The Champion Centre
TAMARIKI TOIORA

EARLY INTERVENTION FOR DEVELOPMENTAL RISK

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PREMATURITY

- Gestational Age (GA) defines prematurity, but birthweight often used (incorrectly) as a proxy. Both are risk factors.
  - ≤ 25 weeks: Extremely Preterm
  - 26-33 weeks :Very Preterm
  - 34-36 weeks: Late Preterm
  - < 1,500 grams: VLBW
  - < 1,000 grams: ELBW
- Multiple causes: IVF, multiple births, smoking, substance abuse, rural distances, poverty, cultural attitudes to prenatal care and birthing expectations etc.,
- Large numbers – a rate around 7%-8% of live births in UK.
- With 700,000 live births per year, that's 50,000 prems
- Every classroom is likely to have at least 1 child born prematurely.

PREMATURITY

- Developmental risk to the child
  - Major impact on development in about 10% of cases; more subtle impact in 50% of cases,
  - Impacts are both short and long-term (physical and mental health), although many do better than the early days/months would suggest
  - Greater risk at younger gestational ages (< 32; <28)
  - Medical fragility (respiratory, brain damage, vision, hearing, etc.) Most EPT children are readmitted to hospital before age 2.
  - Impact may not be apparent in infancy: learning, behaviour, social (EF)
  - We have very few preventative tools because we don't understand the basic biology of premature birth.

PREMATURITY

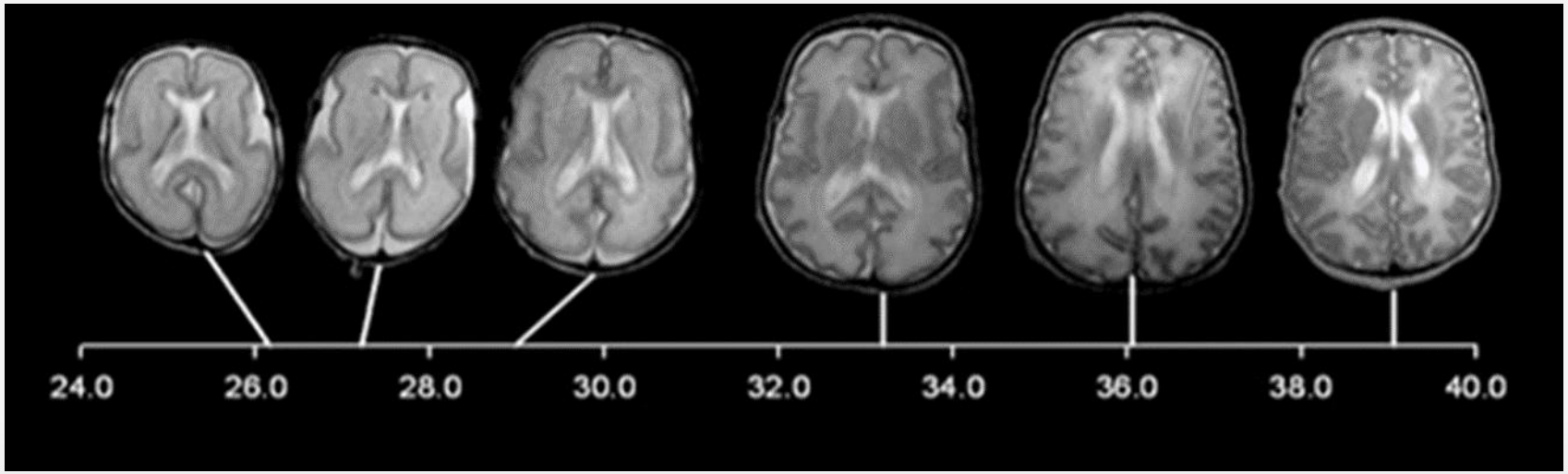
- Impact on the parent:
  - Loss of control of the pregnancy
  - The NICU environment: loss of control of parenting
  - Maternal physical health (what caused the prematurity?)
  - Anxieties about survival and disabilities
  - Maternal mental health
    - 63% of parents of preterm infants have significant symptoms of depression in NICU
    - At age 2 years, 26% of parents of preterm infants (vs 12% FT) have clinically significant mental health problems
  - Strain on family and social dynamics (other children, partner, wider family, work colleagues, loss of income, no baby shower!)
  - Poor knowledge in health professionals (growth charts)
  - Parents not knowing what to expect of development (particularly if first child).
  - Access to intervention and care (rural, poverty, cultural barriers)

NEONATAL IMPACT OF PREMATURITY ON THE INFANT

- Sudden loss of
  - Maternal bio-rhythms (heart, gut, breathing, movement)
  - Maternal body warmth
  - Free floating movement
  - Natural nutrients
  - Intimate relationship
  - Suddenly exposed to:
    - Greater gravity
    - Direct noises of the environment
    - Light
    - Varying temperatures
    - Handling by strangers
- And calling for help is hard!

INTERRUPTED DEVELOPMENT

- Brain:



Damage to brain and sensory impairments (vision, hearing) affects 20-25% of VLBW.

INTERRUPTED DEVELOPMENT

- Body: At 23 weeks
  - Fat stores not yet laid down:
    - 97-99% of children born VLBW or ELBW are <10th percentile for weight and height: don't put on fat; immature gut.
  - Eyes not fully developed:
    - 10% of children born < 26 weeks GA; 2% < 32 weeks.
  - Lungs not fully developed:
    - Chronic lung disease affects 35% of children born <1,500 grams, Asthma is ongoing risk.

NEUROLOGICAL IMPACT ON THE INFANT

- Immature neurological systems lead to difficult to interpret signals/cues
- Common white matter injury (i.e. to the axons)
  - CP: 6-9% of children born ≤ 32 Weeks; 16-28% of those born ≤ 26 weeks.
- Less myelination (i.e. less efficient connections between brain cells)
- Particularly fragile pre-frontal cortex.
  - associated with complex planning, decision-making, behavioural inhibition, working memory and judgement (Executive Function)

Full-term brain at birth

3 months premature brain at term

Brain structures involved in movement, learning and memory disproportionately smaller than full term babies

Woodward, Lianne J, Anderson, Peter J, Austin, Nicola C, Howard, Kelly, & Inder, Terrie E. (2006). Neonatal MRI to predict neurodevelopmental outcomes in preterm infants. *New England Journal of Medicine, 355*(7), 685-694.

EARLY CHILDHOOD DEVELOPMENT: REGULATION, COGNITION, LANGUAGE

LEARNING AND DEVELOPMENT DEPENDS ON REGULATION

- The regulation story (Samaroff). Children need to develop:
  - Physiological regulation as a neonate
  - Emotional regulation as an infant
  - Attentional regulation as a toddler
  - Self-regulation as a pre-schooler
- Prematurity can disrupt this development all along the pathway, but environmental responses can mitigate the challenges.

EMOTIONAL AND BEHAVIOURAL REGULATION

- Clark et al. 2008
  - 95 children (39 EPT, 56 VPT) followed from 2 to 4 years
  - Observed in parent-child interactions in a problem-solving context and cognitive testing. Also parent report.
  - Although they made gains over time (particularly those in the VPT group), both groups showed poorer frustration control, persistence, and sustained attention, than the controls.
  - Better regulation when parenting responsive and sensitive

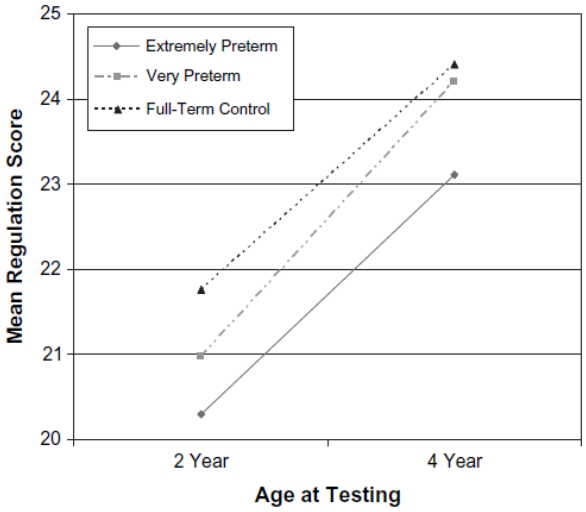


Figure 2. Development of regulation between 2 and 4 years in children born extremely preterm, very preterm, and full term.

Clark, Caron AC, Woodward, Lianne J, Horwood, L John, & Moor, Stephanie. (2008). Development of emotional and behavioral regulation in children born extremely preterm and very preterm: Biological and social influences. Child development, 79(5), 1444-1462.

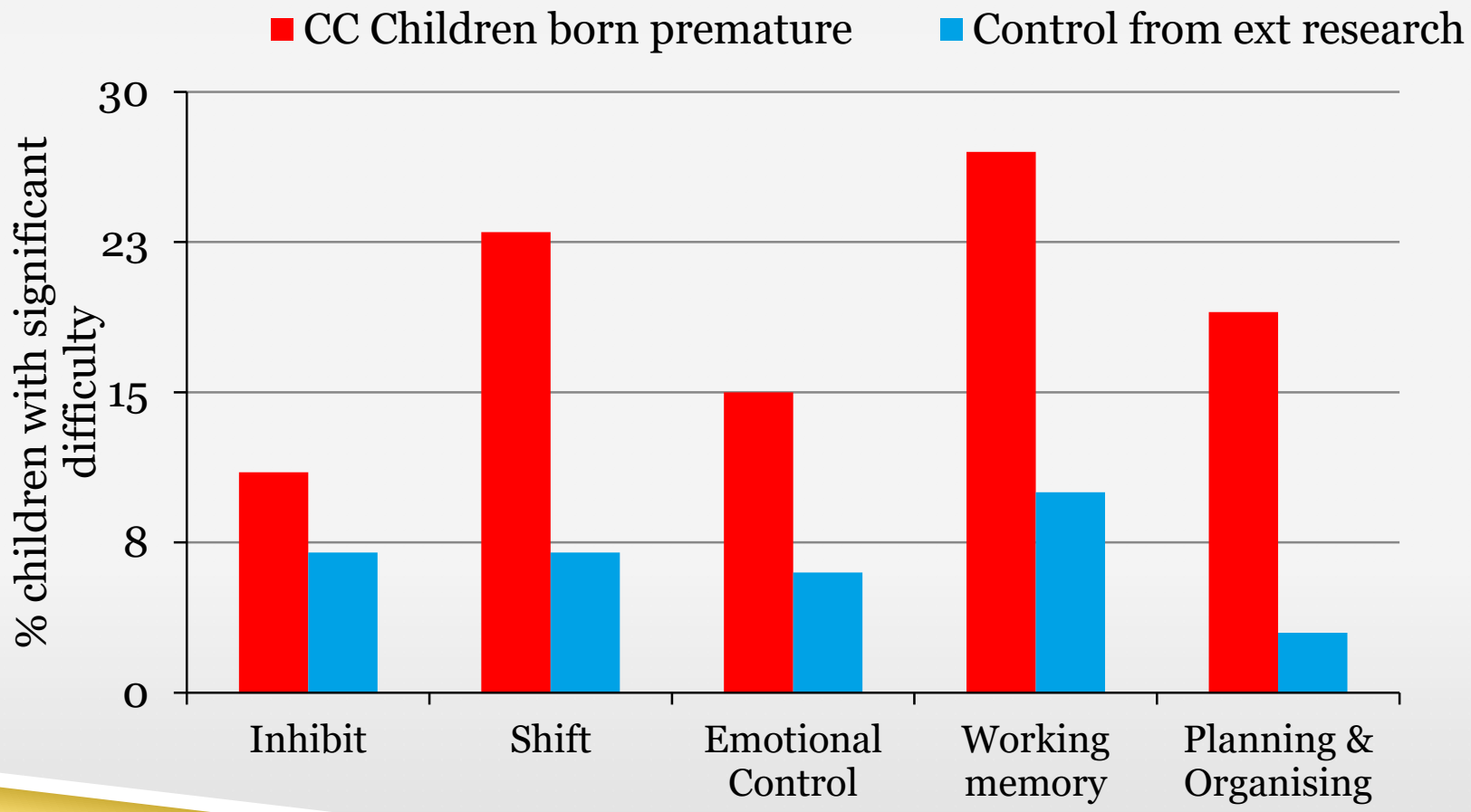
THE INFANT PARENT DYNAMIC

- Reactive, easily distressed infants may be particularly susceptible to unresponsive or insensitive parenting
- Poorly regulated mothers tend to be more active, stimulating, intrusive & at same time, more distant
- Infants at 2.5x risk of regulatory problems if parents have MH problems (Treyvaud et al., 2009)
- Smooth, calm, synchronous parenting helps to develop self-regulation in the infant
- Mutual regulation occurs in the context parent-child interaction, during face-to-face play, feeding and other caregiving tasks.
- Parents help to regulate physiological state by timing the onset of feeding or soothing to sleep
- So EARLY intervention is key.

EXECUTIVE FUNCTION

- Executive Function is characterised by prefrontal cortical controlled
  - Working memory
  - Inhibitory control
  - Cognitive flexibility
- Behaviour Rating Inventory of Executive Function BRIEF (Gioia, Espy and Isquith 2003): Parent questionnaire with five sub-scales:
  - Inhibit: e.g. Is unaware of how his/her behaviour affects others
  - Shift: e.g. Becomes upset with new situations
  - Emotional Control: e.g. Overreacts to small problems
  - Working Memory: e.g. When given two things to do, only remembers first or last
  - Plan/Organise: e.g. Does not complete task even after given directions
- Champion Centre study with the BRIEF:

‘BRIEF' SCORES AT 3 YEARS (N = 29)



EMOTIONAL AND BEHAVIOURAL CHALLENGES AT 4 YEARS

Emotional and behavioural adjustment as measured by Strengths and Difficulties Questionnaire	***Children born premature (EPT & VPT)***	***Children born FT***
Emotional Problems	***16.5%***	***6.5%***
Conduct Problems	***16.5%***	***14%***
Hyperactive/Attentional difficulties	***24.3%***	***11.2%***
Peer relationship problems	***20.4%***	***10.3%***
Overall behavioural difficulties	***23%***	***11.2%***

Woodward, Lianne J, Moor, Stephanie, Hood, Kelly M, Champion, Patricia R, Foster-Cohen, Susan, Inder, Terrie E, & Austin, Nicola C. (2009). Very preterm children show impairments across multiple neurodevelopmental domains by age 4 years. *Archives of Disease in Childhood-Fetal and Neonatal Edition, 94*(5), 339-344.

LANGUAGE OUTCOMES AT 2

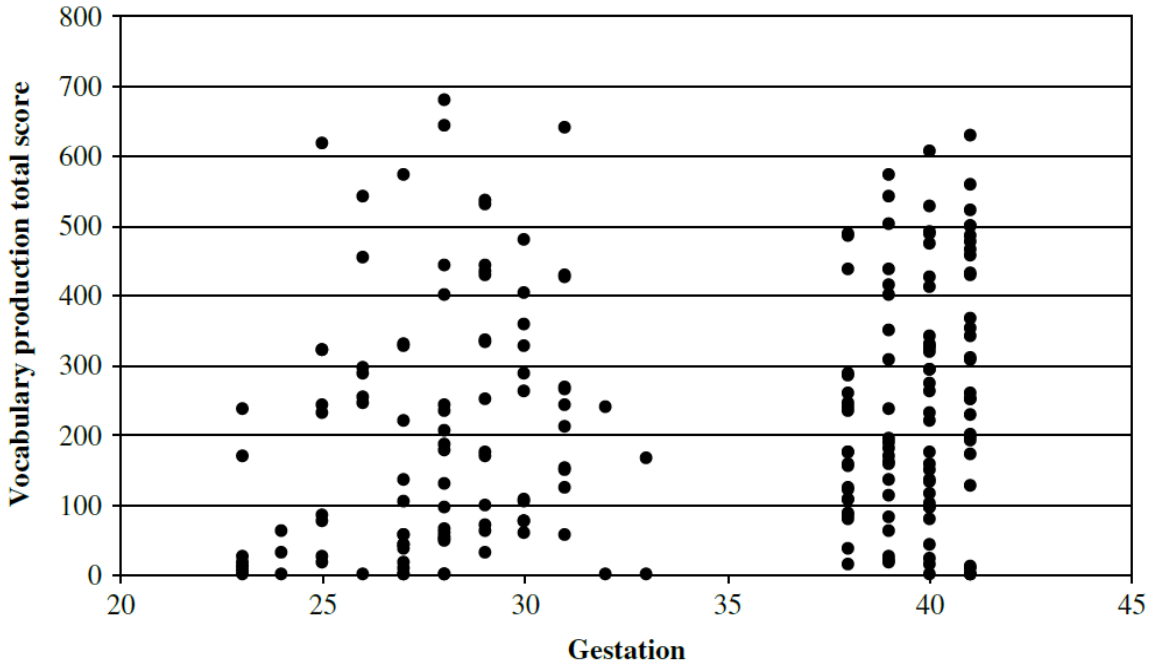


Fig. 1. Relationship between gestational age at birth and children's total vocabulary production.

Foster-Cohen, S., Edgin, J., Champion, P, & Woodward, L. (2007). Early delayed language development in very preterm infants: evidence from the MacArthur-Bates CDI. *J Child Lang, 34*(3), 655-675.

LANGUAGE OUTCOMES AT 4

Table 2. Language Outcomes of Very Preterm and Full-Term Children at Age 4 Years Corrected

CELF-P Scores at 4 Years	Very Preterm (n = 100)	Full Term (n = 104)	F/χ^2	p	D/Φ
Receptive language composite	90.70 (12.22)	97.53 (13.10)	14.70	.001	.54
Linguistic concepts	8.30 (2.52)	9.26 (2.76)	6.69	.01	.37
Basic concepts	8.09 (2.53)	9.32 (2.80)	10.71	.001	.46
Sentence structure	8.91 (2.82)	10.15 (2.61)	10.67	.001	.46
Expressive language composite	93.60 (13.47)	99.09 (13.17)	8.59	.004	.41
Recalling sentences	8.74 (2.97)	9.95 (2.86)	8.70	.004	.42
Formulating labels	9.19 (2.65)	9.95 (2.64)	4.69	.03	.31
Word structure	8.83 (2.96)	9.78 (2.84)	5.49	.02	.33
Total CELF-P score	91.48 (12.38)	98.07 (13.38)	13.21	.001	.51
No language delay at 4 years	69.0	84.8			
Mild language delay at 4 years	16.0	8.6			
Moderate to severe language delay at 4 years	15.0	6.7	6.75	.01	.19

CELF-P, Clinical Evaluation of Language Fundamentals—Preschool. Values are presented as mean (SD) or percent. F = results of multivariate analysis of variance for continuous measures; χ^2 = results of Mantel-Haenszel χ^2 test for dichotomous measures; D = Cohen's D estimate of effect size for continuous outcomes; Φ = Cramer's phi estimate of effect size for dichotomous outcomes.

Foster-Cohen, Susan H, Friesen, Myron D., Champion, Patricia R., & Woodward, Lianne J. (2010). High prevalence/low severity language delay in preschool children born very preterm. *J Dev Behav Pediatr, 31*(8), 658-667.

LANGUAGE IN EARLY CHILDHOOD

- Smaller vocabularies on average but great variation between children
- Language use reflects less use of decontextualized language (past, future, absent object, possession) with decreasing GA.
- Delayed use of morphology (regular and over-regularised)
- Delayed combining of words and syntactic complexity.
- All these effects survive adjustment for family background and child health.
- The observed strength in expressive language noted by teachers in 6 year olds (Pritchard et al study) must therefore be examined carefully.

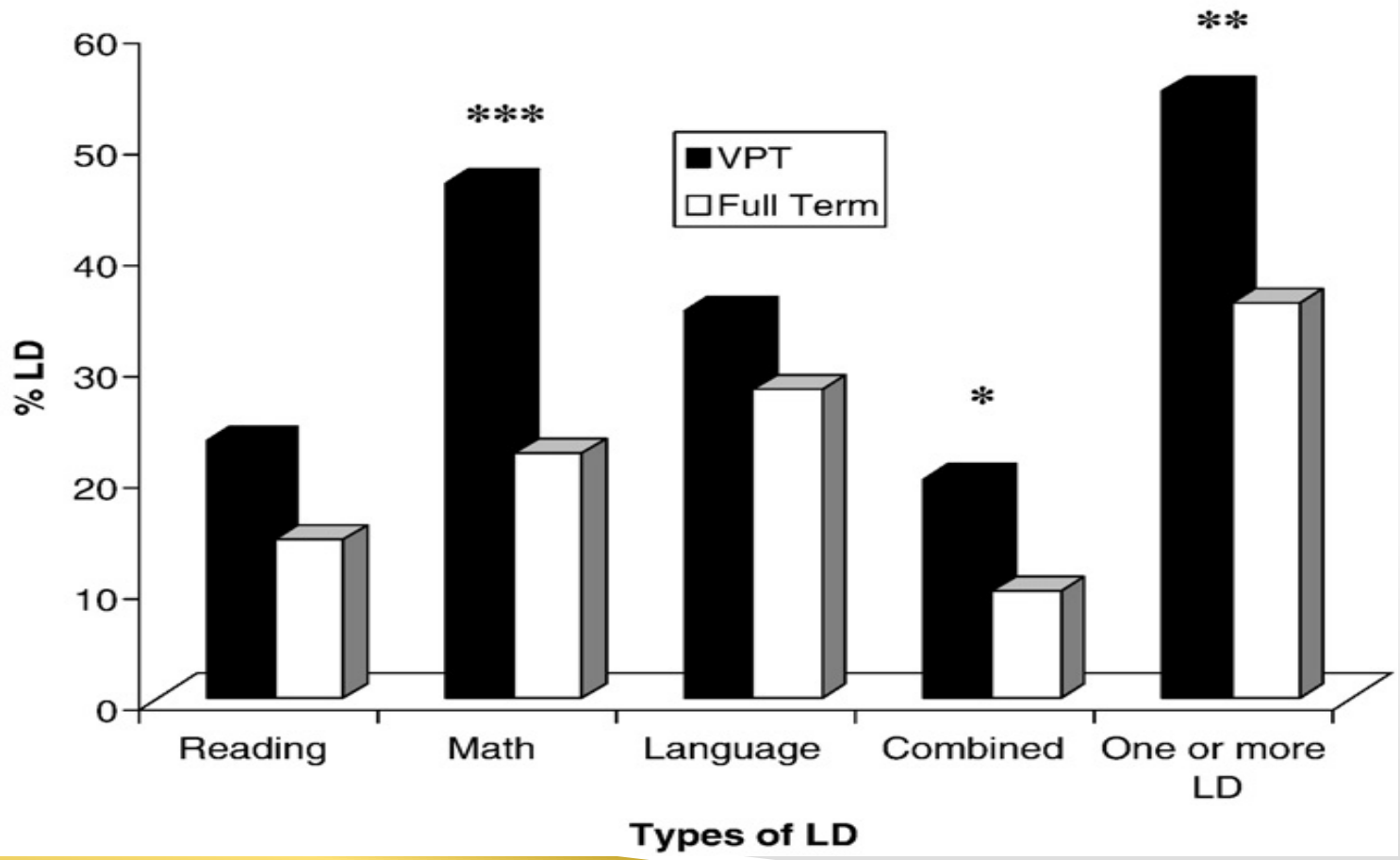
COGNITION

- BSID data from the Canterbury University project suggests:
- At 2 years:
  - 20% more than 6 months behind corrected age in cognitive development
  - 53% average or above (compared to 75% typical pop)
  - 47% delay (compared to 25% typical pop)
  - Of those - 30% mild delay; 7% severe delay
- At 4 years:
  - On average, children born preterm are 11 IQ points lower than FT comparison children

PREMATURE CHILDREN AT 6 YEARS

- Pritchard et al. 2009
  - 102 VPT and 108 FT followed since birth
  - At age 6: comprehensive neurodevelopmental evaluation including teacher reports and national numeracy and literacy tests. Rates of SLD also examined.
  - VPT children did more poorly in all areas except teacher-rated expressive language
  - VPT children 2-3 times more likely to show delays in math, written language, language comprehension, handwriting, spelling and physical education. Twice as likely to have Math LD.
- McCormick et al. 2010
  - 65% have learning disabilities of one or more types; usually reading and maths with maths harder hit.

PREMATURE CHILDREN AT 6 YEARS



OUR RESPONSIBILITY

- "Early identification and raising awareness amongst educators and schools ought to be a priority, alongside developing a better understanding of the risk and protective factors influencing VPT children's educational achievement." (Pritchard et al 2009, p. 222)

MAGNUS

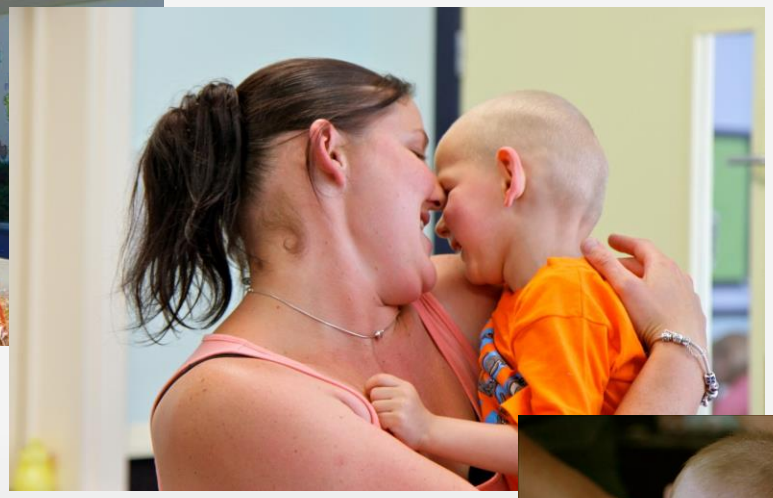
(NOT) OUT OF THE WOODS…

- First parent-infant interactions are key to a healthy infant/child and a healthy parent.
- At the Champion Centre, we intervene as soon as the family is able following discharge from hospital.
- We track the children's development and the coping strategies of the parent(s) from a holistic ecological strengths-based standpoint throughout early childhood.
- Things can go pear-shaped at any age, and children are certainly not 'out of the woods' once they have outgrown the baby stage.

INVESTING IN OUTCOMES

- Encouraging relationship-based neonatal care
- Educating allied health practitioners about the short and long-term consequences
- Educating parents (gently) about what might happen down the track
- Encouraging maternal responsiveness and sensitivity
- Engaging in sustained holistic multi-disciplinary assessment, monitoring, and (where necessary) intervention throughout the early childhood period and into school.

INTERVENTION AT THE CHAMPION CENTRE



CHAMPION CENTRE PREMATURITY PROGRAMMES (A&M AND EI)

- Referrals by paediatrician at fortnightly 'single point of entry' meetings to:
  - Assessment and Monitoring for prematurity
  - Early Intervention
- Criteria for acceptance:
  - A&M: <1500 and/or < 30 weeks gestation and with a high risk of developmental delay.
  - EI: Any degree of prematurity that has an identified disability even if not behaviourly clear (e.g., HIE, CP, major feeding or breathing difficulties)

CHAMPION CENTRE PREMATURITY PROGRAMMES (A&M AND EI)

- Currently 78 infants/children aged between birth and six years:
  - 24-28 weeks (n = 22) *810-965 gms* (EPT) 45% = A&M; 55% = EI
  - 28-31 weeks (n = 51) *1010 – 2010 gms* (VPT) 49% = A&M; 51% = EI
  - 32-36 weeks (n = 5) *1230 – 3430 gms* (MPT) 100% = EI

CHAMPION CENTRE A & M

- Currently 35 (of the 78 prems). But also used for other children at risk, e.g., FAS, post-operative heart, birth complications.
- Weekly attendance during school term weeks for one hour at the Centre until 4 months corrected
- Team: Psychologist, PT/OT, SLT, SW or Kaiwhakapuawai.
- If developing corrected age appropriately, then rotation begins of 8, 12, 18, 24, 36 months corrected and 4 years old uncorrected. (Stay on roll until go to school.)
- Champion Centre booklets about prematurity: infant and toddler separate booklets.
- Can be referred to a fuller programme at any time.

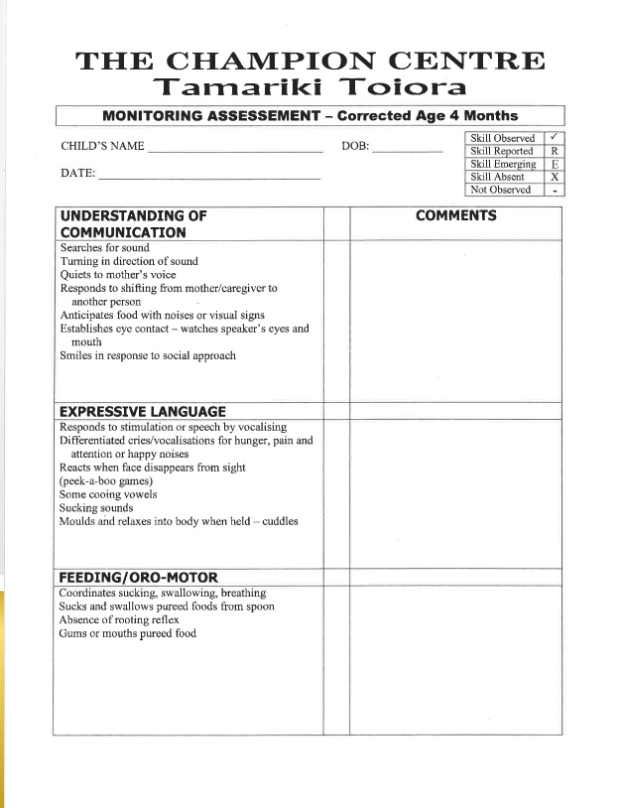
CHAMPION CENTRE A & M

- Fuller programme could be:
  - Regular weekly programme with a full team (full EI) of SLT, EIT, PT/OT, ECE, Music, Computer, FST
  - 'single strand' work, (e.g., speech and language, OT)
  - Play-based coaching at home
  - Expanded Family Support Team (e.g., Behaviour work with a psych; SW support; kaiwhakapuawai)

“She is doing amazingly well at school, reaching all her school expectations and her health is great - she is participating in netball, ballet and swimming at local clubs and is very social among her peers. I think the only thing we notice is that she can get very cold, particularly in the school outdoor pool (she is the only child who wears a wetsuit!!) Hopefully there won't be too many surprises around the corner but I'm sure we and Jess shall work through them if and when they arise. ”

ASSESSMENT SCHEDULE

- Cognition, Communication, Oro-Motor, Self-Care and Fine & Gross Motor evaluation at each visit using *aides memoires* based on Carolina Curriculum, Schaffer and Moersch, Greenspan, HELP.



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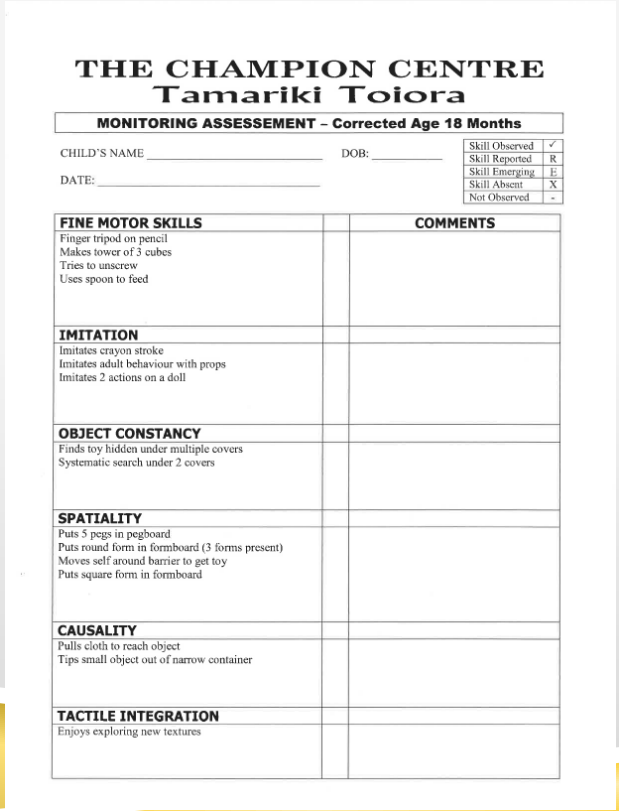
MONITORING ASSESSEMENT – Corrected Age 4 Months

CHILD'S NAME _____ DOB: _____

DATE: _____

Skill Observed	✓
Skill Reported	R
Skill Emerging	E
Skill Absent	X
Not Observed	-

UNDERSTANDING OF COMMUNICATION		COMMENTS
Searches for sound Turning in direction of sound Quiets to mother's voice Responds to shifting from mother/caregiver to another person Anticipates food with noises or visual signs Establishes eye contact – watches speaker's eyes and mouth Smiles in response to social approach		
EXPRESSIVE LANGUAGE		
Responds to stimulation or speech by vocalising Differentiated cries/vocalisations for hunger, pain and attention or happy noises Reacts when face disappears from sight (peek-a-boo games) Some cooing vowels Sucking sounds Moulds and relaxes into body when held – cuddles		
FEEDING/ORO-MOTOR		
Coordinates sucking, swallowing, breathing Sucks and swallows pureed foods from spoon Absence of rooting reflex Gums or mouths pureed food		



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MONITORING ASSESSEMENT – Corrected Age 18 Months

CHILD'S NAME _____ DOB: _____

DATE: _____

Skill Observed	✓
Skill Reported	R
Skill Emerging	E
Skill Absent	X
Not Observed	-

FINE MOTOR SKILLS		COMMENTS
Finger tripod on pencil Makes tower of 3 cubes Tries to unscrew Uses spoon to feed		
IMITATION		
Imitates crayon stroke Imitates adult behaviour with props Imitates 2 actions on a doll		
OBJECT CONSTANCY		
Finds toy hidden under multiple covers Systematic search under 2 covers		
SPATIALITY		
Puts 5 pegs in pegboard Puts round form in formboard (3 forms present) Moves self around barrier to get toy Puts square form in formboard		
CAUSALITY		
Pulls cloth to reach object Tips small object out of narrow container		
TACTILE INTEGRATION		
Enjoys exploring new textures		

ASSESSMENT SCHEDULE: OBSERVATIONAL AND PLAY BASED PROFESSIONAL AND PARENT REPORTS

- Alberta Infant Motor Scale at all visits up to 18 mo corrected
- Infant-Toddler Symptom Checklist at 18 mo corrected
- Bayley Scales of Infant Development (BSID) including ABAS at 2 yrs corrected
- Behavioral Inventory of Executive Function (BRIEF) at 3 yrs corrected
- Bureau Auditory Comprehension Test
- Parent reports:
  - Infant/Toddler Checklist of Social and Emotional skills at 4, 8, and 12 mo
  - Infant/Toddler speech and language reported language sample (in house) at 18 mo
- EC Teacher reports at 4 yrs (uncorrected) Social Emotional Checklist
- In addition, the following are used as needed:
  - Neuro-Sensory and Motor Developmental Assessment
  - Infant/Toddler Sensory Profile
  - Preschool Language Scale (PLS)

ASSESSMENT VISITS

- At the Champion Centre unless the child too unwell to travel
- First visit preceded by a home visit and history taking/relationship building.
- Weekly Centre visits until 4 months corrected
- Once on the Monitoring rotation, team leader contacts family about 6 weeks ahead of visit and sends written confirmation and relevant parent report measures to family about 4 weeks ahead.

ASSESSMENT VISITS

- Psych greets the family and 'settles' them in the room before inviting the other 2 team members to join. (Can reduce the # team members in the room using 2-way mirror.)
- 3-person assessment occurs in a warm, welcoming room where there is space and time for conversation about the child. Key family members encouraged to attend. Parent(s) encouraged to ask questions/express concerns.
- Often one team member is doing an assessment (e.g., BSID) while the others are either talking with the parents or/and watching and gleaning information for their own areas, which are then supplemented when their turn with the child comes. (PT/OT outside in garden.)

CHAMPION CENTRE A & M

- At end of visit, family given brief overview (prior to a mailed written report which includes ideas for ongoing development).
- Copies of report also go to child's paediatrician, and social welfare caseworker if there is one.
- Parents always encouraged to call if they have concerns
- Keeping in contact with:
  - Parents/family/whānau
  - Paediatrician, GP, neurologist, maternal mental health services
  - Early Childhood Education Centre
  - Plunket (well-child service)
  - CYF (social welfare)
  - Other specialist services (e.g., for hearing, vision)

SOME NUGGETS FROM EXPERIENCE

- The early weekly visits allow a genuine relationship with families to be developed; then it is easier to sustain as the visits become less frequent: more likely to share concerns and to follow advice.
- Frequent enough visits so that concerns can be allowed to build a bit before taking action. Prevents over-pathologising prematurity.
- Follow up non-attenders and maybe take the team to the home.
- Multi-disciplinary team is vital. Psychologist support to help parents process the experience of their child's birth and interrupted development is crucial.
- Neonatologists/paediatricians are pretty good at picking the infants who will only need monitoring: sustaining good relationships with these professionals very important from a programme planning point of view

SOME NUGGETS FROM EXPERIENCE

- Impact of overall child health must be taken into account. Can mask development or knock fragile children back.
- Supporting parents in all arenas of their lives important (e.g., twins separated in daycare because of different developmental levels not OK)
- Persuading some families to stay with the A&M programme can be hard. Assessment results can help adjust parent perceptions.
- Even when things are moving along well, the visits to the Centre can be anxiety provoking for parents ("Will he pass?"). Their feelings must be acknowledged.
- Transition to school can be really tough and the children won't qualify for specific educational professional support.
- Parents may want to put the whole rough start in life behind them, but teachers need to understand the implications of prematurity if they are to teach well. We need to normalise prematurity so that it is no longer so 'charged'.

REFERENCES

- Abel, Kathryn M, Wicks, Susanne, Susser, Ezra S, Dalman, Christina, Pedersen, Marianne G, Mortensen, Preben Bo, & Webb, Roger T. (2010). Birth weight, schizophrenia, and adult mental disorder: is risk confined to the smallest babies? *Archives of General Psychiatry, 67*(9), 923-930.
- Clark, Caron AC, & Woodward, Lianne J. (2015). Relation of perinatal risk and early parenting to executive control at the transition to school. *Developmental science, 18*(4), 525-542.
- Clark, Caron AC, Woodward, Lianne J, Horwood, L John, & Moor, Stephanie. (2008). Development of emotional and behavioral regulation in children born extremely preterm and very preterm: Biological and social influences. *Child development, 79*(5), 1444-1462.
- Foster-Cohen, Susan H., Edgin, Jamie. O., Champion, Patricia R., & Woodward, Lianne. J. (2007). Early delayed language development in very preterm infants: evidence from the MacArthur-Bates CDI. *J Child Lang, 34*(3), 655-675.
- Foster-Cohen, Susan H., Friesen, Myron D., Champion, Patricia R., & Woodward, Lianne J. (2010). High prevalence/low severity language delay in preschool children born very preterm. *J Dev Behav Pediatr, 31*(8), 658-667. doi: 10.1097/DBP.0b013e3181e5ab7e
- Hack, Maureen. (2009). Adult outcomes of preterm children. *Journal of Developmental & Behavioral Pediatrics, 30*(5), 460-470.
- Lindström, Karolina, Lindblad, Frank, & Hjern, Anders. (2009). Psychiatric morbidity in adolescents and young adults born preterm: a Swedish national cohort study. *Pediatrics, 123*(1), e47-e53.
- McCormick, Marie C, Litt, Jonathan S, Smith, Vincent C, & Zupancic, John AF. (2011). Prematurity: an overview and public health implications. *Annual review of public health, 32*, 367-379.
- Miles, Margaret Shandor, Holditch-Davis, Diane, Schwartz, Todd A, & Scher, Mark. (2007). Depressive symptoms in mothers of prematurely born infants. *Journal of Developmental & Behavioral Pediatrics, 28*(1), 36-44.
- Pritchard, Verena E, Clark, Caron AC, Liberty, Kathleen, Champion, Patricia R, Wilson, Kimberley, & Woodward, Lianne J. (2009). Early school-based learning difficulties in children born very preterm. *Early human development, 85*(4), 215-224.
- Treyvaud, Karli, Anderson, Vicki A, Howard, Kelly, Bear, Merilyn, Hunt, Rod W, Doyle, Lex W, . . . Anderson, Peter J. (2009). Parenting behavior is associated with the early neurobehavioral development of very preterm children. *Pediatrics, 123*(2), 555-561.
- Woodward, Lianne J, Moor, Stephanie, Hood, Kelly M, Champion, Patricia R, Foster-Cohen, Susan, Inder, Terrie E, & Austin, Nicola C. (2009). Very preterm children show impairments across multiple neurodevelopmental domains by age 4 years. *Archives of Disease in Childhood-Fetal and Neonatal Edition, 94*(5), 339-344.

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THANK YOU!

Questions?