CE programmes, as part of Disability Support Services Child Development Services (MoH), or as part of a network of early intervention and school aged special education services which aligns to the NZ national curriculum "Te Whaariki" (MoE)
- Both the MoH and the MoE consider CE as no better or worse than other programmes
- CE includes components of best practice paediatric rehabilitation interventions provided by NZ registered professionals

After consideration by the PGAG and endorsement by the Clinical Governance Committee\* the recommendation for Conductive Education Programmes in children with Cerebral Palsy is to:

# Purchase on a case by case basis

Considerations for case-by-case may include:

- Was the child receiving conductive education services prior to becoming an ACC client?
- Availability of conductive education services in the child's area
- Does the proposed provider have a Child Development Services contract with the MOH?
- Is the proposed provider a registered early education centre or kindergarten?

<sup>\*</sup> This was determined as a pragmatic for a low risk area and endorsed by the CGC on the 26 October 2016

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# 8 Appendices

# 8.1 Appendix 1: Lists of CE Centres and trusts in New Zealand<sup>vii</sup>

The centres and trusts listed below were those easily found on the internet. Conductive education programmes or trusts that are not listed on the internet will not be on this list.

# 8.1.1 Centres

- Naenae Primary School, Lower Hutt
- Conductive Education Waikato, Hamilton
- GlowKids, Auckland
- Addington School of Conductive Education, Christchurch
- Conductive Education Canterbury
- Cashmere Conductive Education, Cashmere High School, Christchurch
- Woodstock Conductive Education, Woodstock School, Hamilton

# 8.1.2 Trusts

- Conductive Education Taranaki Trust,

- Conductive Education Wellington Trust
- Adult Conductive Education Trust,
- Integrated Neurological Rehabilitation Foundation

ACC Research: Evidence-Based Healthcare Evidence Update

http://www.conductive-education.org.nz/CEAnnualReport2016.pdf

# 8.2 Appendix 2: Mapping of reviews, systematic reviews and included primary studies

Appendix 2: Mappi			<u>, , , , , , , , , , , , , , , , , , , </u>		ondary			_		
			_		y					
	Zhang et al, 2003 (ACC Report)*	a ∑a	Tuersley-Dixon et al, 2010 (critical narrative)	Siddowson, 2016 (University of Auckland Report)	Antilla et al, 2008	Novak et al, 2013	t al,	Ludwig et al, 2000	Miles Morgan Carson St School Evaluation, 2010	This report (Barry, 2016)
	hang et a :003 (ACC Report)*	Franki et al, 2012 (SR)	uersley-Dixe et al, 2010 (critical narrative)	Siddowson, 2016 University or Auckland Report)	a et 008	k et	Darrah et al, 2004	g et	files Morgal Carson St School Evaluation, 2010	This report Barry, 2016
	nang 303 Rep	ank 012	t al, (cri	ddo 20 nive Auch	utiii SC	oval 20	arra 20	dwi 20	es l' sars Set Set valu	his arry
	72 27	고 2	Tue e	Si (U)	₹	ž	Ď	Lu	.≝O ⊕	_ (B <sub>0</sub>
Primary Study										
Coleman et al, 1995	•	•	•				•	•	•	
Catanese et al, 1995 Hurr et al, 1997		•	•				•	•		
Reddihough et al, 1998	•	•	•				•	•		
Bairstow et al, 1992	•		•					•	•	
Cottam et al, 1985	•									
Hur et al, 1995	•						•			
Heal, 1974	•	•								
Stiller et al, 2003 Wright et al, 2005		•	•	•					•	
Odman and Oberg, 2005		•	•	•						
Odman and Oberg, 2006		•	•							
Odman and Oberg, 2009		•	-							
Woolfson, 1999a		•								
Woolfson, 1999b		•								
Blank et al, 2008			•	•						•
Liberty, 2004			•	•						•
Lind, 2003 Parkes et al, 2002			•							
Sutton, 2002			•							
Robinson et al, 1989			•							
Swain and Walker, 2003			•							
Wilson, 2001			•							
Lambert, 2004				•					•	
Heal 1972a							•			
Heal 1972b							•			
Clarke, 1973 Cotton, 1974							•			
Titchener, 1983							•			
Shields, 1989							•		-	
Sigafoos, 1993							•	•		
Bochner, 1999							•	•	•	
Lind, 2000							•			
Dowrick, 1993									•	
Butler and Darrah, 2001									•	
Rosenbaum, 2003 Stukat, 1995									•	
Butler and Darrah, 2001									•	
Hill, 1990									•	
Morgan and Hogan, 2005									•	
Effgen and Chan 2010										•
Dalvand et al, 2009								L		•
Dougles Taylor 0007			Litera	ature reviews		ı				
Bourke-Taylor, 2007 Pedersen et al, 2000		•		•	•	-			•	
French and Nommensen,										
1992	•				•					
Ratliffe, and Sanekane,									•	
2009										
Antillo of all 2000			Syster	natic Reviews	8	1		ı		
Antilla et al, 2008 Tuersley-Dixon et al, 2010				•		•			•	
Novak et al, 2013										
Darrah et al, 2004	•		•	•	•	•			•	
Franki, 2012			-	-	-				-	•
Zhang et al, 2003 (ACC)*										•
			E	valuation						
Miles Morgan, Carson St				•						
School Evaluation, 2010			Health To	chnology Re	nort	l				
Ludwig et al, 2000			i icaitii Te	ciliology Re	•				•	
Lucing of al, 2000			<u> </u>			<u> </u>				

Systematic Rev	view				
Study	Methodology	Outcomes & results	Quality assessment		Reviewer comments and
					evidence level
Franki et al. (2012)  Journal of Rehabilitative Medicine, 44, pg 396 - 405  Study design: Systematic review  Objective: Provide an	Number of studies: n=58 articles met the inclusion  n = 10 of these were on CE, four of these were included in the 2003 EBH report.  Literature search: Web of Science, PubMed, Cochrane Library, PeDRO, CINAHL Time period: January 1995 – December 2009	Results reported only for Conductive Education  n = 10 of these were on CE, four of these were included in the 2003 EBH report.  - The six that were not included in the 2003 report were either published after 2003 or were excluded based on study design.  Included studies: Included in 2003 report:	Do most included studies use a control group AND random assignment?  Did most included studies use a control group OR a before and after measurement	N Y	CEBM critical appraisal tool:  Level A Study design: The study design of the systematic review is high quality, it is graded as the 'trustworthiness' of the study and its findings is high.  The main weakness is that it does not report the effect size reported within the studies.
overview of the effectiveness of conceptual approaches and additional	Assessment of methodological quality: Used the Conduct score system proposed by the American Academy for Cerebral Palsy and Developmental Medicine AACPDM (2008 version, see www.aacpdm.org) – grading	- Coleman et al, 1995 - Catanese et al, 1995 - Hurr et al, 1997 - Reddihough et al, 1998	Is it unlikely that important relevant studies were missed?	Y	Reviewer comments:
therapies used in lower limb physical therapy of children with CP and supports the development of clinical guidelines	similar to that used by the Centre for Evidence-Based Medicine (CEBM)  - Assessed by 3 independent evaluators, kappa coefficient was used to assess difference in scoring between evaluators.  - Level of evidence similar to SIGN grades where 1 or I is for RCTS or SRs and 5 or V is expert opinion.  Data extraction:	Not included within the 2003 report:  - Stiller et al, 2003  - Wright et al, 2005  - Odman and Oberg, 2005  - Odman and Oberg, 2009  - Woolfson, 1999a and 1999b  Main findings:  No Level II (Smaller RCTs, systematic reviews of cohort studies) evidence was found to	Was the process to select studies clearly defined and reproducible?  Was the process to extract data clearly defined and was the outcome presented in a table?	Y	Effect sizes were not reported. However the main findings are in agreement with previous CE reviews.
	<ul> <li>Articles were first screened by one author then run past two subsequent assessors</li> <li>Information on intervention, numbers of patients, topographic distribution of CP age of patients, type, frequency and</li> </ul>	support effectiveness of CE (from 2 RCTs).  Body function and structure: Effectiveness of CE only demonstrated with level IV (eg. case series, cohort without concurrent control groups, case control studies) evidence on language skills.	Was the methodological quality of each study assessed? How large was the	Y Not	

timing, results and conclusion.  Inclusion criteria:	Activity level: Effectiveness of CE only demonstrated with level IV evidence for gross motor skills and individual motor goals. Conflicting evidence for participation and	effect size?  How precise was the effects size?	Not reported
• English only studies  Exclusion criteria:	Author conclusions / review findings:  The number of studies was too small,		
<ul> <li>Non-systematic and general reviews</li> <li>Case-studies</li> <li>Expert opinions, editorials</li> <li>Postsurgical interventions</li> <li>Mixed interventions</li> </ul>	<ul> <li>and quality too low to make conclusions about the effectiveness or ineffectiveness of CE</li> <li>Effects of physiotherapy and CE are heterogeneous as CP population is heterogeneous making it difficult to</li> </ul>		
	conclude effects of CE.		

# 8.4 Appendix 4: Evidence Tables: Included Primary Studies

Evidence table 2	Evidence table 2. Primary Studies							
Study	Methodology	CE Intervention	Outcome measures	Quality assessmen	t	Conclusions		
Blank et al, 2008. Archives of Physical Medical rehabilitation, 89, pg 251 – 259.  Study design: Individual cohort	Number of participants: n=67 met screening criteria (out of 143 assessed), 3 were withdrawn so total of n = 64 included in analyses of these:	Intervention:  B-A-B design.  B-phases: 4.5 month period with conventional special education	Objective quantitative measurements Preferred and non-preferred hands separately. Each task repeated 3 times, mean reported -grip force on a small cylindrical 20g object	Were the criteria used to select subjects clearly defined?  Was the intervention (or exposure to a variable) independent of other	Y	Reviewer comments Study design potentially flawed. There was no comparison group and all children underwent BAB study design. So it is hard to discount follow-on effects of CE and SE, or if the effects of CE training are long lasting.		
study, B-A-B design – multiple case-control design  Research question: To study effects of	<ul> <li>n = 59 had bilateral spastic CP</li> <li>n = 3 hemi paretic</li> <li>n = 2 dyskinetic</li> <li>n = 3 cerebellar CP</li> <li>Children with CP, aged 3 – 6 years</li> </ul>	for 7hrs/day, had 2 individual therapy sessions of 30min per week consisting of physio, and an	-finger tap -hand tap -pinchgrip -drawing analysis system -3D ultrasound based movement analysis system	changes over time?  Did fewer than 20% of the subjects drop out?	Υ	Hard to determine how significant the measured improvements were in relation to improved function within the child, although the		

conductive education in children with CP on	were recruited over a 4 year period	additional OT programme	Measures of ADLs (in a subgroup of 33 children)	Were reliable and valid measurement methods used?	Y	improvements in hand function appear to be specifically found
their hand motor functions and activities of daily living	Inclusion criteria: Determined on examination by	(60min/wk) tailored for each child	Independent research blind to	How large was the effect size?	Small to medium	after the CE phases of the study.
	child neurologist:		treatment period assessed			CEBM critical appraisal tool:
Funding:	A well-defined type of CP	A-phases: 9	patients' measurements.			
Supported by the	(spastic, dyskinetic, or	month. Children		How precise was the	No Cls	Level C: which is graded as 'a not
association of the	ataxic)	participated in 3 4-	Findings:	effect size		very appropriate design to
German Health	Gross Motor Function	week inpatient	Relatively best hand			measure an effect, impact or
Insurances for	Classification system score of	blocks of CE.	improvements were among			causal relation'
Employees and Workers	II (n = 16),	During intervening 3 months children	children at Level III for both			The 'trustworthiness' is limited
workers	III (n = 38) and	continued	hands			based on study design. The main
	IV (n = 10)	individual	Elementary motor functions (ie.			limitations of the study are that
	<ul> <li>Intelligence level of at least</li> <li>60 on the Kaufman</li> </ul>	programs at	Grip strength) did not change.			the effects of the CE programme
	Assessment Battery for	individual schools	drip strength) did not change.			may not be independent of other
	children (K-ABC): Mean for	at home.	ADLs: CE improved ADL			changes (eg natural
	included group: 86±13	de nome.	competence (mean of 20%), no			development of the child) and
	No severe behavioural	Measures taken at	improvement with SE alone			that it is hard to determine how
	disorders that would		proveemen.emen.e			significant to every day function.
	interfere with group sessions	-start, and end of	Parents describe improvements			
	No other neurologic	phase A, and End	with manipulative skills			However it does appear to be
	disorders	of Phase B2k	·			better than special education
	No neurodegenerative		No consistent significant			alone.
	disease	CE program	interdependencies between a			
	<ul> <li>Caregivers willing to give</li> </ul>	Standing and	child's age, severity baseline			
	informed consent for	walking 14.9%	measurement at the beginning			
	participation	Hand 16.8%	of the study, parental education			
	p an overposition.	Cognitive program	and therapeutic effects.			
	Exclusions:	6.9%				
	Not meeting criteria?	Movement	Effects on Hand functions			
	G	program: 22.1%	-improvement in coordination			
	Analyses:	Individual	hand functions (up to 25%			
	Results from the two 'B' phases	program: 39.3%	compared to baseline) with			
	were averaged to take into		preferred hands compared to no			
	account any improvements that	Motor parts of	improvement with special			
	would normally come about due	program 52.6% of	education alone			
	to age.	time and 28.8% to	Augh an agus live!			
		ADLs, 18.6% to	Author conclusions			

cognitive	In children with spastic types of	
education	CP, intensive CE delivered in 3 –	
	4 week blocks within 9 months	
	of conventional treatment and	
	special education improved co-	
	coordinative hand functions to a	
	greater extent than special	
	education with conventional	
	treatment alone.	

Evidence table 2	. Primary Studies					
Study	Methodology	<b>CE Intervention</b>	Outcome measures	Quality assessmen	t	Conclusions
Dalvand et al, 2009.	Number of participants:	Intervention:	Objective quantitative	Were criteria used to		Reviewer comments
Hong Kong Journal of	N = 45 recruited over a 4 year	Children took part	measurements	select subjects clearly	Υ	This was a comparison of three
Occupational	period in Iran	in one of the three	CDER: Assessment of 16 ADLs	defined?		techniques that aim to promote
Therapy, 19 (1), pg 14		techniques	before and after intervention .	Was the intervention		independence in ADLs in children
- 19.	N = 15 in each experimental	(Bobath, CE or	Scoring performed according to	independent of other	N	with CP.
	group:	education to	instruction manual, unclear who	changes over time?	'	
Study design:		parents) for 3	investigator was that			No indications of long term
Quasi-experimental	- CE	months four	administered the assessments	Did fewer than 20%	Υ	changes that may arise from CE,
clinical trial with	- Bobath and	sessions per week		drop out?		and no calculations of variability
pre/post design	<ul> <li>education to parents</li> </ul>	that were 3 hours	Findings:			between subjects/within groups.
		long.	Significantly different increases	Were reliable and	.,	
Research question:	Participants were matched		in general CDER score,	valid measurements used?	Υ	Small sample sizes for each of
To compare the effect	according to sex, age and IQ as	Measures taken at	calculated with Kruskal Wallis	useur		the three groups.
of the Bobath	measured by the Goodenough	Before and after	test across all groups. CE	How large was the	Not	
technique, conductive	test. There were no significant	the interventions	appeared to have the biggest	effect size?	reported	CEBM critical appraisal tool:
education (CE) and	differences in these measures at		change.			
education to parents	baseline			How precise	N/A	Level C – not at an appropriate
in activities of daily			Specific ADL subskills showing			level to measure an effect,
living (ADLs) in	Inclusion criteria:		significant change:			impact or causal relation based
children with cerebral	Children with CP diagnosed by a		Household chores, eating,			on study design.
palsy aged 4 – 8 years	child neurologist, aged 4 - 8 years,		toileting, level of bowel control,			
in Iran	normal IQ		personal hygiene, bathing,			Although changes in means are
			dressing, movement in a familiar			reported and the Kruskal-Wallis
Funding:	Exclusions:		setting, community			is used for calculating
None disclosed	Not meeting criteria? Unclear		transportation, money handling,			significance no effect sizes were
			ordering food in public			reported.

Analyses: Client Development Evaluation Report (CDER) used to evaluate	Effects on Hand functions	"Trustworthiness" of study is limited
ADLs for participants.	Author conclusions In children with spastic types of CP, intensive CE delivered in 3 – 4 week blocks within 9 months of conventional treatment and special education improved co- coordinative hand functions to a greater extent than special education with conventional treatment alone.	
	All three approaches resulted in significant improvement in ADL performance after interventions. The CE group performed sub-skills better than other groups (no statistical significance seen at baseline)	

Evidence table 2. Primary Studies								
Study	Methodology	CE Intervention	Outcome measures	Quality assessmen	t	Conclusions		
Effgen et al, 2010	Number of participants:	Intervention:	Objective quantitative	Was the sample		Reviewer comments		
Physiotherapy Theory	N = 9 children aged from 42 – 72	Program provided	measurements	randomly selected?	Unclear	Small sample size patient		
and Practice 26(1), pg 22 - 39.	months and diagnosed with CP  Average GMCSS score was Level	by staff of teachers, OTs, PTs, and SLTs	Four gross motor objectives around Mobility, stability and transfer activities that were	Was the sample size large enough?	N	selection unclear, exploratory study only		
Study design: Case series of 9 children, described as	III (walks with assistive devices; limitation walking outdoors and in the community). Measure by	supported by parents, no 'conductors' were	integrated throughout the day into the child's activities. Kappa statistics were used to	Is it likely data dredging took place?	N	No indications of long term changes that may arise from CE.  No comparison groups – how do		
a systematic observational study and exploratory study	experience  N = 6 had spastic diplegia	used although the programme was closely modelled	determine differences between raters.	Are reliable and valid measurement methods used?	Υ	we know what changes are due to CE and what ones are not?		
Research question: To study the	N = 2 had spastic quadriplegia N = 1 had ataxia	on the Peto Institute's CE principles.	These differed between children and were measured differently for each individual child and	How large was the effect size?	Not calculated	No standardised comprehensive pre and post intervention assess were done		

frequency of			their capabilities	
occurrence/practice of	Inclusion criteria:	Children	and supulmines	Study attempted to capture
gross motor	- Preschool children, all were	participated in a	Findings:	activity related behaviour
behaviours in a CE	learning to walk	full day CE 5 days a	Overall by the end of the first	changes that arose from CE
preschool program		week for 11	term (October to January) 83%	program activities
and the attainment of		months each year,	of individual gross motor	, , ,
individualised gross	Exclusions:	each classroom	objectives had been achieved.	CEBM critical appraisal tool:
motor objectives in	Not mentioned	had 6 students.	94% by July.	1
preschoolers with CP		The CE curriculum		Grade D-: The 'trustworthiness'
'		was tailored to the	Other child related objectives:	of the study is very low based on
Funding:		needs of the	72% by May, and 89% by July.	study design. And control group
Authors stated no		participant		, , ,
conflicts of interest to			<b>S</b> ome increases were seen in	This means that although there
disclose		Measures taken:	incidences of transfers and	is a 55% chance the measured
		Experienced PT not	mobility (eg assisted walking	effects are from the CE
		involved in CE	intervals)	intervention there were not
		treatment 4 times		enough controls in place to
		a year	Author conclusions	discount other possible
			Children did not achieve	influences thus it is more open
			objectives that were not	to bias.
			practiced, suggesting a	
			relationship between practice,	Although there were some
			achievement and gross motor	statistically significant changes
			objectives. Evidence suggests CE	found for some measures no
			programs may provide	effect sizes were calculated.
			opportunities to practice gross	
			motor skills to achieve gross	
			motor objectives. More	
			research is needed	

Evidence table 2. Primary Studies							
Study	Methodology	<b>CE Intervention</b>	Outcome measures	Quality assessment	t	Conclusions	
Liberty et al, 2004	Number of participants:	Intervention:	Objective quantitative	Was criteria used to		Reviewer comments	
International Journal	N = 29 children (n = 10 girls, and n	Programme of	measurements	select subjects clearly	Υ	No control group, small sample	
of Rehabilitation	= 19 boys)	systematic task	Uniform Performance	defined?		sizes. The authors were	
Research 27(1), pg 17		routines	Assessment System (UPAS) an	Mas the intervention		transparent with their included	
- 25.	Aged 16 – 95 months with motor	incorporating	objective standardised measure	Was the intervention independent of other U	Unclear	groups and reported the raw	
	disorders. 23 attended NZCE , 6	functional skill	of development over a range of	changes over time?		scores before and after the	

Study design: Case- series / qualitative study  Research question: To investigate an early intervention programme in New Zealand based on the	did not.  N = 26 of the 29 had cerebral palsy, 17 of these had spastic quadriplegia, 4 had other types of quadriplegia, 3 had hemiplegia, one had diplegia, 1 had an unspecified form of CP. 3 others had motor disorders.	training.  Parents individually guided children through each routine each session under supervision of a conductor.	skills. Designed to measure children's progress up to age six.  Findings: Overall 23 children attending NZCE gained skills. 19 increased their score by more than the 11 points.	Did fewer than 20% of subjects drop out?  Were reliable and valid measurement methods used?  How large was the effect size?	Y Y Medium	intervention for each individual child. Although there was individual variability within these groups and no group variability was measured.  No effect size was found for intensity of the program
principles of CE by measuring the functional skills of young children with CP in natural contexts over a 12-month period.  Funding: University of Canterbury and NZ Education and Health Boards	N = 5 children had epilepsy and had medication for it, 6 had vision problems, one child was deafblind.	Sessions were 3 hours in duration with 5 – 10 children in each session, 1 – 5 times a week. Families had information and guidelines for carrying out similar routines at home. Averaged by 7.4hrs per week.  CE equipment constructed locally  Measures taken: UPAS administered pre-test and after 12 months, administered at child's home or Early childhood centre	Significant gains were seen across all the CP groups.  Individual raw scores of each child were included, and although significant differences were calculated after the intervention for each group (based on impairment level) of CP children there was individual variability within these groups and no group variability was measured.  Author conclusions CE may benefit young children with motor dysfunction as well as concomitant disorders and severe developmental delay.  Gains were not related to intensity, age or a product of maturation but maybe to change patterns of maternal/child interactions.	How precise?	No CI s included	CEBM critical appraisal tool:  Level C (non-controlled before/after study): 70% = not a very appropriate level to measure an effect impact or causal relation based on study design  Possible underlying reasons were that the intervention or exposure was not independent of other changes  The effect size is medium and the precision (in the form of confidence intervals) is not reported

# 8.5 Appendix 5: Studies excluded from Critical Appraisal - Reviews of Systematic Reviews

Review of Systematic Reviews				
Study	Methodology	Outcomes & results	Quality assessment	Reviewer comments and evidence level
Anttila et al. (2008)	Number of studies: N = 21 Systematic Reviews,	Results reported only for Conductive Education	Clearly defined research question	Reviewer comments:
American Journal of Physical Medicine and	Of these n = 4 were completed on Conductive education	The four reviews included were:  Darrah et al, 2003	Two people selected studies and extracted data	The findings of this review are similar to that found by the 2003 review produced by ACC. This is that the number and quality of
Rehabilitation 87	Comprehensive literature search:	Ludwig et al, 2000 Pedersen 2000	Comprehensive literature search	studies is too low make a conclusive statement about the
<b>Study design:</b> Review of	Medline, CINAHL, the Cochrane Database of Systematic Reviews, Database of	French and Nommensen, 1992	carried out	effectiveness of CE.
systematic reviews	Abstracts of Reviews of Effects, American College of Physicians Journal Club, Health	Of these reviews only Pedersen 2000 was not included in the original EBH report.	Authors clearly state how limited review by publication type	Not included in final report as it is a review of reviews that
Objective: To evaluate the methodological validity of SRs and their clinical	<ul> <li>Technology Assessment database and the Physiotherapy Evidence Database.</li> <li>Time period: from earliest time available to August 2007</li> </ul>	Overall these reviews covered 1 RCT and 21 observational studies, 7 of the observational studies were included in more than one review.	Included and excluded studies listed	contained articles already revised in the ACC 2003 report
usefulness when targeting a heterogeneous	Assessment of methodological quality: Assessed using a modified version of a method described and validated by Oxman et al, 1991.	Pedersen et al 2000 was not included in the ACC 2003 report as the search strategy and	Characteristics of included studies are provided	
population and looking at variable applied	J. Clinical Epidemiology 44, pg 1271 – 8 and Clinical Epidemiology 44, pg 91 - 8.	whether critical appraisal was completed is not clear.	Scientific quality of included studies assessed and	
interventions such as PT and CE in children with CP	Studies were independently screened by two reviewers	Author conclusions:	documented	
chiluren with CP	Data extraction:  One of two reviewers extracted the data.	The number of studies was too small, and quality too low to make conclusions about the effectiveness or ineffectiveness of CE	Scientific quality of included studies assessed appropriately	
	Inclusion criteria:  • Systematic reviews  Exclusion criteria:	<ul> <li>Effects of physiotherapy and CE are heterogeneous as CP population is heterogeneous making it difficult to conclude effects of CE.</li> </ul>	Appropriate methods used to combine individual study	

- Inter - Not : - No r	a systematic review rvention criteria not fulfilled a CP population esults reported guage	findings  Likelihood of publication bias assessed	
		Conflicts of interest declared	
		Are results of study directly applicable to patient group targeted by guideline?	

Review of Systematic Reviews				
Study	Methodology	Outcomes & results	Quality assessment	Reviewer comments and evidence level
Novak et al. (2013)	Number of studies:	Results reported only for Conductive	Clearly defined	SIGN evidence level: 1-
Developmental Medicine and Child Neurology, 55, pg	n=166 articles met the inclusion  n = 2 of the Systematic Reviews found were on Conductive Education	The two reviews included were:	research question  Two people selected studies and extracted data	Reviewer comments: The findings of this review are similar to that found by the 2003
885 - 910 <b>Study design:</b>	Comprehensive literature search:	Darrah et al, 2004 Tuersley-Dixon et al, 2010	Comprehensive literature search	review produced by ACC. This is that the number and quality of studies is too low make a
Systematic review of systematic reviews	<ul> <li>CINAHL, Cochrane Database of SRs,         Database of Reviews of Effectiveness,         EMBASE, ERIC, GoogleScholar, MEDLINE,         OTSeeker, PEDro, PsychBITE, PubMED,     </li> </ul>	Overall the reviews included 1 RCT and 21 observational studies, 7 of the observational studies were included in more than one	carried out  Authors clearly state how limited review by	conclusive statement about the effectiveness of CE.  Not included because Darrah
<b>Objective:</b> To describe systemically the	SpeechBITE  Time period: up to December 2012	review.	Included and excluded studies	et al, 2004 included in original report and Tuersley-Dixon et al, 2010 although described
best available evidence for CP interventions using the GRADE system to complement	Assessment of methodological quality: Graded using the Oxford Levels of Evidence that uses GRADE, a colour coding scheme (green, yellow and red with a traffic light system and a determination of the quality of	Author conclusions:     Both reviews showed conflicting evidence. This has led to the majority of studies showing no difference of CE to any treatment.	listed  Characteristics of included studies are provided	as a SR does not fit the criteria for an SR as it did not grade papers / critically appraise articles using a

these findings with the Evidence Alert Traffic Light System in order to provide knowledge translation guidance to clinicians about what to do.	evidence and strength of recommendation. An Intervention outcome (ICF level) was also given  Data extraction:  Two independent raters extracted the data.  Inclusion criteria:  Published studies about intervention for children with CP: SRs, provision of intervention by health professional, human participants, more than 25% with CP,  Exclusion criteria:	This evidence was given a Yellow actions as the quality of evidence was low and strength of recommendation weak	Scientific quality of included studies assessed and documented  Scientific quality of included studies assessed appropriately  Appropriate methods used to combine individual study findings	standardised methodology.
	- Diagnostic reviews, prognostic studies, interventions aimed at preventing CP - Provided low levels of evidence (unless there was no available SR - Adult participants, although if predominantly studied children was included - Reviewed disciplines rather than individual interventions - A secondary study with already published results - Unpublished or not peer-reviewed		Likelihood of publication bias assessed  Conflicts of interest declared  Are results of study directly applicable to patient group targeted by guideline?	

# 8.6 Appendix 6: Evidence Tables – Excluded Systematic Review

Systematic Review					
Study	Methodology	Outcomes & results	Quality assessment	t	Reviewer comments and
					evidence level
Tuersley-Dixon et	Number of studies:		Clearly defined	Υ	SIGN evidence level:
al. (2010)	n=16 articles met the inclusion	A 'quasi-experimental' design was used in n =	research question		
		7 studies.			Not graded as it does not fit pre-
Educational	n = 6 of these were included in the 2003 EBH		Two people selected	γ	set criteria for a systematic
psychology in	review	Authors noted the complexities in comparing	studies and extracted	'	review as no grading was done

		,		,	
practice, 26, pg	the other 10 studies. Some were not	children with CP between different groups as	data		
353 - 373	experimental studies thus would have not been	the nature and severity of the levels of	Comprehensive		Reviewer comments:
	included in the 2003 report, the others were	disability of individuals with CP is variable.	Comprehensive literature search	Υ	Methodology of this review is not
Study design:	published after August 2003.		carried out		clear. Unclear whether it is a
Systematic review		Comparison also difficult as the intensity of	carried out		systematic review even though it
	Literature search:	CE and the alternative treatment was often	Authors clearly state	Υ	has been identified as one by
Objective:	PsycINFO and Medline databases	different. This means that improvements	how limited review by		Novak et al, 2013. No clear
To review the	Time period: from earliest time available	seen from either programme could be due to	publication type		grading or assessment of critical
empirical research	to August 2007	intensity rather than the programme itself.			appraisal however comments are
to investigate the			Included and	١	made about the quality of
specific claims that	Assessment of methodological quality:	Also CE programmes vary in content between	excluded studies listed	N	evidence and experimental
CE improves motor	Not reported	countries limiting ability to produce	listed		design that is used.
skills, thinking skills		conclusive findings.	Characteristics of		
and independence	Data extraction:		included studies are	Υ	Article appears to be more of a
and the counter	Not reported	Overall the reviews included 1 RCT and 21	provided		literature review that critiques
claim that it may		observational studies, 7 of the observational			the study methodologies rather
cause harm.	Inclusion criteria:	studies were included in more than one	Scientific quality of	Υ	than systematic review that
	Studies on CE in CP children	review.	included studies		critically appraises primary
			assessed and documented		studies using standardised
	Exclusion criteria:		documented		measures
	Not reported	Author conclusions:	Scientific quality of	γ	
		The number of studies was too small,	included studies	ľ	
		and quality too low to make conclusions	assessed		
		about the effectiveness or	appropriately		
		ineffectiveness of CE			
		Effects of physiotherapy and CE are	Appropriate methods	Υ	
		heterogeneous as CP population is	used to combine individual study		
		heterogeneous making it difficult to	findings		
		conclude effects of CE.	illianigs		
			Likelihood of	N	
			publication bias		
			assessed		
			Conflicts of interest		
			declared		
			Are results of study	l	
			directly applicable to	Υ	
			patient group		
			targeted by		
			guideline?		

# 8.7 Appendix 7. Grey literature summaries

# 8.7.1 Carson Street Evaluation overview

This evaluation has been included within this report as an add-on the critically appraised literature component. As it has not undergone the processes required of publication within a peer-reviewed journal it does not fit the criteria for critical appraisal, however as it is directly related to the report and has been referred to within documentation used by other government agencies (the AUT Stock take report produced for the Ministry of Health) it will be outlined below. It is categorised as grey literature.

#### Overview

This evaluation consisted of four parts:

- A literature review:
- consultation with key stakeholders, including parents;
- observation in early intervention and primary school classes; and
- collection and analysis of data on costs and student outcomes.

# Objective of Evaluation

To focus on the features, processes and cost effectiveness of the early intervention trial (2007 - 2009) and provide recommendations for ongoing program design and delivery to meet the educational needs of students in the early vears with CP and other motor disorders.

#### Literature review:

#### ACC Reviewer comment on methodology of review:

Search strategy and terms not clear, and this was not a critical appraisal of the literature. It is a description of both academic and grey literature from government and non-government agencies up to 2010 and has been commissioned by the Western Australia Department of Education to Miles Morgan Australia Pty Ltd an external provider that provides research, policy an evaluation services. Included literature appears to be a mixture of systematic reviews, literature reviews, primary studies, conference proceedings and book chapters. No critical appraisal has been done.

# CE at Carson St School

CE program has expanded its early intervention focus to become a program that offers ongoing CE programs for kindergarten, pre-primary aged children with severe motor disabilities. They have a transdisciplinary team comprising of a teacher conductor, education assistants and a speech pathologist. They also offer Conductive Education classes for school-aged students with severe motor disabilities and provide services from primary aged students (up to Year 4). The classes for older students are much more varied than the ones for kindergarten aged children. The focus of this report was on the early intervention program for pre-primary / kindergarten children.

# Findings:

Due to the variation in delivery of CE programs, how it is delivered in different ways and in different contexts makes it difficult to form a single statement with regards to how effective it is. This is due to the inconsistency in data as the CE program and how it itself has been measured, and makes it difficult to determine whether it is or is not any more beneficial than other therapy techniques for children with CP. There is variety in settings, staffing, age and nature of students, professional roles, funding mechanisms and the program's relationship to the educational curriculum – this makes it difficult to ascertain specific criteria defining CE as a programme.

Ratliffe and Sanekane (2009) a literature review that included single case examples describe three models of CE (original source: Wagner, 1994):

- Pure model: programs delivered at the Peto Institute in Budapest.

- Adaptive model: programs delivered following model used at institute but without trainee conductors in team, and integrates local cultural traditions and values
- Alternative model: Characterised by groups and centres. Run by teachers or therapists that do not have formal qualifications in CE and don't necessarily adhere to Peto techniques. This has been predominant in Australia.

#### Conclusions:

Literature review and evaluation do not provide sufficient evidence to suggest that CE should be the only model provided for young children with cerebral palsy and other related motor disorders.

Evaluation found evidence of student's making satisfactory progress, high levels of parental satisfaction, improved levels of parental coping, strong teach confidence in participant outcomes.

However although highly regarded by the participants – "It was not possible to know which gains should be attributed to CE as a teaching practice and which could be attribute to other factors which might reasonably be expected from any effective intervention of comparable intensity and quality".

#### Stakeholder consultation:

N = 18 parents involved

Of these, n = 5 participated in one-on-one semi-structured interviews, and n = 13 attended a 3-hour forum. Overwhelming response from parents was positive on the following outcomes:

- improved mental and physical health for themselves and child;
- improved communication
- opportunity for child to socialise
- enhanced motor skills, and
- behavioural changes

Carson St staff: Including the principals, registrar, Program Co-ordinator

# 8.7.2 Auckland Uniservices Stocktake

# Aims:

- 3. To create a baseline of quality and diversity of CDS and CE provision with which the Ministry can measure future progress
- 4. Develop a self-assessment and reporting instrument in collaboration with the Ministry, CDS/CE providers and service user groups to extend this baseline and assess progress towards improving outcomes for children

# **Research questions:**

- 1. How do service quality and delivery models compare to current international best practice in child development services?
- 2. How does the current political/social environment impact on services?
- 3. What services are being delivered?
- 4. What are the unmet needs and service gaps?

A mixed-methods approach was adopted incorporating survey and case study methodologies. These included document analysis, an online survey and interviews (face-to-face, or telephone with key stakeholders). Semi-structure interviews with Key stakeholders (case-studies) took place in Auckland, Canterbury-West Coast and Northland. N = 77 interviews with 137 individuals.

Interview asked about: types of clients, barriers and facilitators, parents asked to describe their experiences.

# **Information regarding Conductive Education**

#### Outcome of Literature review

Review referenced the Carson St Evaluation. Main outcome was: "Despite the rapid growth of CE worldwide and perceived benefits, the research literature highlights the need for good quality evidence-based research on the effectiveness of practice and outcomes.

No clear outline of search strategy for the literature review, and almost all primary studies pre-2004 are included within the ACC Evidence based review. Primary studies published after these have been included within this evidence-based analysis either as part of the Franki SR or as primary research if not covered in the systematic review. Carson St Evaluation referenced frequently and presentation slides also included so information in review is not limited to peer-reviewed literature.

Regarding CE: studies that investigate the effectiveness of CE are largely small scale (small numbers of participants with variable function) with indicative results only.

Included References: Anttila, 2008; Blank et al, 2008; Bourke-Taylor et al, 2007; Darrah et al, 2003; Lambert, 2004; Liberty, 2004; Miles Morgan Australia, Pty ltd, 2010; Odman and Oberg, 2005; Stiller et al, 2003; Sutton, 2006; Tuersley-Dixon and Fredrickson, 2010; Wright et al, 2004.

# Survey results

N = 4 for CE

Results for CE services were not reported separately from Child development services. With the now N's being included with n = 29 for CDS services we do not know whether the CE service results are in agreement with CDS. No clear justification for grouping both together, or whether there were differences between the groups.

# **Overall conclusions**

CE underpinned by same principles of good practice identified in other models of care for integrated service provision. As with other models there is a lack of recent good quality evidence-based research on its effectiveness.

International literature identifies family-centred working as a best practice particularly in relation to early intervention, similar to that described by the CDS and CE services included within this stocktake.

The stocktake appears to be an analysis of the process and operations around CDS and CE services rather than how effective the programmes are for the child's development against other services. There is no comparison to non-CDS/CE services.

# 8.8 Appendix 8: Guideline search

Guideline	Methodology	Recommendation for how CE could be used
Cerebral Palsy Clinical Practice Guideline (CP-CPG).	A variety of clinical practice guidelines, consensus statements and evidence-	Page 48.  3.1 Musculoskeletal – lower limb therapy GMFCS I –  III. 0 – 5 Years
Waikids; Waikato Child and Youth Health. Waikato District Health Board, Child Development Centre Therapy team.  www.waikatodhb.health.nz/assets/forhealth-professionals/Primary · PDF file	based practice were reviewed. When these weren't available, expert opinion and professional consensus were included.  Detailed structure of methodology unclear regarding conductive education.	Page 52. 3.2 Musculoskeletal – lower limb therapy GMFCS IV – V, 0 – 5 Years Listed as an intervention  Pg 66 4.2 Upper limb intervention – therapy MACS III – V, 0 – 5 years Listed as an intervention  Pg 105 6.3 Communication – expressive language Listed as an option for children to refer to
		8.0 Community access; 0 – 5 years Listed as an accessible option for children to be referred to by the CDC therapist

**NICE guidelines and HTA documents:** No results found. A recent draft guideline regarding cerebral palsy is currently undergoing consultation by NICE. It covers the diagnosis, assessment and management of CP in children and young people from birth up to their 25<sup>th</sup> birthday. Different aspects of care are covered within the draft guideline however conductive education was is not mentioned as a specific programme of management within this guideline.

The guideline can be found at:

https://www.nice.org.uk/guidance/GID-CGWAVE0687/documents/draft-guideline-3

Cigna or Aetna: No results found

National Guideline Clearinghouse: No results found

NHMRC (Australia): No results found

# 8.9 Appendix 9: External peer review – interpretation

"The core conclusions, that CE is insufficiently supported by research evidence because of the negative findings of higher quality studies; the limited number of high quality studies, and the wide variation in the description of CE are well supported by the research evidence presented here. The consistency of finding of this and the previous ACC report, and the high quality published systematic reviews add weight to these conclusions. However, based on my wider clinical and research expertise, I would add a number of caveats to these conclusions in order to add context to them.

First, while the evidence for CE is negative or untrustworthy in these studies, several of the studies describe components of best practice paediatric rehabilitation (or therapy), namely, child/parent education and tailored, context and task specific intervention as part of CE. This observation was also made by Liberty. This description reflects what would be expected of any evidence-based rehabilitation service and are key components described in several (but not all) studies of CE in this review. I suggest that the studies on the effect of CE are interpreted in this context. The greatest barrier in advancing research into CE is the absence of a clear description of it.

Second, children enrolled in CE tend to have high levels of physical impairment, therefore comparison to other services or interventions should be comparing this subset of the population of children with CP across services/interventions.

Third, the criticism that there was limited generalisation in the CE studies is also generally true of most interventions for most children with a wide variety of impairments to body structures and body functions. For moderate to severely physically disabled children one would only expect to see task specific improvement with very limited generalisation. Aside from Botox treatment, and constraint induced movement therapy (CIMT), I am not aware of any intervention that produces generalizable change for children with, for example, high muscle tone. Both Botox and CIMT have other limitations such as short duration (Botox) and high parental demand (CIMT) therefore these are not directly comparable to CE in what they offer children or families. If lack of generalisation were a reason to not fund CE then this is equally true of any other intervention for this population I can think of.

Similarly a criticism of a lack of follow up was made. I am not aware of any longitudinal study that evaluated the long term effects of a specific rehabilitation intervention (several have evaluated the long term trajectory of children with disabilities, but not intervention

specific). Given the relatively small size of the populations of significantly physically disabled children that tend to access CE (Widdowson) and the wide range of influences on their long term outcomes, this sort of study is difficult to envisage happening. To not fund any intervention on the basis of the absence of this information is ethically questionable for a population that the information cannot be obtained for. As for the point above, the same criticism could be made of any intervention provided to the population that access CE.

Fifth, generally interventions for children with cerebral palsy at best, lead to gains in what is trained, (i.e., improvement in the ability that was practiced during intervention) with very limited evidence, that I am aware of, of cross over between improvement in impaired body structures and body functions (such as muscle strength) and reduced restrictions in activities or role participation (Novak, 2014). Therefore the conclusion of this review that the lack of change in non-practiced tasks, is equally true of any paediatric rehabilitation intervention. This finding from Novak's mapping of outcomes for children with CP against the ICF domains highlights the importance of clarity about which domain (body structure/ function; activities or participation) we (the funder, interventionist, researcher or family) wish to see change in, and that intervention should focus directly on addressing that domain. Like most interventions for children with CP, CE research has tended to target Impairments in motor functions, and discrete Activities rather than enhanced Participation in valued life roles, despite the dominant interest of consumers and families in the long term, being maximal participation in valued life roles.

Finally, the intensity of CE reported in these studies is very high and sustained compared to other paediatric rehabilitation interventions (although normal compared to education).

Therefore, if significant gains (evident in high quality studies) are not evident with this level of intensity then its effectiveness should be seriously questioned. The level of intensity of CE is also a reason to caution its comparison to other therapy options applied at much lower intensity"