

# A SYSTEMATIC REVIEW OF PARENT-MEDIATED INTERVENTIONS FOR CHILDREN WITH DOWN SYNDROME AGED 0-6



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*Experience, Research & Practice,  
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# WHAT IS A COCHRANE REVIEW?



*“Cochrane Reviews are systematic reviews of primary research in human health care and health policy, and are **internationally recognized as the highest standard in evidence-based health care resources**”*

*(Cochrane.org, 2018)*

## **Cochrane Reviews in SLT:**

- Speech and language therapy interventions for children with primary speech & language delay or disorder
- Speech and language therapy to improve communication skills of children with Cerebral Palsy
- Speech therapy for children with dysarthria acquired before 3 years of age
- Non speech oral motor treatment for children with developmental speech sound disorders

# CURRENT REVIEW: BACKGROUND & MOTIVATION

- Language development is a particular area of weakness for young children with Down syndrome
- Importance of responsivity & language input for children with language disorder including Down syndrome
- Intervention involves considerable commitment from clinicians and families so we need to synthesise evidence of the effectiveness
- ‘Cascading Model’ (Roberts et al, 2014)

Effective training,  
coaching &  
support from  
clinician

Implemented with a  
high level of accuracy,  
consistency &  
frequency by the  
parents

Improvements in  
child language  
outcomes



WHAT DO WE  
MEAN BY PARENT  
MEDIATED  
INTERVENTIONS?



Intervention	Target Population	Basic Goals	Interventionist	Procedures
<p><b>The Hanen Programme for Parents ('It Takes Two To Talk'):</b> <i>Girolametto &amp; Weitzman</i></p>	<p>Preschoolers with language disorders (+/- ID); +/- intentional communication &amp; motivated parents with childcare &amp; transport</p>	<p>Increase frequency &amp; complexity of parent-child interactions &amp; intentional communication nonverbally &amp; verbally</p>	<p>Parent (trained in <b>groups &amp; individually</b> by SLT)</p>	<p>Follow child's lead; arrange for high frequency of communication but wait for the child to respond; model targets &amp; recast attempts</p>
<p><b>Responsivity Education/ Prelinguistic Milieu Teaching (RE/PMT):</b> <i>Fey, Warren &amp; Yoder</i></p>	<p>Preschoolers with language disorders (+/- ID/ASD); + intentional communication &amp; &lt; 5 spoken words</p>	<p>Increase parental responsivity to child communication; increased frequency &amp; complexity of child nonverbal communication</p>	<p>SLT delivers PMT to child &amp; RE to parents</p>	<p>Follow child's lead; arrange for high frequency of communication but wait for the child to respond; model <b>nonverbal</b> targets &amp; <b>request imitation</b>; recast target imitation</p>
<p><b>Enhanced Milieu Teaching:</b> <i>Kaiser &amp; Roberts</i></p>	<p>Preschoolers with language disorders (+/- ID/ASD); + intentional communication; verbally imitate; ≥ 10 spoken words &amp; MLU &lt;3.5</p>	<p>Increased development &amp; frequency of use of words &amp; early word combinations to MLU of 3.5</p>	<p>Parents (trained <b>intensively &amp; individually</b> by SLT)</p>	<p>Follow child's lead; arrange for high frequency of communication but wait for the child to respond; model <b>nonverbal/verbal targets &amp; request imitation</b>; recast imitation of target</p>
<p><b>Focused Stimulation:</b> <i>Ellis Wesimer, Leonard, Fey, McConkey</i></p>	<p>Preschool &amp; school-age children with language disorders (+/- ID/ASD); prepared to use words &amp; early grammatical constructions</p>	<p>Increase development of words; early word combinations &amp; later grammatical structures</p>	<p>Usually delivered by SLT, but parents can be trained</p>	<p>Follow child's lead; arrange for high frequency of <b>verbal</b> targets but wait for the child to respond; model targets &amp; recast child attempts but <b>NOT requesting imitation</b></p>

# PREVIOUS SYSTEMATIC REVIEWS OF PARENT MEDIATED INTERVENTIONS

	Participants	Types of Studies	Types of interventions	Outcome
Law et al (2003) <i>Cochrane Review</i>	Children with Primary Language Disorder	RCTs	3 studies of PMI included	No difference between clinician & parent Standardised language tests ✗
Oono et al (2013) <i>Cochrane Review</i>	Children with ASD aged 1-6	RCTs	17 studies; 14 parent-child interaction (PACT; Pivotal Response tx; DIR/Floortime; Lovaas) (n=919)	Parent-child interaction ✓ Reported receptive vocab ✓ Autism Severity ✓ Child language ✗ Parental Stress ✗
Roberts & Kaiser (2011)	Children with language impairments +/-ID aged 18-60 months	RCTs/ non-random studies and pre/post ax with comparison group (waitlist/ therapist implemented)	18 studies Intervention implemented only by parents (excluded dialogic book reading): 8 Hanen; 1 EMT; 1 Focused Stimulation & others	Parental responsiveness & use of language models ✓ Receptive and expressive language; vocabulary, expressive morphsyntax and rate of communication ✓
Te Kaat van den Os et al (2017)	Children with DD 12-60 months	RCTs (large and small)	7 studies: 3 Hanen; 3 RE/PMT; 1 EMT (n=228; DS = 93)	Parental responsiveness ✓ Frequency of intentional acts; verbal/ vocal turns; vocabulary diversity & MLU ✓ Expressive vocab ✗

# METHODS FOR CURRENT REVIEW

- **Types of Studies:** Randomised/Quasi randomised Controlled Trials
  - *“The RCT is seen as the ‘gold standard’ intervention design, because with sufficiently large numbers and random assignment, all potential factors other than the become evenly distributed between the groups and thus unlikely to affect the results” (Ebbels, 2017; 226)*
- **Types of Participants:** Caregivers of children with DS aged 0-6; monolingual; all levels of severity; extract DS data separately
- **Types of interventions:**All types of PMI/PCIT compared to
  - a) General stimulation/ Therapy as usual; b) No treatment or waitlist control c) Clinician delivered intervention
- **Outcomes:**
  1. Expressive/ Receptive language (1, 12 & 24 months post) & Parent Stress
  2. Parental behaviour/responsivity; parental satisfaction; child nonverbal communication & socialisation; negative behaviours and language attrition; compliance with treatment

# SEARCHES

- Searched 18 databases & trial registers, hand searched reference lists; 'Whatworks' database & contacted professional organisations and colleagues (March 2016, updated January 2018)

7395 records identified & 5 additional records through other sources

5080 screened after duplicates removed

5024 excluded by title and abstract

56 full-text articles assessed & 53 excluded as:

9 = no DS

1 = not 0-6

4 = not a tx study

5 = PMI in both arms

6 = not RCTs

9 = Intervention did not target S,L & C

5 = results for DS not available

14 = combination of reasons

3 Studies

# STUDY I: GIROLAMETTO, WEITZMAN & CLEMENTS-BATEMAN, 1998

## Participants

- 12 Children aged 29-44 months; IQs 59-103.
- $\geq 10$  single words/ signs with no word combinations.
- All families were intact and middle class. Mothers aged between 23- 34; 10 completed 3<sup>rd</sup> level; 7 homemakers.

## Interventions

- **Intervention group (n=6):** Hanen Parent Programme adapted for focused stimulation
  - 9x weekly 2.5 hr group sessions and 4x individual home sessions (~ 26.5 hrs). Mothers chose 20 target words to model and used signs as they spoke. Children did not participate in any other therapy during the parent program.
- **Control group (n=6):** Continued to receive language intervention through their regular preschool services

## Main Findings

- Children in the intervention group did not use more spoken words as determined by the MacArthur Communicative Development Inventory (CDI)
- Used more of target words according to parental report and free play interaction; did not generalise to semi structured probe.
- Mothers used the target labels & focused stimulation techniques more often than control group but did not increase their complexity or their rate of interaction.

# STUDY 2: KARASLAAN & MAHONEY, 2013

## Participants

- 15 children with Down syndrome aged 2 -6.
- Mothers had a mean age of 42.4 years, a mean education level of 9 years, and all were married. Maternal occupation was not reported.

## Interventions

- **Intervention group (n=7):** received weekly individual 'Responsive Teaching' in centre/home for 1.5-2 hours, over 6 months (~ 48 hrs) as well as their standard early intervention services two-days per week during the intervention.
- **Control group (n=8):** received the same two-day per week early intervention services as the experimental group. Parents could observe but did not participate actively in their children's intervention.

## Main Findings

- Children in the Responsive Teaching group made greater increases in their language and interactive engagement (attention & initiation) scores compared to the control group.
- The mothers also made significantly greater increases in the responsiveness and affect and decreases in directiveness compared to control group mothers.

# STUDY 3: KAISER, ROBERTS, OETTING, & LOEB, (2013)

## Participants

- 18 children with Down syndrome aged between 30 and 54 months
- Nonverbal IQ between 50 and 80; TLS  $\leq$  11th percentile on the PLS-4; MLU 1.00- 2.00; 10 productive words; an ability to verbally imitate seven of 10 words during an imitation screening task & normal hearing
- Parents aged 30 - 50 yrs; 61% 3<sup>rd</sup> level Ed +; 50% home-makers. One father.

## Interventions

- **Intervention group (n=8):** Parents attended one 3-hr workshop on EMT intervention & then children received individual EMT delivered by a clinician while another clinician trained the parent. 24 sessions (30min), twice a week for 12 weeks in clinic & 12 x 20min sessions weekly at home. (~19 hrs).
- **Control group (n=10):** received similar individual EMT intervention sessions (24 clinic and 12 home) but only delivered by clinicians.

## Main Findings

- No differences in child receptive/expressive language on standardised ax , parent report, language samples or in trained and untrained activities immediately, 6 or 12 months post.
- Higher use of utterances with language targets in trained activities (not untrained) immediately and six months after the intervention.
- Parents used significantly more EMT strategies; generally remained significant over time

## SUMMARY OF FINDINGS

- Evidence is limited and incomplete: 3-small scale, low quality studies involving 45 children
- Studies used different outcome measures & interventions vs control conditions
- Inconsistent findings for effects on language development
- Consistent effect on changes in parental behaviour/responsivity
- No measure of parental stress/satisfaction, child behaviour or compliance with treatment
- Extremely limited information on treatment fidelity – particularly parent implementation
- High risk of bias for allocation concealment & blinding of outcome assessors
- Quality of evidence (GRADE) was ‘very low’ indicating that *we have very little confidence in the outcomes and that further research is very likely to have an important impact on our confidence in the estimate of the treatment effect.*

# WHERE TO FROM HERE? IMPLICATIONS FOR **RESEARCH**

- Need well-designed feasibility studies/ randomised controlled trials
  - Adequately powered
  - Detailed intervention (manualised)
  - Treatment fidelity (Lieberman-Betz, 2015)
    - Implementation fidelity (therapist)
    - Intervention fidelity (parent)
    - Dosage, adherence, quality, and participant responsiveness
  - Consider [Moderators](#)
  - Valid, reliable and similar outcome measures
  - Primary & secondary outcomes
  - Parents & Clinicians together? (Hampton & Kaiser 2016)

# **MODERATORS INFLUENCING SUCCESS OF PARENT MEDIATED INTERVENTIONS**

## **Therapist**

- Relationship with family
- Age, education, training, experience & expertise in intervention
- Implementation of techniques (quality & quantity)

## **Parent**

- Age, gender, educational background, employment, cultural background/ ethnicity
- Motivation & attitude to indirect intervention
- Stress/ resources/ support & work/caring responsibilities
- Current communication & interaction style
- Implementation of techniques (quality & quantity)

## **Child**

- Age & gender
- Communication/ language/ intellectual capacity
- Personality/ behaviour & general health
- Presence & age of siblings
- Co-morbid factors

## **Therapy**

- Group/ Individual
- Intensity/ Dosage
- Teaching & Coaching Strategies

## WHERE TO FROM HERE? IMPLICATIONS FOR **PRACTICE**

Caffeine: because  
drinking wine at 9am  
makes you a "bad  
parent" or something

PARENT-MEDIATED INTERVENTION

## WHERE TO FROM HERE? IMPLICATIONS FOR **PRACTICE**

- Currently insufficient evidence to determine the effects of PMI to promote language and communication of children with Down syndrome (≠ evidence of no effect)
- Use clinical expertise, family preferences and best practice guidelines
- Consider culture, stress, resources and SES of families
- **Individualised:** Sessions & language and vocabulary targets
- Longer intervention durations (6-months +, throughout childhood).  
Children with ID.. *“may require more intensive and longer term language intervention to ensure improvements in their functional and social communication measured across context and over time”* (Roberts & Kaiser, 2011; 308)
- Consider ongoing maintenance & follow up following parent-training

## SELECTED REFERENCES

- Fey, M.E., McCauley, R.J., and Gillam, R.B. (2017). Interventions Targeting Emerging Communication and Language. In R. J. McCauley, M. E. Fey, and R. B. Gillam (Eds). *Treatment of language disorders in children* (2<sup>nd</sup> ed), pp 23-25. Baltimore: Paul H. Brooks
- Girolametto, L., Weitzman, E., & Clements-Baartman, J. (1998). Vocabulary intervention for children with Down syndrome: parent training using focused stimulation. *Infant-Toddler Intervention*, 8(2), 109-125 | 17p.
- Kaiser, A. P., Roberts, M.Y., Oetting, J., & Loeb, D. (2013). Parent-Implemented Enhanced Milieu Teaching With Preschool Children Who Have Intellectual Disabilities. *Journal of Speech, Language & Hearing Research*, 56(1), 295-309. doi:10.1044/1092-4388(2012)11-0231
- Karaaslan, O., & Mahoney, G. (2013). Effectiveness of responsive teaching with children with Down syndrome. *Intellectual and Developmental Disabilities*, 51(6), 458-469. doi:Cn-01118952
- Lieberman-Betz, R.G. (2015). A systematic review of fidelity of implementation in parent-mediated early communication intervention. *Topics in Early Childhood Special Education* 35(1), 15-27
- Oono, I. P., Honey, E. J., & McConachie, H. (2013). Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews*(4). doi:Cd009774
- Roberts, M.Y., & Kaiser, A. P. (2011). The Effectiveness of Parent-Implemented Language Interventions: A Meta-Analysis. *American Journal of Speech-Language Pathology*, 20(3), 180-199. doi:10.1044/1058-0360(2011)10-0055
- Roberts, M.Y., Kaiser, A.P., Wolfe, C.E., Bryant, J.D. and Spidaleri, A.M (2014). Effects of the Teach-Model-Coach-Review instructional approach on caregiver use of language support strategies and children's expressive language skills. *Journal of Speech, Language and Hearing Research*, 57, 1851-1869.
- Te Kaat-van den Os, D. J. A., Jongmans, M. J., Volman, M. J. M., & Louteslager, P. E. M. (2017). Parent-Implemented Language Interventions for Children with a Developmental Delay: A Systematic Review. *Journal of Policy & Practice in Intellectual Disabilities*, 14(2), 129-137. doi:10.1111/jppi.12181