

# Cerebral Palsy - Early Identification

## Results from four co-design workshops

4 co-design workshops (7-13 participants each) included 12 parents (children ranging GMFCS I-V, diagnosis received between 8-36months of age) and 14 clinicians

discovery workshop  
(Auckland)

### CLINICIAN-FAMILY COMMUNICATION

Diagnostic information not always communicated  
Clinician reluctance to verbalise CP possibility  
Wording is important – say ‘at risk of’ or ‘monitoring for CP’ instead of ‘wait and see’  
Ask families what they already know before conveying (or not) information

discovery workshop  
(Waikato)

### SERVICE PROVISION

System is complex, inefficient  
Juggling multiple appointments  
Some Whānau find it difficult to accept ‘help’, ask questions or bring up problems  
Lack of diagnosis counselling  
Continuity of care – may ‘fall through the cracks’ particularly if ‘mild’

### EARLY EXPERIENCE

Fear, shock, isolated, unsupported, adjusting to new normal, trying to cope  
Uncertain, lack of information – ‘what might it be?’, ‘how bad is it going to be?’, ‘what’s next?’

prototyping workshop  
(Auckland)

### INFORMATION

Not knowing who to go to for advice, where to find information  
Insufficient information resources  
Digital information is overwhelming, not NZ relevant and not always trustworthy  
Not knowing the ‘variety’ of CP  
Information=empowerment

prototyping workshop  
(Waikato)

## FAMILY EXPERIENCE THROUGH CO-DESIGN

### HONEST OPEN COMMUNICATION

- Convey CP suspicions early to family
- Wording – say ‘at risk of CP’ rather than ‘wait and see’
- Consider wider family context
- Acknowledge whānau knowledge and lived experience
- Talk about cognitive early
- Talk about alternative treatments

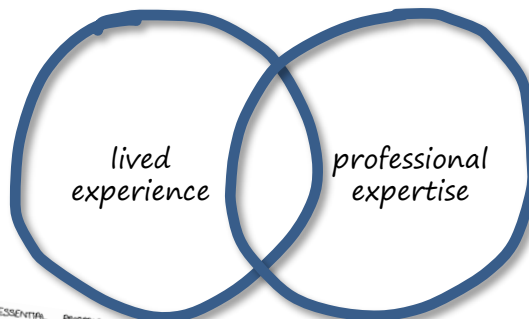
### RESOURCE PACK GIVEN WHEN CP IS SUSPECTED

- Personal stories
- Family tips, professional tips
- Includes current research and complementary options
- Visual diagram mapping out people involved in provision of care and their roles
- Where to go down the track and who is involved
- Recommended ‘go to’ websites

## CO-CREATED SOLUTIONS



### THINKING BIG



### CONNECTED CARE

- Clear service map
- Have a health navigator
- Pastoral support and grief counselling
- Have multi-disciplinary consultations

**Working together** – relationship with whānau forming a foundation from which to support holistic needs

**Spiritual & emotional wellbeing** – people to reflect together and learn from each others experiences

**Equitable access** – through different modes of information sharing: technology, telehealth, health navigator, physical information resource

**Regional hub** – can be referred by health professional & self-refer. Has coordinated appointments in one place (hearing, dental, vision, splinting etc.), organised according to child age, accessible information, one care plan, well being support

