EVIDENCE-BASED ASSESSMENT

PRACTICES FOR

CHILDREN WITH CEREBRAL PALSY

Submitted by

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Statement of Authorship and Sources

This thesis contains no material that has been extracted in whole or in part from a thesis that I have submitted towards the award of any other degree or diploma in any other tertiary institution.

No other person's work has been used without due acknowledgment in the main text of the thesis.

All research procedures reported in the thesis received the approval of the relevant Ethics/Safety Committees where required.

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List of Abbreviations

CFCS: Communication Function Classification System

COPM: Canadian Occupational Performance Measure

CINAHL: Cumulative Index to Nursing and Allied Health Literature.

EDACS: Eating and Drinking Abilities Classification System

GAS: Goal Attainment Scale

GMFCS: Gross Motor Function Classification System

GMFM: Gross Motor Function Measure

MACS: Manual Abilities Classification System

PEDI: Paediatric Evaluation of Disability Inventory

PRISMA: The Preferred Reporting Items for Systematic Reviews and Meta-Analyses

ICF-CY: International Classification of Functioning Disability and Health (Child-Youth version)

ICF: International Classification of Functioning Disability and Health

WHO: World Health Organisation

Operational definitions

Assessment

> "the overall process of selecting and using multiple data collection tools and various sources of information to inform decisions required for guiding therapeutic intervention throughout the therapy process" (Laver Fawcett, 2013, p. 5).

Evidence-based assessment tool

> Assessment instrument that has both published instructions available on how to administer, score and interpret the assessment, and acceptable levels of reliability and validity when used with the population of interest—in this case children with cerebral palsy.

Evidence-based assessment

> A process where research is used to guide assessment tool selection and findings are integrated with clinician expertise and family preferences, within the context of available resources.

Notes on format and style used in this thesis

Unpublished content and accepted manuscripts within the thesis are supported by 6th edition American Psychological Association referencing style. A numbered format is used throughout the thesis with appendices listed alpha-numerically. For consistency, numbering of sections headings in the accepted manuscripts follows the chapter heading style and numbering system. References for accepted manuscripts sit with the manuscript.

Thesis summary

Evidence-based practice has been adopted by the healthcare sector as a framework to achieve safer, scientifically defensible and cost-effective clinical care. Consistent with this framework is an increasing expectation for healthcare professionals to be evidence-based in relation to assessment. Evidence-based assessment uses research to guide tool selection and integrates the assessment tool findings with health professional expertise and family preferences, within the context of available resources. Evidence-based assessment tools can provide objective information about a child's capabilities, strengths and difficulties, guide goal setting and interventions, and objectively evaluate outcomes and progress over time, thereby, potentially assisting families to anticipate future resources. Many assessment tools have been developed and evaluated psychometrically for use with children who have cerebral palsy. Routine use of evidence-based assessment tools can prevent and assist with the management of secondary musculoskeletal impairments and their sequelae for children with cerebral palsy.

Despite the availability, promotion and reported benefits of use of many assessment tools, the uptake of evidence-based assessment tools by paediatric therapists (occupational therapists, physiotherapists and speech pathologists) in day-to-day practice has been slow. Outcomes from knowledge translation studies to embed use based on known barriers have been modest, suggesting further investigation is needed to understand why evidence-based assessment is not easily adopted in practice.

The aim of this thesis was to develop an in-depth understanding of what is needed for therapists to embed evidence-based assessment tools for children with cerebral palsy into

their practice. The research to achieve this aim addressed objectives related to: 1) the published literature; 2) understanding therapists' assessment practices in different organisational contexts; and 3) the evidence-based assessment experiences of parents of children who have cerebral palsy.

Three empirical studies were completed. A systematic review investigating the extent and types of assessment tools being used by therapists for children with cerebral palsy was conducted following PRISMA guidelines in Study 1. A mixed-methods approach was taken in Study 2 to investigate therapists' assessment behaviours in two different Australian-based organisations. Findings from Study 2 suggested further investigation of the parent perspective would be helpful to fully understand therapists' behaviours. A scoping review of the published literature preceded a qualitative study using interpretive description to understand parents' experiences of evidence-based assessment for their child with cerebral palsy in Study 3.

The systematic review identified that only a few of the available evidence-based assessment tools were used often, and all focused on gross motor function. The mixed method approach utilised in Study 2 confirmed therapists' low overall use of evidence-based assessment tools, however, therapists' use varied across organisations. Therapists' assessment tool behaviours could be categorised on a continuum that ranged from *I don't* to *We do*. Factors related to the organisation, the assessment tool and collaboration with families were influential. The 'Cultural Cone for Evidence-based Assessment' framework was developed, representing the relationships among contextual influences and therapist use of evidence-based assessment. Investigation of the assessment interactions from parents' perspectives identified *protection* of child identity and self was central to parents'

experience of assessment. The interpretive description—the 'Steering Wheel for Collaborative Assessment'—that emerged from the results suggests involving parents at the start rather than the end of an evidence-based assessment process is important.

This thesis explored evidence-based assessment practices through the lens of organisations, practitioners and parents. Findings suggest knowledge translation strategies that align evidence-based assessment with family-centred care and focus on *how* evidence-based assessment tools are used with families is needed. This proposed shift in practice may make it easier for therapists to embed evidence-based assessment tools within therapy practice.

Chapter 1 Introduction

1.1 Background

Equitable access to quality health and therapy services that enable children with disabilities to participate fully in social life is a right under the UN Conventions on the Rights of Persons with Disabilities (The United Nations, 2006, art. 18), and the Rights of the Child (The United Nations, 1989, art. 15). Assessment underpins clinical reasoning and decision making and guides the direction for intervention, thereby providing the cornerstone for services that will allow these rights to be realised. Assessment is where health and therapy interventions are initiated, planned, monitored and evaluated. The quality of service provision depends on the quality of assessment, so it is important to get assessment right (Hollon, 2017). Without high-quality assessment, it is not possible to accurately determine the impact of chosen interventions and services on child health, functioning, participation and quality of life (Hollon, 2017; Laver Fawcett, 2013).

Assessment is defined by Laver Fawcett (2013) as:

> the overall process of selecting and using multiple data collection tools and various sources of information to inform decisions required for guiding therapeutic intervention throughout the therapy process (p. 5).

Current best practice recommendations for assessment include the use of valid standardised assessment tools (Laver Fawcett, 2013). The work undertaken for this thesis explored allied health practitioners' assessment practices with children who have cerebral palsy and their families. An increased understanding of practitioner assessment practices has, by

improving the quality of assessment, the potential to benefit children with cerebral palsy and their families, as well as therapists and service providers.

The collective term, cerebral palsy, is a used to describe the most common physical disability manifesting in childhood (Oskoui, Coutinho, Dykeman, Jetté, & Pringsheim, 2013; Reddihough & Collins, 2003). Five key features are common to all definitions of cerebral palsy: (1) it is a group of disorders; (2) it is permanent but with symptoms that can change; (3) there is a disorder of movement and/or posture and motor function; (4) it is due to non-progressive disturbance/lesion; (5) the disturbance/lesion arises in the developing or immature brain (Rosenbaum et al., 2007; Smithers-Sheedy et al., 2014). The key features of cerebral palsy are often accompanied by other disturbances related to sensation, perception, vision, cognition, gastro-oesophageal and intestinal function, epilepsy and pain (Novak et al., 2013). Progressive musculoskeletal changes associated with childhood growth and co-existing disturbances in body function can result in life reducing deformity and pain (Holmes, Brock, & Morgan, 2018; Parkinson, Gibson, Dickinson, & Colver, 2010; Wawrzuta et al., 2016). Together, with environmental constraints, this complex disorder can significantly, but variably, impact health, functioning, participation and quality of life throughout the lifespan (Makris, Dorstyn, & Crettenden, 2019; Usuba, Oddson, Gauthier, & Young, 2014). The variety and often subtle, early clinical features of cerebral palsy can make early identification challenging in some settings (Boychuck et al., 2019).

The evidence base for the effectiveness and efficacy of interventions for people with cerebral palsy has expanded. The majority of interventions however are supported by inconclusive or lower-level evidence (Novak et al., 2013). Systematic reviews and clinical guidelines provide helpful information in knowing which interventions are more likely to

yield positive outcomes from an intervention, although less able to precisely predict how an individual child with cerebral palsy will respond (Damiano, 2014). The heterogeneous, and often complex, presentation of cerebral palsy requires management to be individualised to the child. The quality of interventions and services is contingent on the quality and thoroughness of an individualised assessment process (Greenhalgh, Howick, & Maskrey, 2014).

This introductory chapter provides an outline of the research field, the purpose of the research and the structure for the work undertaken. An initial description outlines the following features: pertinent frameworks informing current paediatric practice; assessment in relation to these frameworks; current assessment practices; and barriers to changing assessment practice. The research purpose, objectives and thesis structure follow these sections.

1.2 Influential frameworks in paediatric disability and healthcare

Current views about what constitutes best practice in assessment for children with cerebral palsy are informed by three prominent theoretical frameworks: the International Classification of Functioning Disability and Health (ICF) (WHO, 2001); Evidence-based practice (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996); and, Family-centred care (Arango, 2011; King & Chiarello, 2014). Each framework has been transformative for healthcare provision for children with disabilities over the past decades. The confluence of these influential frameworks provides the context for current clinical practice.

1.2.1 International Classification of Functioning Disability and Health

In the healthcare context, disability is currently understood through the conceptual framework and classification system adopted by the World Health Organization—the ICF (WHO, 2001). The ICF framework integrates two valid but dichotomous models of disability—medical and social—to provide a holistic, bio-psychosocial model of health and disability. The framework is unique in its presentation of human functioning as a continuum of health and disablement relevant to all individuals irrespective of health conditions (Mitra & Shakespeare, 2019). The ICF framework provides a common platform for communication between people with disabilities, researchers, healthcare workers, and policy-makers in relation to the lived experience of a health condition (Colver, 2005; Rosenbaum & Stewart, 2004).

The ICF framework focuses on health and functioning and recognises individual disablement as arising from dynamic interactions between an individual's health condition and their environment (WHO, 2001). Five interacting components provide a scaffold for viewing an individual's health condition. Three components relate to the individual's functioning and disability: body functions and structures (anatomical body parts and physiological function of body systems); activity (execution of a task or action by an individual); and participation (involvement in a life situation). Two components relate to contextual factors: environmental—physical, social and cultural; and personal, such as age, gender and background (Majnemer, 2012; WHO, 2001). Disability is described in terms of impairments, activity limitations and participation restrictions. Bi-directional influences exist between components such that an intervention in one component area can impact another, but not necessarily in a linear or causal manner.

The ICF framework has influenced the way information and data about health and disability is conceptualised, gathered and interpreted (Jelsma, 2009). Of importance has been the recent focus on developing assessment tools to capture constructs across all components of the ICF; for example, the Young Children's Participation and Environment Measure (YC-PEM) (Khetani, Graham, Davies, Law & Simeonsson, 2015) and Focus on the Outcomes of Communication Under Six (FOCUS) (Thomas-Stonell, Oddson, Robertson, Walker, & Rosenbaum, 2015). These ICF-related assessment tools can potentially be used in clinical settings to identify, plan and evaluate the impact of individual interventions across the breadth of functioning, disability and health (Cerniauskaite et al., 2011). An accompaniment to the ICF classification system—the International Classification of Functioning Disability and Health, Child-Youth (ICF-CY) (WHO, 2007)—was published specifically for use with children and young people (aged 0–18 years), in recognition of the unique developmental and environmental changes occurring during childhood. The ICF-CY framework recognises the variety of influences on a child's functioning and therefore the different avenues by which a child's wellbeing can be enhanced (Rosenbaum & Stewart, 2004). A resolution to merge the ICF-CY into the ICF was adopted by the World Health Organisation in 2012 to create one ICF classification framework with more comprehensive coverage of all aspects of functioning across the lifespan (WHO, 2012).

1.2.2 Family-centred care

Family-centred care is an approach to healthcare decision making that focuses on the development of equal partnerships between families and service providers (Kuo et al., 2012). Principles of family-centred care include: the development of relationships founded on dignity and respect; open exchange of information so families can make informed

choices; ability to respond to family choices and priorities; and collaborative family-provider partnerships that support and strengthen child and family functioning (Dunst, Trivette, & Hamby, 2007; King & Chiarello, 2014; MacKean, Thurston, & Scott, 2005). Key elements include an emphasis on child and family strengths, family choice and control, and collaborative family-provider relationships (Espe-Sherwindt, 2008).

The family-centred approach is supported by an ecological family-systems theory of development (Bronfenbrenner, 1981) that adopts a strengths-based and family-focussed approach to intervention (Dunst & Trivette, 2009a). The fundamental premise is that the family provides the most knowledgeable and proximal influence and support to a child's development and wellbeing (King, Teplicky, King, & Rosenbaum, 2004). In contrast to traditional deficit-based and child-focussed models, intervention within family-centred care has a focus on help-giving in the form of informal supports and resources geared towards building family capacity. Collaborative partnerships are described as having two practice components—relational and participatory (Dunst et al., 2007). Relational practices display empathy, active listening and positive beliefs in family capabilities (Dunst et al., 2007). Participatory practices promote family involvement in the therapy decision making process (Dunst & Trivette, 2009a). Family-centred care is well established in the literature as being strongly associated with positive outcomes and is now accepted as best practice in the childhood disability field (Brewer, Pollock, & Wright, 2014; Dunst & Trivette, 2009b; Järvikoski, Härkäpää, Martin, Vasari, & Autti-Rämö, 2015; Shevell et al., 2019).

1.2.3 Evidence-based practice

Evidence-based practice is an approach to decision making that is applicable across healthcare professions; it builds on the ethos of evidence-based medicine defined as "the

conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett et al., 1996, p. 71). Four sources of information underpin evidence-based decision making: best available clinical research evidence; individual clinical expertise (proficiency developed from clinical practice); patient values and preferences; and, locally available resources (Sackett et al., 1996). Consideration of information from all sources—research, clinician and patient—is advocated to guard against not only ineffective and unsafe practices becoming entrenched and out of date, but also the inappropriate and ineffective application of research. Evidence-based practice is considered an ethical and professional responsibility that is integral to improving and delivering quality healthcare (Deville, McEwen, Arnold, Jones, & Zhao, 2015; Hush & Alison, 2011). Considerable attention has been given to promoting evidence-based practices related to interventions and therapist access, appraisal, and use of research to inform practice (Dijkers, Murphy, & Krellman, 2012; Dizon & Grimmer-Somers, 2011; Humphris, Littlejohns, Victor, O'Halloran, & Peacock, 2000; Iles & Davidson, 2006). More recently, attention has turned to the notion of evidence-based assessment (Danielson, Månsdotter, Fransson, Dalsgaard, & Larsson, 2019; Youngstrom et al., 2017).

1.3 Assessment: gathering the best evidence for best practice

Assessment practice has been influenced in recent decades by the evidence-based practice movement, the professional and consumer desire for improvement in the quality of care, and market-driven economic policies (Jette, 2005). Demonstrable evidence of clinical efficacy, robust governance and cost-effectiveness of healthcare and therapy services is now required by funders of healthcare and therapy services (Access Economics, 2008; Laver Fawcett, 2013). The use of exclusively intuitive and informal methods of

assessment—personal observations and judgements, and subjective documentation of outcomes—is challenged by a re-orientation towards quality appraisal, outcomes and cost effectiveness of care (Hollon, 2017; Laver Fawcett, 2013; Stokes & O'Neill, 2008). By incorporating all the elements of evidence-based practice (Sackett et al., 1996) evidence-based assessment is considered, for the purposes of this thesis, to be: *an assessment process where research is used to guide assessment tool selection and findings are integrated with clinician expertise and family preferences, within the context of available resources.*

1.3.1 Evidence-based assessment tools

The expectation for objective measurement to be part of usual assessment practice is now articulated in definitions of assessment across healthcare professions (Majnemer, 2010; Speech-Language & Audiology Canada, 2010; Van Sant, 2010). An assessment tool is used to collect data about the client that can support the therapists' clinical judgement during the assessment process (Laver Fawcett, 2013). The measurement properties of assessment tools need to be evaluated to ensure appropriate scaling, accuracy, reliability (consistency and reproducibility of scores), validity (extent to which the tool measures what it purports to measure), and responsiveness (ability to detect clinically meaningful changes over time) (Majnemer, 2012). Poor assessment tool development and/or limited psychometric testing may mean a tool is not fit-for-purpose for clinical or research use. The term 'evidence-based assessment tool' is used in this thesis to *describe assessment tools with published instructions on how to administer, score and interpret, and whose measurement properties have been assessed and have demonstrated acceptable levels of reliability and validity when used with children with cerebral palsy.* An evidence-based assessment tool can accurately measure the construct of interest that relates directly to the service or treatment

objectives and is relevant to the child and family (Jerosch-Herold, 2005). Evidence-based assessment tools are responsive to change (if designed for this purpose) and meet one or more of the purposes of measurement—to describe, discriminate, predict future status, or evaluate outcomes and changes in status over time (Majnemer, 2012; Vargus-Adams & Martin, 2011). Assessment tools include classification systems, scales, tests and outcome measures (Jette, Halbert, Iverson, Miceli, & Shah, 2009; Majnemer, 2010).

An increase in research focus on prevention and improving outcomes for children with cerebral palsy has led to a rapid increase in the number of evidence-based assessment tools available for clinical use (Colver, Fairhurst, & Pharoah, 2014). Selected areas of health and functioning across a range of ICF areas can be captured using evidence-based assessment tools. In some instances, generic or cerebral palsy-specific assessment tools may not capture the unique needs and priorities of a child and family. Furthermore, suitable assessment tools may not yet exist or be difficult to access, meaning individual functional goal areas that are important to the child and family may be missed (Engelen, Ketelaar, & Gorter, 2007; Steenbeek, Gorter, Ketelaar, Galama, & Lindeman, 2011). Also, only a few of the available discriminative tools are validated to detect clinically important change over time (McDougall & Wright, 2009). Patient-reported outcome measures can potentially address child and family priorities more easily; however, further research is needed on the responsiveness and measurement error for outcome measures in the neurodisability field (Janssens et al., 2016; Knox, 2016). Individualised goal setting is essential in determining child and family priorities and areas requiring more detailed assessment. However, goals that are overly broad and loosely set make it difficult to accurately measure and document change if it has occurred (McDougall & Wright, 2009). Individualised assessment tools

such as the Canadian Occupational Performance Measure (COPM) (Law et al., 1990) and Goal Attainment Scaling (GAS) (Ottenbacher & Cusick, 1990) can measure outcomes that are meaningful to the individual child and family when goals are developed collaboratively and therapists are skilled in predicting goal achievement. The complementary use of generic and individualised assessment tools in clinical practice is widely recommended (McDougall & Wright, 2009; Palisano, 2006; Playford, Siegert, Levack, & Freeman, 2009; Steenbeek et al., 2011). When matched and used together, an individualised assessment tool can describe the relevance of a change measured by a generic tool, which in turn can help explain factors contributing (or not contributing) to goal attainment (Steenbeek et al., 2011). Within the evidence-based practice paradigm, clinicians need to keep up to date with the emergence of new tools, their psychometric properties and relevance to practice, and develop and maintain the necessary skills to select and implement tools with fidelity in the clinical setting—a task that can be overwhelming for clinicians and expensive for departments in terms of materials and professional development (Knox, 2016; Pavão, Silva, Dusing, & Rocha, 2017; Wright & Majnemer, 2014).

1.3.2 Benefits of using evidence-based assessment tools

Incorporating evidence-based assessment tools into clinical practice benefits the healthcare process and stakeholders. For children and families, evidence-based assessment tools can provide clear, objective information about their child's strengths and difficulties and demonstrate changes and progress over time. Prognostic information can assist families to anticipate future resources that may be necessary (Majnemer, 2010; Russell et al., 2010). Information from evidence-based assessment tools can inform the setting of measurable individualised goals that are meaningful, realistic and attainable (Majnemer, 2010).

Routine use of evidence-based assessment tools is critical to the prevention and management of secondary musculoskeletal impairments and their sequelae for children with cerebral palsy (Elkamil et al., 2011). If left undetected and unmonitored, musculoskeletal impairments can lead to issues such as severe contractures, pain, hip dislocation, scoliosis, skin breakdown, poor nutrition and respiratory compromise (Dobson, Boyd, Parrott, Nattrass, & Graham, 2002). Progressive musculoskeletal deformity is associated with reduced levels of motor function (Bartlett et al., 2014), pain (Parkinson et al., 2010), reduced quality of life in the long term (Gajdosik & Cicirello, 2002), and high personal, medical and attendant care costs (Access Economics, 2008). Regular surveillance and early detection of primary and secondary impairments enable timely referral and management (Hägglund et al., 2014).

For therapists, results from evidence-based assessment tools provides objective information to inform clinical judgement and decision making. When combined with parent and child preferences and knowledge, information from objective measurement informs realistic and meaningful goal setting and the ability to monitor outcomes of interventions. Including evidence-based assessment tools as part of the assessment process provides accountability to clients and families, the service, and professional organisations (Laver Fawcett, 2013; Majnemer, 2012; Stokes & O'Neill, 2008). A systematic review of the evidence for interventions for children with cerebral palsy highlighted uncertain outcomes from approximately 70% of interventions currently used (Novak et al., 2013). Given these uncertain effects and the unique presentation of each child with cerebral palsy, it is essential that evidence-based assessment tools be used to evaluate outcomes from individual interventions and clinical programmes (Hanna et al., 2007; Novak, Hines, Goldsmith, &

Barclay, 2012). Gathering and applying information from evidence-based assessment tools contextualises research information within clinical practice for individual children and families.

Incorporating evidence-based assessment tools into practice enables service organisations, policy makers and funders to demonstrate the effectiveness and efficiency of existing programmes, identify gaps in services and justify new programmes. Service quality can be assessed in terms of child outcomes, parent satisfaction and overall programme goals. Evidence-based assessment tools are important in demonstrating how or if allied health interventions improve health outcomes, productivity and quality of life into adulthood and decrease the significant economic costs of cerebral palsy at the individual and societal level (Access Economics, 2008).

1.3.3 Use of evidence-based assessment tools in clinical practice

Therapists' recognition of the importance of using evidence-based assessment tools is widely reported (Duncan & Murray, 2012; Feuerstein et al., 2017; Grimmer-Somers, 2007; Russell et al., 2010; Schreiber, Stern, Marchetti, & Provident, 2009). Given this recognition and the wide-ranging applications and benefits reported, it could be anticipated that uptake of evidence-based assessment tools within clinical practice would easily ensue. However, recent surveys of allied health practitioners from different areas of practice indicate that evidence-based assessment tools are yet to be embedded into clinical practice, suggesting adoption of evidence-based assessment tools into daily practice is not straightforward (Chard, 2006; Diamantis, 2006; King, Wright, & Russell, 2011; Saleh et al., 2008; Stapleton & McBrearty, 2009).

The extent of evidence-based assessment tool use varies across clinical area of practice, location and discipline. In the management of low back pain, 40% of physiotherapists from New Zealand routinely used evidence-based assessment tools (Copeland, Taylor, & Dean, 2008), while 10% of occupational therapists working in rheumatology in the United Kingdom used evidence-based assessment tools (Blenkiron, 2005). A similar observation was made of Irish therapists working with adults with disabilities, where consistent use of available evidence-based assessment tools was low (Stapleton & McBrearty, 2009). In the United Kingdom, Diamantis (2006) reported 27% of occupational therapists working in private practice used evidence-based assessment tools all of the time, while an earlier study reported 10% of paediatric occupational therapists across all settings using standardised assessments all of the time (Howard, 2002). Higher rates of use were found in a survey of Canadian paediatric occupational therapists, physiotherapists and speech pathologists (Hanna et al., 2007): 59% percent of therapists used evidence-based assessment tools at least weekly with variable use between settings. A nationwide survey of randomly selected American Physiotherapy Association members reported a non-use rate of 52%, with almost half of non-users indicating they had no intention to use evidence-based assessment tools in the future (Jette et al., 2009). A nationwide survey of occupational therapists from the United States reported similar proportions of non-use (Piernik-Yoder & Beck, 2012). Overall, levels of actual and intended use of assessment tools appear to be low but variable between settings and areas of practice.

Generic issues arise in the literature related to which assessment tools are used by therapists. In three different nationwide surveys of physiotherapists from North America, approximately 20% of assessment tools used were reported to be "home-grown" with no

psychometric evaluation (Burtner, McMain, & Crowe, 2002; Jette et al., 2009; Kay, Myers, & Huijbregts, 2001). Similarly, over 30% of Irish occupational therapists reported using their own non-standardised, department-based assessments (Stapleton & McBrearty, 2009) and 22% use non-validated assessments for children. Fidelity of implementation of evidence-based assessment tools is also a reported problem. Assessments are frequently modified or used outside the recommended client population and age range (Beckers & Bastiaenen, 2015; Hanna et al., 2007; Piernik-Yoder & Beck, 2012). Poor fidelity and use of non-standardised assessment tools have potentially harmful consequences for decision making, service quality and future development of the child and family (Beckers & Bastiaenen, 2015; Laver Fawcett, 2013).

1.3.4 Use of evidence-based assessment tools for children with cerebral palsy

The assessment practices of therapists working specifically with children with cerebral palsy have been reported in a small number of studies. A Scottish survey of 17 physiotherapists working in metropolitan, rural and community settings reported low levels (30%) of routine use of six assessment tools, of which two were validated for children with cerebral palsy (Craig, 1999). A Canadian study of 85 occupational therapists and 62 physiotherapists for young children with cerebral palsy used telephone interviews to ascertain typical practices using case vignettes (Saleh et al., 2008). Sixty-seven percent of occupational therapists and 91% of physiotherapists reported using at least one evidence-based assessment tool for at least one of the four vignettes, with most focusing on gross motor function (Saleh et al., 2008). Higher frequencies of assessment tool use were reported in this study; however, the assessment tool used most often by occupational therapists was a non-standardised checklist—the Talbot Battery (Talbot, 1993).

A cross-sectional survey by McConnell, Johnston, and Kerr (2012) investigated the upper limb management practices of experienced physiotherapists and occupational therapists for children with cerebral palsy. Similar to Hanna et al. (2007), the most frequently used tool by occupational therapists—the Erhardt (Erhardt, Beatty, & Hertsgaard, 1981)—has no published evidence of psychometric evaluation. Physiotherapists reported high levels of use of assessment tools to quantify aspects of body structure and function, such as range of motion (64%) and muscle strength (63%). Available evidence-based assessment tools for evaluating activity-level constructs of the ICF—the Assisting Hand Assessment (Krumlinde-Sundholm & Eliasson, 2003) and Shriners Hospital Upper Extremity Evaluation (Davids et al., 2006) and classification tools, such as the Manual Abilities Classification System (MACS) (Eliasson et al., 2006), were not used by therapists.

As in other fields of practice, the studies by Craig (1999), Saleh et al. (2008), McConnell et al. (2012), and Hanna et al. (2007) suggest a wide variation in the amount and types of assessment tools available to therapists for children with cerebral palsy. Assessment tools do not appear to be used routinely and, when used, may not cover the breadth of ICF components or have the psychometric evaluation necessary for quality assessment and clinical decision making. The studies reported here may be an overestimate of actual use due to the social desirability bias that can come with self-reporting measures (Adams, Soumerai, Lomas, & Ross-Degnan, 1999). Some available evidence-based assessment tools are not being used, suggesting a gap between the development of evidence-based assessment tools and their use in therapy for children with cerebral palsy. Understanding what tools are being used, by whom and how often, would help in understanding usual

practice and possible areas for change to improve assessment practices for children with cerebral palsy.

1.3.5 Barriers to using evidence-based assessment tools in clinical practice

Common themes emerge from the literature investigating barriers to therapists' uptake of evidence-based assessment tools in practice. Practitioner-related barriers included access to tools, knowledge, skills and confidence in selecting and using assessment tools (Huijbregts, Myers, Kay, & Gavin, 2002; King et al., 2011; Law et al., 1999). Time was cited often, but was not a consistent barrier to use (Jette et al., 2009; King et al., 2011; Schreiber et al., 2009; Stapleton & McBrearty, 2009). A perceived low value of assessment tools and burden for patients were reported by health practitioners as barriers to use (Colquhoun, Letts, Law, MacDermid, & Edwards, 2010; Jette et al., 2009). Lack of peer and managerial support, and limited resources within organisations were reported as a significant barrier in some settings (Duncan & Murray, 2012; Thomas & Law, 2013; Wedge et al., 2012). Hanna et al. (2007) identified only a small variance (6% to 7%) attributable to organisational 'measurement culture' effects within Canadian paediatric treatment centres. Greater variation in assessment tool use arose between therapists within centres suggesting personal level factors may be important determinants of use and an area needing consideration to effect change in practice. The most highly reported barrier across all paediatric studies was the inability of children with complex needs to complete the assessment, and the difficulty of finding assessment tools to address the spectrum of health issues and ICF components—an issue also reported in adult rehabilitation settings (Craig, 1999; Douglas, Swanson, Gee, & Bellamy, 2005; Hanna et al., 2007; Stokes & O'Neill, 2008). Factors related to the individual therapist and interpersonal relationships between

therapists and families have also been suggested as areas needing consideration in order to understand therapists' use of assessment tools (King et al., 2011; Russell et al., 2010).

1.4 Knowledge translation to increase the use of evidence-based assessment tools

Identifying strategies that can effectively move assessment tools from research into practice is an important but persistent challenge (Cane, O'Connor, & Michie, 2012; Graham et al., 2006; Grol, Wensing, & Eccles, 2005). Early knowledge translation efforts using traditional educational approaches to promote uptake of evidence-based assessment tools had limited success and also highlighted the complexity of changing clinicians' behaviour (Ketelaar, Russell, & Gorter, 2008; Novak & McIntyre, 2010). Although known barriers to therapists' use of assessment tools are cited in the literature, direct removal of obvious barriers does not predictably elicit the desired change in clinician behaviour (Nilsen & Bernhardsson, 2013). Direct causal links between identified barriers and eventual uptake of evidence-based practice cannot be assumed as numerous organisational and individual factors interact to influence clinicians' behaviours (Cane et al., 2012; Nilsen & Bernhardsson, 2013).

A recent systematic review of the effectiveness of interventions in increasing the use of standardised outcome measures by allied health professionals identified a positive effect overall, with improvements reported in 9 of the 11 studies; however, improvements were modest (Colquhoun et al., 2016). Definitive conclusions about what interventions were effective in promoting uptake could not be drawn due to low study quality and poor reporting on intervention descriptions. The modest effects were attributed, in part, to the reliance on education-only approaches and lack of theory-informed behaviour change strategies, and insufficient prior exploration and understanding of the barriers to use.

To guide knowledge translation the 'Knowledge to Action' framework has been proposed by Graham et al. (2006) to help plan and implement proposed changes in practice (Figure 1.1). Central to the framework is the development of the knowledge 'product'—a distillation of the knowledge and desired behaviour into a useable form for healthcare professionals. When an understanding of usual practice and the desired practice is sufficiently developed the 'product' is implemented as part of an 'Action cycle' involving users. The 'product' is adapted to the local context with strategies selected and tailored to promote uptake of the desired product, with uptake evaluated as part of a cyclical process. The original framework uses unidirectional arrows to denote the sequence of action steps. It has been proposed, however, that the arrows in the action cycle be made bidirectional to reflect the dynamic back and forth nature of implementation in actual practice (Li & van der Wees, 2015).
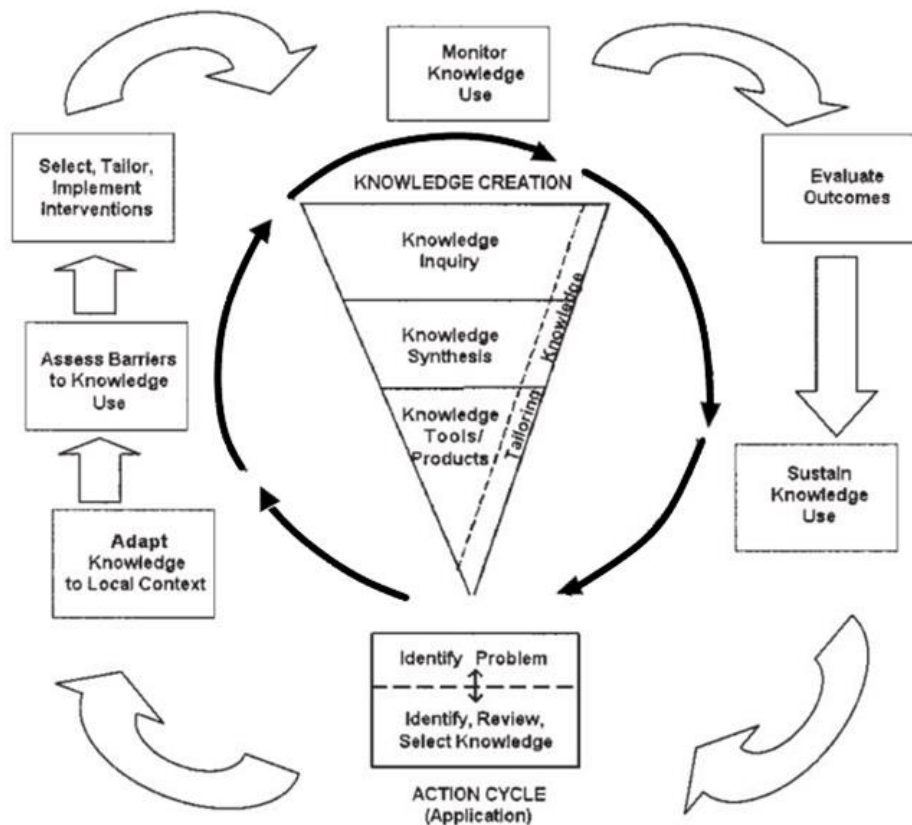
Figure 1.1. Knowledge to action process (Graham et al., 2006). Reprinted with permission.

Knowledge translation using the 'Knowledge to Action' framework is likely to be more effective when behaviour change strategies can be matched to known contextual barriers (Boaz, Baeza, & Fraser, 2011; Duncan & Murray, 2012; Grol & Wensing, 2004). In-depth exploration is needed to understand the nature of therapists' evidence-based assessment practices to discern actual barriers from perceived barriers within the real-world context of practice. Different epistemological approaches—qualitative and quantitative—are needed to address this gap in the understanding of therapists' assessment behaviours and the actual barriers to uptake (Nilsen & Bernhardsson, 2013). Studies that strive to understand the

contextualised evidence-based assessment behaviours of allied health practitioners working with children with cerebral palsy and their families are needed but do not currently exist.

Including evidence-based assessment tools in the therapy process for children with cerebral palsy is essential to ensure high quality assessment that is evidence-based and aligned with best practice. Evidence-based assessment underpins clinical decision making and enables interventions to be evaluated, individualised and accountable to multiple stakeholders. Studies suggest that evidence-based assessment tools are not widely used by paediatric therapists in day-to-day practice, and current knowledge translation interventions to promote their use, based on currently known barriers, have unpredictable or modest outcomes.

Further understanding of this research-practice gap is needed to inform knowledge translation interventions in order to increase therapists' use of evidence-based assessment tools. In particular, an in-depth understanding is needed of usual practice and why therapists find it difficult to embed evidence-based assessment tools in day-to-day practice when working with children with cerebral palsy and their families.

1.5 Research aim

The overall aim of this thesis was to generate a body of knowledge that can help inform translation of evidence-based assessment tools into clinical practice for children with cerebral palsy in a way that aligns with best practice. Specifically, this research aimed to develop an in-depth contextualised understanding of what is needed for allied health therapists (occupational therapists, physiotherapists and speech pathologists) to more easily

embed evidence-based assessment tools within clinical best practice for children with cerebral palsy and their families.

This aim was met by research conducted sequentially and related to: 1) the published literature; 2) allied health practitioner assessment practices; and, 3) the assessment experiences of families. A range of research methods was used to address the objectives of the research programme.

Specifically, the objectives of the research programme were:

1. To evaluate what is currently known about the extent of allied health practitioners' use of evidence-based assessment tools for children with cerebral palsy. This objective was met through systematic review of previously published literature reporting allied health practitioners' use of assessment tools for children with cerebral palsy.

2. To design and conduct a study aimed at understanding the contextual and personal influences on allied health practitioners' use of evidence-based assessment tools and the extent of use, within two different community organisations (one large, one small) in Victoria, Australia. The findings from this study informed the research direction and remaining objectives of the thesis.

3. To identify what is known from previous studies about parents' experiences of formal assessment for their child with cerebral palsy. This objective was met through a scoping review of published studies reporting the assessment experiences of parents of children with cerebral palsy.

4. To design and conduct a study to understand parents' experiences of evidence-based assessment for their child with cerebral palsy. A qualitative research design using interpretative description was taken to meet this objective.

1.6 Thesis structure

The structure of this thesis is centred around three papers accepted for publication and a scoping review linking the second and third paper. Each chapter addresses a single study—commencing with an introduction that is followed by the study and ending with a conclusion. Introductions to Chapters 2 and 3 include an extended discussion and justification for the research design of the study that incorporates the theoretical orientation and data collection methods adopted, followed by the aim, objective and specific research questions. A final overarching discussion chapter provides an overall synthesis of the work.

1.7 Thesis outline

An overview of the chapters succeeding this introduction is now provided.

1.7.1 Chapter 2: A systematic review of the literature

This chapter reports the findings of Study 1—a systematic review of the literature summarising current evidence on the extent, type and gaps in the use of evidence-based assessment tools for children with cerebral palsy. An introduction outlining the review type and method precedes the published paper (O'Connor, Kerr, Shields, & Imms, 2016a); this is then followed by an update of the systematic review. The updated review findings are discussed in relation to the original systematic review. Conclusions from the systematic review are summarised and the area of research need that informs the next study and chapter is identified.

Publication: O'Connor, B., Kerr, C., Shields, N., & Imms, C. (2016a). A systematic review of evidence-based assessment practices by allied health practitioners for children with cerebral palsy. *Developmental Medicine and Child Neurology*, 58(4), 332-347. doi:10.1111/dmcn.12973

1.7.2 Chapter 3: Understanding allied health practitioners' use of evidence-based

assessments for children with cerebral palsy

The introduction to Chapter 3 includes an extended methods section to provide background and rationale for the mixed methods research design chosen for Study 2. The accepted manuscript arising from Study 2 (O'Connor, Kerr, Shields, & Imms, 2019) is followed by a conclusion highlighting the main findings and implications for the direction taken for the next stage of the thesis.

Publication: O'Connor, B., Kerr, C., Shields, N., & Imms, C. (2019). Understanding allied health practitioners' use of evidence-based assessments for children with cerebral palsy: a mixed methods study. *Disability and Rehabilitation*, 41(1), 53-65. doi:10.1080/09638288.2017.1373376

1.7.3 Chapter 4: Caregiver experiences of evidence-based assessment for children with

cerebral palsy: A scoping review

The purpose of the scoping review conducted and described in Chapter 4 was to determine what published research evidence existed about parents' experiences of formal assessment for their child with a disability. This review was needed to identify gaps in knowledge in our understanding of parents' experiences and to inform the design of Study 3. The scoping

review is preceded by an introduction and followed by a conclusion outlining the findings from the review.

1.7.4 Chapter 5: Parents' experiences of evidence-based assessment practices for their child with cerebral palsy

This chapter includes the final published paper in this thesis (O'Connor et al. 2019). The purpose of Study 3 was to explore formal evidence-based assessment from the perspective of parents of children who have cerebral palsy. The chapter commences with an introduction and overview of the qualitative approach taken to meet the study aim. A conclusion follows the early online published manuscript.

> **Publication:** O'Connor, B., Kerr, C., Shields, N., Adair, B., & Imms, C. (2019). Steering towards collaborative assessment: A qualitative study of parents' experiences of evidence-based assessment practices for their child with cerebral palsy, 1-10. *Disability and Rehabilitation* (in press).

1.7.5 Chapter 6: Overall Discussion and Conclusions

This final chapter presents a synthesis of the research findings from the studies in the preceding four chapters. The findings are considered in relation to the overall aim of the research and the strengths and limitations of the work. The significance and implications of the research are discussed in relation to both healthcare professionals, families, educators and researchers and the proposed directions for future research.

Chapter 2 A systematic review of the literature

2.1 Introduction

This chapter provides an overview of the methodological approach chosen in relation to addressing the first objective of the thesis. The methodological approach is followed by Study 1 (the systematic review published in 2016), and an update of the review conducted in 2019. The findings from the systematic review and update are then discussed with implications drawn with regard to the need for and direction of the subsequent studies in this thesis. Supplementary information for Study 1 and a journal commentary arising from the published paper can be found in Appendix A.

Many approaches can be taken to reviewing the large volumes of health science literature now available to inform clinical and policy decisions. Different terms are used to describe different types of reviews. A number of authors have published pre-defined criteria to distinguish between review types (Grant & Booth, 2009; Paré, Trudel, Jaana, & Kitsiou, 2015). Although different classifications have been used, groupings of the main review types, or typologies, have similarities that help clarify the review terminology and the different dimensions of the review process (Grant & Booth, 2009). Reviews of health information are grouped according to the methods used to search, appraise, synthesise and analyse the literature (Grant & Booth, 2009). Irrespective of the selected approach to the review, it is important that the review process is transparent, and the primary goal of the review is clearly identified (Paré et al., 2015). The approach taken to the review needs to consider the aim, the breadth of the review question and the pragmatic trade-off between the time available to conduct the review and its scientific rigor (Grant & Booth, 2009; Paré

et al., 2015). The typology developed by Grant and Booth was available at the start of this research programme and has been used in this thesis to describe the type of review employed—a systematic review.

The first objective of this thesis was to evaluate what is currently known about the extent of allied health practitioners' use of evidence-based assessment tools for children with cerebral palsy. Specifically, the primary and secondary research questions were as follows:

1. What is currently known about the extent of use of evidence-based assessments by allied health practitioners in the management of children with cerebral palsy?

    a. Are evidence-based assessments used by allied health practitioners when working with children with cerebral palsy?

    b. If so, what assessment tools are used?

    c. Who uses assessment tools?

    d. How often are evidence-based assessments used by allied health practitioners?

A systematic review of the literature was chosen to address this objective and specific research questions. Systematic reviews follow a robust scientific protocol to summarise multiple primary sources of available evidence on the same question (Liamputtong, 2013b). Systematic reviews use methods that limit bias in the following ways: reproducible and structured criteria are used to select articles; quality assessment of research designs and study characteristics are appraised; and a structured or narrative synthesis of the evidence is conducted (Grant & Booth, 2009). The systematic review process in itself is subject to bias, but if conducted rigorously, bias can be limited and reliability and accuracy of the conclusions improved (Mulrow, 1994). To promote preparation and transparent reporting

of systematic reviews, an evidence-based checklist—'The Preferred Reporting Items for Systematic Reviews and Meta-Analyses protocols' (PRISMA-P) (Moher et al., 2015)—is recommended to guide authors in the systematic review process. Study 1 followed the PRISMA-P reporting recommendations.

2.2 Paper 1: A systematic review of evidence-based assessment practices by allied health practitioners for children with cerebral palsy

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O'Connor, B., Kerr, C., Shields, N., & Imms, C. (2016). A systematic review of evidence-based assessment practices by allied health practitioners for children with cerebral palsy. *Developmental Medicine and Child Neurology*, 58(4), 332-347. doi:10.1111/dmcn.1297

A systematic review of evidence-based assessment practices by allied health practitioners for children with cerebral palsy

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AIM The routine use of psychometrically robust assessment tools is integral to best practice. This systematic review aims to determine the extent to which evidence-based assessment tools were used by allied health practitioners for children with cerebral palsy (CP).
METHOD The Preferred Reporting Items for Systematic Reviews and Meta-Analysis protocols 2015 was employed. A search strategy applied the free text terms: 'allied health practitioner', 'assessment', and 'cerebral palsy', and related subject headings to seven databases. Included articles reported assessment practices of occupational therapists, physiotherapists, or speech pathologists working with children with CP aged 0 to 18 years, published from the year 2000.
RESULTS Fourteen articles met the inclusion criteria. Eighty-eight assessment tools were reported, of which 23 were in high use. Of these, three tools focused on gross motor function and had acceptable validity for use with children with CP: Gross Motor Function Measure, Gross Motor Function Classification System, and goniometry. Validated tools to assess other activity components, participation, quality of life, and pain were used infrequently or not at all.
INTERPRETATION Allied health practitioners used only a few of the available evidence-based assessment tools. Assessment findings in many areas considered important by children and families were rarely documented using validated assessment tools.

Optimizing health and quality of life outcomes for children with cerebral palsy (CP) is an aspiration shared by families, clinicians, and researchers. The use of robust assessment tools in allied health practice is an essential step towards achieving this and needs to be guided by 'best practice' frameworks in health and childhood disability.

An assessment tool is any device that collects data about the client that can support the therapist's clinical judgement during the assessment process.[1] Within the framework of evidence-based practice,[2] assessment involves the integration of findings from psychometrically robust assessment tools, if and when available, with findings from informal assessments, clinical expertise, and other information sources.[1] An evidence-based assessment tool has published instructions on how to administer, score, and interpret and has demonstrated acceptable levels of reliability and validity when used with the population of interest – in this case, children with CP.[3] Evidence-based assessment tools have constructs that relate directly to the service or treatment objectives and are relevant to the child and family.[4] They are responsive to change, if designed for this purpose. Such tools meet one or more of the distinct purposes of measurement which is to describe, discriminate, predict, or evaluate change over time.[5,6] Thus assessments include classification systems, scales, tests, and outcome measures.

There are many benefits of routinely using evidence-based assessment tools in clinical practice. When appropriately selected and used,[7] evidence-based assessment tools provide objective information about a child's strengths, predicted and actual progress over time, and changes associated with interventions and programmes.[8] Within the Family-Centred Practice[9] framework, valid and reliable assessment tools assist therapists to collaborate with children and families in functional goal setting, intervention planning, and in evaluation of outcomes.[3,10,11] Routine use of evidence-based assessment tools is effective in preventing secondary musculoskeletal impairments and their sequelae[12,13] in children with CP. Such impairments are associated with reduced motor function,[14] pain,[15] and quality of life in the long term,[16] and with high personal, medical, and attendant care costs. Early detection through regular surveillance enables timely referral and management. Use of evidence-based tools enables therapists to remain professionally accountable to children and families, organizations and their funders, and to inform the practice–research cycle.[17,18]

The International Classification of Functioning Disability and Health, Child and Youth version (ICF-CY)[19] framework can guide therapists in evaluating intervention outcomes across the domains of body structures, body functions, activities, and participation.[20,21] Vargus-Adams and Martin[22,23] have reported on the 'Domains of Importance' identified by children and youth with CP and their families. Domains included: mobility, self-care, communication, comfort, and participation in community life. This confirms the importance of clinicians employing tools that assess outcomes across all ICF domains, as well as pain and quality of life.

Despite the known benefits of evidence-based assessment, professional endorsement, and educational efforts, and the recognized importance of standardized assessment by allied health practitioners,[24–26] recent surveys suggest that routine use in clinical practice remains low, with consistently half or less of allied health practitioners using such tools in clinical practice.[6,27–30] In the area of CP management, the number of evidence-based assessment tools has increased rapidly over the past 15 years; many robust tools have been available for some time.[21] In spite of this, assessment and intervention practices for children with CP have been reported as variable and inconsistently matched with recommended 'expert best practice'.[31]

The purpose of this study, therefore, was to determine the extent to which allied health practitioners use evidence-based assessment tools in their clinical practice for children with CP. We wanted to ascertain: (1) if standardized assessments were used by allied health practitioners when working with children with CP and, if so, (2) what assessment tools were being used, by whom, and how often. Findings of this review will provide evidence about whether the assessment tool used by allied health practitioners reflects currently accepted frameworks for best practice in CP management.

METHOD

A systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis protocols (PRISMA-P) 2015 guidelines.[32]

Search strategy

An a priori search strategy was developed using the free text terms: 'allied health practitioner', 'assessment', and 'cerebral palsy', and their related subject headings. The search was adapted for the following electronic databases: CINAHL, Embase, Medline, PsycINFO, Cochrane Library, ERIC, and Web of Science. The primary search was conducted in January 2014 and updated in May 2015 (see Appendix S1, online supporting information). All retrieved articles were imported into the bibliographic database, EndNote X7 (Thomson Reuters [Scientific] LLC, Philadelphia, PA, USA). Reference lists of full text articles were manually searched and citation tracking was performed on included articles via Google Scholar.

What this paper adds
- A few evidence-based assessment tools are used a lot; a lot are used a little or not at all.
- Gross motor function is the focus of frequently used evidence-based tools.
- Use of evidence-based assessment tools for children with CP does not appear aligned with best practice in many settings.

Selection criteria

Articles were included if they met all of the following criteria: (1) the study population included occupational therapists or physiotherapists or speech pathologists, or their written records; (2) the study population had a defined clinical caseload that included children with CP aged 0 to 18 years; and (3) the study described assessment practices in a clinical setting or the clinical use of assessment tools developed specifically for children with CP. Additional inclusion criteria were that articles needed to be full-text journal publications reporting research studies in English from the year 2000 onwards. This publication period was chosen as it coincided with the emergence of currently accepted frameworks for practice, i.e. the ICF,[33] Evidence-based Practice,[2] and Family-Centred Practice.[9] Articles were excluded if they reported investigations of therapeutic interventions, clinimetric properties of measures, or solely on barriers and facilitators to assessment tool use.

Study selection

Initial screening by one reviewer (BOC) removed duplicates, conference proceedings, review articles, and articles in languages other than English. Decision rules for selection criteria were piloted on a subset of 50 titles and abstracts to ensure consistency between assessors. Study selection was performed by two independent reviewers (BOC and CK) in two stages. In stage 1, selection criteria were applied to the title and abstract with reasons for study exclusion documented. Results were compared and agreement reached through consensus where differences occurred. When a decision could not be made, articles were retained for the next stage. In stage 2, the same selection criteria were applied to the full text of the article with reasons for exclusion documented. When differences occurred consensus was sought and, if not reached, a third reviewer (CI) was consulted and a final decision achieved through discussion. Authors were contacted if more information was needed to determine eligibility for inclusion.

Data extraction

A data collection form was developed and trialled independently by two assessors to check for consistency in data items extracted. Following minor modification, the final form was independently applied by each assessor to each included article to extract data on study and participant characteristics, study quality, and study findings. When articles reported on knowledge translation intervention studies, only baseline data were extracted to reflect usual clinical practice. Extracted data were compared between assessors to check for accuracy and agreement before anal-

ysis. Inconsistencies between reviewers were reconciled by discussion.

Data synthesis

Due to heterogeneity in study design, data collection methods, and reporting of study outcomes it was not feasible to combine data in a meta-analysis. A narrative approach was used to synthesize data on study quality and risk of bias, allied health participants and their work context, reporting of assessment tool use, overall use of standardized assessments by allied health therapists, the specific assessment tools used, their frequency of use, and characteristics of the tools in high use.

Risk of bias assessment

It is essential that criteria are applied to survey research to assess the extent of scientific rigour, potential sources of bias, and overall generalizability of study results.[34] Assessing the risk of bias of non-experimental survey research using existing quantitative tools is problematic as items related to intervention are not applicable. Items for appraising the conduct and reporting of survey research were derived from Kelley et al.[35] and applied to included articles. As the included studies used questionnaires or checklist survey instruments, the risk of bias assessment focussed on validation and administration of these instruments in addition to study design and sampling methods. Appraisal of the included knowledge translation intervention studies was restricted to sampling and baseline data collection methods only, as the intervention and outcome components were not of specific interest to the review question.

Sources of bias affecting the external validity of included studies were assessed on the basis of study design, sampling method, response rates, and sample size. Included studies were classified using the Oxford Centre for Evidence-Based Medicine's (OCEBM) 'Levels of Evidence' rubric.[36] Each study was graded from levels 1 to 5 according to the study design and sampling method, where level 1 indicated the most robust design.

Response rates are an important indicator of the response bias of survey research.[34,37,38] Baruch and Holtom[38] recommended a benchmark response rate of 55% for individual survey responses and 35% to 40% for organizational surveys, with a 20% standard deviation (SD). They recommended that downward variations be accompanied by an explanation or analysis if non-responders and responders differ in ways that could affect the generalizability of results. We employed a '3-star' rating with criteria based on these values and the reporting of non-usable questionnaires. One star was allocated when the usable response rate was below 1SD of the benchmark,[38] within 1SD without explanation, or the usable response rate could not be determined. Two stars were awarded when the usable response rate was within 1SD of the benchmark with an explanation for refusals or non-usable responses. Three stars were awarded when usable response rates were

at or above the benchmark with an explanation provided for refusals and/or non-usable responses. The likelihood of self-selection and response biases influencing the study's external validity was considered for each study.

Assessment of internal validity was based on the data collection tool and method. Validity and reliability of the data collection tools used in each study was categorized using a 3-star rating system, with criteria based on the tool's development and testing. One star was allocated for tool validity if there was no detail or minimal external review reported on the tool's development. Two stars were given where there was evidence of tool revision following single pre-test in a sample similar to the study group. Three stars were given when there was evidence of tool revision after at least two rounds of pre-testing in a sample similar to the study group or when acceptable tool validity had already been established. Rating and criteria for tool reliability was one star when no reliability testing was reported, two stars for a pre-existing tool with results of preliminary reliability testing reported, and three stars were awarded for a developed or pre-existing tool with acceptable reliability statistics reported.

RESULTS

The electronic searches identified 4843 citation records after removal of duplicate copies (Fig. 1). After screening of the titles and abstracts, 104 articles were retrieved for full-text review. Manual searching of reference lists generated a further nine articles. Of the 113 articles, 99 were excluded for the reasons listed in Figure 1, resulting in 14 articles that met the inclusion criteria.[26,31,39–50] Of the 14 studies, 10 were cross-sectional surveys of allied health practitioners, using mixed methods[31,39,42,43,45–47] and quantitative approaches.[26,44,50] One study conducted a retrospective audit of files.[41] The remaining studies were knowledge translation intervention studies that adopted before-and-after,[40] case report,[49] and cluster randomized controlled trial[48] research designs. The 14 studies investigated clinical assessment practice by a range of allied health professionals – from a variety of countries – in different clinical settings for children with CP (see Table I).

Risk of bias

The outcome of the risk of bias assessment is summarized in Table II. External validity, as considered via the OCEBM's Levels of Evidence,[36] response rates, and sample sizes was strong in four articles[31,44,45,48] and adequate in five articles.[26,40,41,43,49] External validity was reduced in one study[39] because of a high number of unusable and unexplained responses and, in another,[46] due to a small sample size. Eligible population sizes were not defined in three studies[42,47,50] making it difficult to determine actual or useable response rates. However, one of these studies[50] used multiple methods of recruitment to maximize their number of respondents. The possibility of response and self-selection biases should be considered when interpreting findings in 4 of the 14 included studies.[39,42,46,47]
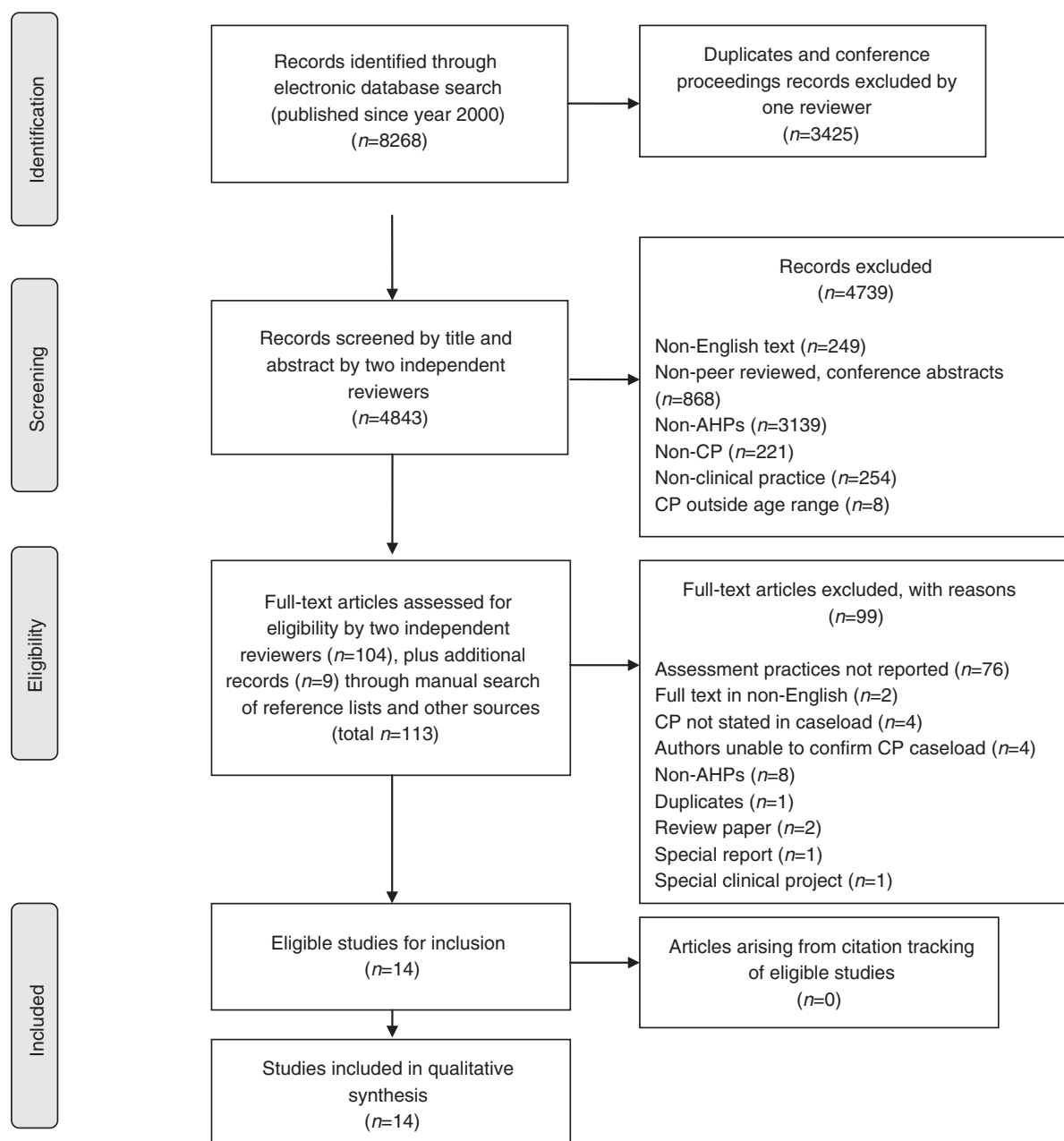
Figure 1: PRISMA flow diagram. CP, cerebral palsy; AHP, allied health practitioner.

The internal validity of eight studies[26,31,40,41,44,46,48,49] was strong (Table II). Study-specific questionnaires were used in 11 studies.[26,39,40,42–45,47–50] Two studies used checklists: one a pre-existing checklist for a file audit[41] and the other a study-specific checklist for direct observation of clinical practice.[46] Clinicians were commonly asked to self-report on their actual or hypothetical clinical practice via postal and online surveys[26,39,40,42–45,47,50] and telephone interviews.[31] Additional data sources such as independent review,[46] peer review,[48] and medical chart review[42,49] were used in three studies to improve the validity of results. Five studies scored three stars for the tool validation process.[26,31,40,44,48] Two studies scored three stars for tool

reliability testing[40,48] (Table II). Potential threats to internal validity, such as recall and social desirability biases and tool validity and reliability issues, need to be considered when interpreting the findings of six included studies.[39,42,43,45,47,50]

Participants and settings

The 14 included studies (Table I) reported on the assessment practices of physiotherapists (11 studies[26,31,39–44,46,48,49]), occupational therapists (nine studies[26,31,41–46,48]) and speech pathologists (six studies[26,41,42,47,48,50]). Participants were recruited from professional body registers,[31,45,47] national publically funded services,[26,40–42,44,46,50] and sole

Table I: Description of studies

Source	Design	Sample	Workplace setting	Country	Years (y) working in child disability mean (SD)	Percentage (%) AHP seeing children with CP	Percentage (%) data referring to children with CP	Characteristics of children with CP	Percentage (%) of therapists using standardized assessments and timeframe		
									OT	PT	SP
Hendriks et al.[42]	Cross-sectional survey mixed	32 OT; 40 PT; 28 SP working in therapeutic toddler classes	Multidisciplinary classroom-based day-care programmes in medical setting	Netherlands	ND	ND	49	0–5y	Unable to extract data[a]	Unable to extract data[a]	Unable to extract data[a]
Howard[45]	Cross-sectional survey mixed	212 OT members of national professional body	Hospital 24%; specialized clinic 44%; school 72%; home 60%; other 32%	UK	8.4 (6.38)	82	ND	0–19y	47 (≥half the time)	NA	NA
Lannin et al.[43]	Cross-sectional survey mixed	14 OT; 45 PT referrers to Botox Clinic	Public hospitals, community- and centre-based rehabilitation programmes, and private practice	Australia	70% more than 10	100	100	ND	56 (always)	56 (always)	NA
Debuse et al.[39]	Cross-sectional survey mixed	12 PT hippotherapy subgroup members of professional body	Special school 7%; national health service 36%; volunteer 36%; self-employed 14%	UK	4 (0–10) in hippotherapy	100	100	ND	NA	25 (ND)	NA
		36 PT licensed hippotherapists	Special schools 13%; self-employed 74%	Germany	11 (2–28) in hippotherapy	100	100	ND	NA	0% (ND)	NA
Hanna et al.[26]	Cross-sectional survey quantitative	72 OT; 63 PT; 74 SP employees in children's rehabilitation programmes	Community ambulatory rehabilitation programme 100%	Canada	9.1 (0.1–38.0)	ND	40[b]	ND	59 (daily or weekly); 11 (few times per year)	59 (daily or weekly); 11 (few times per year)	59 (daily or weekly); 11 (few times per year)
Saleh et al.[31]	Cross-sectional survey mixed	85 OT; 62 PT employed in paediatric rehabilitation	OT urban 61.2%; suburban 17.6%; PT urban 69.4%; suburban 9.8%	Canada (Quebec)	OT user=8.2 (8.1); non-user=9.1 (9.4); PT=12.4 (9.6)	100	100	0–4y; GMFCS II and IV, uni- and bilateral CP	67 (at least once in 1 or more of 4 case studies)	92 (at least once in 1 or more of 4 case studies)	NA

Table I: Continued

Source	Design	Sample	Workplace setting	Country	Years (y) working in child disability mean (SD)	Percentage (%) AHP seeing children with CP	Percentage (%) data referring to children with CP	Characteristics of children with CP	Percentage (%) of therapists using standardized assessments and timeframe		
									OT	PT	SP
Russell et al.[40]	Before and after, without control mixed	122 PT employees from community rehabilitation centres	Large and small rehabilitation centres, preschools, schools, home, and community. Rural and remote 27.8%	Canada (east and west)	32% <5 74% >5	100	100	0–19y	NA	NA	NA
Wright et al.[46]	Cross-sectional study with Delphi survey mixed	3 OT; 1 PT employed in seating assessment clinics	Centres with multidisciplinary paediatric regional seating assessment service	Northern England, Scotland, Ireland	ND	ND	50	6mo–18y	0 (ND)	0 (ND)	NA
Joginder Singh et al.[47]	Cross-sectional survey mixed	157 SP national conference attendees; listed members of professional body working with children with developmental disabilities	Hospital 15%; schools 17%; private practice 51%; non-government 6%; other 35%	Australia	14.26 (9.66)	58	ND	0–12y (for listed members)	NA	NA	Unable to extract data[c]
		65 SP professional body members and Ministry of Health	University 9%; hospital 69%; school 0%; private practice 15%; non-government 9%; other 34%	Malaysia	5.91 (5.09)	77	ND	All ages	NA	NA	Unable to extract data[c]
McConnell et al.[44]	Cross-sectional survey quantitative	40 OT; 54 PT employees of national health service	Hospital 1%; specialized clinic 7.5%; schools 36.2%; community 25.5%; mixed 29.8%	Northern Ireland	12.0 (8.5)	100	100	All GMFCS Levels	NA	NA	NA
Tantilipikorn et al.[41]	Retrospective audit	Clinical medical records of 269 OT, PT, SP, social work, educator, orthotist	4 public hospitals; 2 special schools	Thailand (central region)	ND	100	100	0–14y	'Rarely reported' (1–3y)	'Rarely reported' (1–3y)	'Rarely reported' (1–3y)

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Table I: Continued

Source	Design	Sample	Workplace setting	Country	Years (y) working in child disability mean (SD)	Percentage (%) AHP seeing children with CP	Percentage (%) data referring to children with CP	Characteristics of children with CP	Percentage (%) of therapists using standardized assessments and timeframe		
									OT	PT	SP
Campbell et al.[48]	Cluster randomized control trial	49 OT; 32 PT; 36 SP with single communityre-habilitation service provider	Community-based settings across large geographical area; rural and metropolitan	Australia	ND	100	ND	ND	Unable to extract data[d]	Unable to extract data[d]	Unable to extract data[d]
Schreiber et al.[49]	Case report	18 PT employed in outpatient service	Paediatric outpatient facility: 1 primary clinic, 3 satellite clinics	USA	ND	ND	—[e]	0–18y	NA	NA	NA
Watson and Pennington[50]	Cross-sectional survey quantitative	265 SP employees in paediatric services within national health service and others	Schools 87%; homes 53%; health centres 38%; child development centre 23%; hospitals 17%	UK	ND	86	86	Preschool–25y	NA	NA	NA

Note: Sources listed in chronological order of publication.
[a]Data reports child cases as opposed to discipline-specific figures. [b]Data provided in personal communication from author. [c]Data format for proportion of therapists using assessments provided as mean factor score. [d]Data format for proportion of therapists using assessments provided as T score. [e]Personal communication from author – CP reported as 'a common diagnosis in clinics'. NA, data not collected in study for discipline group; ND, characteristic of interest not described in paper; OT, occupational therapists; PT, physiotherapists; SP, speech pathologists; CP, cerebral palsy; GMFCS, Gross Motor Function Classification System.

Table II: Study quality

Source	Oxford CEBM level	Sampling method	Response rate/ usable response rate with strength rating[a]	Sample size allied health practitioner	Data collection tool	Tool validity and reliability	Data collection methods
Hendriks et al.[42]	Level 3 (prevalence)	Convenience sample of therapists treating 84 children (25% of 327) stratified by site and class size from 42 therapeutic toddler classes across 16 of 17 eligible centres in the Netherlands. Eligible AHP population size not defined	ND/ND*	100	Questionnaire developed for study. File review	Validity* Reliability*	Self-report survey with review of own files
Howard[45]	Level 1 (prevalence)	Randomly generated sample of 300 (25% of eligible population) members of national OT professional body in the UK	71%/<71%***	212 (18% of population)	Questionnaire developed for study	Validity ** Reliability*	Postal self-report survey
Lannin et al.[43]	Level 3 (prevalence)	Convenience sample of 145 known OT and PT referrers to a single Botox Clinic in NSW, Australia	42%/41%**	59	Questionnaire developed for study	Validity** Reliability*	Postal self-report survey
Debuse et al.[39]	Level 1 (prevalence)	All PTs in hippotherapy subgroup (21 eligible) of PT professional body in the UK	81%/57%**	12	Questionnaire developed for study	Validity** Reliability*	Postal self-report survey
	Level 1 (prevalence)	Random stratified sample 92 (13%) from total population of 708 eligible PTs licensed in hippotherapy in Germany	74%/39%**	36 (5% of all registered)	Questionnaire developed for study	Validity** Reliability*	Postal self-report survey
Hanna et al.[26]	Level 3 (prevalence)	Convenience sample of all OT, PT, and SP employees from 16 of 19 Ontario, Canada children's rehabilitation programmes. 488 questionnaires sent. Eligible AHP population size not defined	43% /43% **estimated	209	Questionnaire developed for study	Validity*** Reliability*	Postal self-report survey
Saleh et al.[31]	Level 1 (prevalence)	Total population sample of 167 OTs and PTs in paediatric rehabilitation in Quebec, Canada. Located via 2003 provincial licensing bodies and snowballing technique	88%/88%***	147	Existing questionnaire with minor modifications	Validity*** Reliability*	Telephone interview survey using hypothetical case studies
Russell et al.[40]	Level 4 (treatment benefits)	Convenience sample of PTs from 28 of 35 eligible community rehabilitation centres, in east and west Canada. Eligible AHP population size not defined	ND*[b] (80% of eligible sites)	122	Questionnaire developed for study	Validity*** Reliability***	Online self-report survey
Wright et al.[46]	Level 3 (prevalence)	OTs and PTs from 5 randomly selected paediatric seating assessment clinics from 10 eligible centres stratified by region providing a daily or weekly regional service. Eligible AHP population size not defined	ND* (30% of eligible sites)	4	Checklist developed for study Delphi survey	Validity* Reliability*	Direct observation with video recordings reviewed by 2 independent reviewers

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Table II: Continued

Source	Oxford CEBM level	Sampling method	Response rate/ usable response rate with strength rating[a]	Sample size allied health practitioner	Data collection tool	Tool validity and reliability	Data collection methods
Joginder Singh et al.[47]	Level 3 (prevalence)	Convenience sample of 100 SP conference attendees; and stratified sample of 400 members of Australian SP professional body taken from website listings of SP working with children with developmental disabilities. Eligible AHP population sizes not defined	36%/31%**	157	Questionnaire developed for study	Validity** Reliability*	Self-report postal survey
	Level 1 (prevalence)	Total population (111 eligible) of members of Malaysian SP professional body and Malaysian Ministry of Health	61%/59%***	65	Questionnaire developed for study	Validity ** Reliability*	Self-report postal survey
McConnell et al.[44]	Level 1 (prevalence)	Total population (210 eligible) of OT and PT employees of national health service in Northern Ireland	74%/45%**	94	Questionnaire developed for study	Validity*** Reliability*	Self-report postal survey
Tantilipikorn et al.[41]	Level 3 (prevalence)	Stratified sample of 269 of 555 medical records of children with CP admitted between 2007 and 2009 from 6 participating services in Central region, Thailand	NA	269 (48% of records)	Pre-existing criteria	Validity NA Reliability*	File audit
Campbell et al.[48]	Level 2 (treatment benefits)	Randomized sample of 154 eligible OTs, PTs, SPs, Psyche and social work from one large rehabilitation service provider with 16 sites across New South Wales, Australia.	88%/88%***[b]	135	Questionnaire developed for study	Validity*** Reliability***	Self-report and peer-report
Schreiber et al.[49]	Level 4 (treatment benefits)	All 18 eligible PTs in a single multi-site outpatient service in USA	100%/100%***[b]	18	Questionnaires developed for study. File review	Validity* Reliability*	Self-report and electronic medical record
Watson and Pennington[50]	Level 3 (prevalence)	Convenience sample of paediatric SPs mostly from national health service providers across UK. Eligible SP population size not defined	ND*/27 non-usable responses	265	Questionnaire developed for study	Validity** Reliability*	Online self-report survey

[a]Strength rating criteria for usable response rates. Benchmark for mean response rate for surveys taken from Baruch and Holtom:[38] individual=50%; organization=37% with standard deviation 20%. [b]Criteria applied to baseline data. Self-report questionnaire: a pro forma completed by the respondent (Sitzia and Wood[37]), Interview questionnaire: an interview with a fixed set of questions (Sitzia and Wood[37]). Response rate=total returned questionnaires used as numerator in calculating response rate (Baruch and Holtom[38]). Usable response rate=useable questionnaires used as numerator in calculating response rate. ND, not able to determine usable response rate for allied health professionals. *Low: usable response rate below 1 standard deviation of the benchmark, or usable response rate within 1 standard deviation of benchmark with no explanation provided for refusals or un-usable responses and not able to determine usable response rate. **Medium: usable response rate within 1 standard deviation of benchmark with explanation provided for refusals or un-usable responses OR response rate at or above the benchmark without explanation provided for refusals or un-usable responses. ***High: usable response rate at or above the benchmark with explanation provided for refusals and/or un-usable responses. Tool validity criteria: NA, not available; *no detail or minimal external review reported on tool development; **evidence of revision after single pre-test in sample similar to study group; ***evidence of revision after at least two rounds of pre-testing in sample similar to study group or tool with known validity established. Tool reliability criteria: *no preliminary reliability testing provided; **pre-existing tool with results of preliminary reliability testing reported; ***developed or pre-existing tool with acceptable reliability statistics. CEBM, Centre for Evidence-Based Medicine; AHP, allied health practitioner; OT, occupational therapists; PT, physiotherapists; SP, speech pathologists; CP, cerebral palsy.

Table III: Proportion of therapists using identified assessment tool as reported in each included study

Use Level	Proportion (%)	Occupational therapists	Physiotherapists	Speech pathologists
High Use	>80		**GMFCS**[40] **GMFM-88**[40]	BPVS[50] CELF[50] DLS[50] RAPT[50] STAP[50]
	70–79	Talbot Battery[31]	**GMFM**[26,31]	
	60–69	**Goniometry**[44] PDMS[26] VMI[26]	**Goniometry**[44]	Bracken-BCS[50] Bus Story[50] CCC[50] DEAP[50] PVCS[50] Reynell-DLS[50] STASS[50] TROG[50] PLS[26,50]
	50–59	m-ABC[45] MMT[44] VMI[45]	AIMS[26] **GMFCS**[40] MMT[44]	
	40–49	TVPS[45]	**GMFM-66**[40] ROM tool undefined[26]	ACE[50] CELF[26] Frenchay[50] G-FTA[26]
	30–39	Erhardt[45] Grip strength[44] **mAshworth**[43] ROM tool undefined[46] TVPS[26]	Grip strength[44] **GMFM-88**[40] **mAshworth**[43] PDMS[26] ROM tool undefined[46]	EVT[50] CLEAR[50] Reynell-DLS[50]
	20–29	PDMS[31] Sensory Profile[26] **Tardieu**[43] VAS[44] VMI[31]	**GMFM-66**[40] **Tardieu**[43] VAS[44]	Boehm-TBC[50] ERRNI[50]
Low use	10–19	Ashworth[43,44] BOTMP[26,45] Clonus[44] **COPM**[26] Draw-a-Man Test[45] DVPT[26] MAP[45] MVPT[45] NRS[44]	AIMS[31] Ashworth[43,44] BOTMP[26] Clonus[44] **GMFCS**[26] Goniometry[31] NRS[44] PDMS[31]	EOWPVT[26] G-FTA[50] **PPVT**[26] Rossetti[26] SPAT[26] SPELT[26] VAPS[50]
	01–09	AIMS[26] ASBI[26] Batelle-DI[31] **BFMF**[44] De Gangi-Burke[31] DVPT[45] ETCH[26] FACES Pain Scale[44] **HHD**[44] **MACS**[44] **MUUL**[44] m-ABC[26] MAI[43] **Paediatric Pain Profile**[44] PEDI[31] QUEST[31] ROM tool undefined[26] **SFA**[26] TVMS[26] Tardieu[44] WeeFIM[31]	Chailey Levels of Activity[39] FACES Pain Scale[26] **GAS**[26] **GMFM**[39] **HHD**[31,44] **Paediatric Pain Profile**[44] MAI[26,43] MMT[31] **PEDI**[26] ROM tool undefined[39] **Tardieu**[44] TUDS[49]	APP-R[26] ASBI[26] CDI[26] Nuffield-DPAT[50] SSI[26] TACL[26] TOLD[26]
	Reported not (0%) in use	**ABILHAND**[44] **AHA**[44] **QUEST**[44] **SHUEE**[44]	**ABILHAND**[44] **AHA**[44] **BFMF**[44] Erhardt[44] 30s walk test[49] **GMFM-66**[49] **MACS**[44] **MUUL**[44] **PEDI**[49] **QUEST**[44] **SHUEE**[44]	
	Reported as 'rarely used'	**CP QOL-Child**[41] **WeeFIM**[41] **GMFM**[41] **PedsQL**[41]		**PEM-CY**[50] **CAPE**[50] **LAC-G**[50]

Displays the proportion of a therapy discipline using each tool as reported in each of the studies e.g. the PEDI was reported in three studies and is repeated in three cells this display. Hanna et al.[26] (frequency: at least once in the last month); Saleh et al.[31] (frequency: at least once in one of four vignettes); Debuse et al.[39] (UK data only, no tools used in German population); Russell et al.[40] (data from west and east provinces reported); Tantilopikorn et al.[41] (discipline not specified); Lannin et al.[43] (PT and OT data combined); McConnell et al.[44] (PT and OT data combined for some tools); Howard,[45] Wright et al.[46] (PT and OT data combined); Schreiber et al.[49] (frequency: in previous 2mo among 18 therapists); and Watson and Pennington[50] (used to assess an identified speech, language, and communication domain). Emboldened tools demonstrate acceptable validity for use in CP population. Tool abbreviations used in this table are provided in full in Appendix S2 (online supporting information).

service providers.[48,49] Seventy per cent of allied health practitioners provided services to children with CP in the community through centre- and home-based programmes, and through schools. Assessment practices in specific fields of CP intervention (hippotherapy,[39] upper limb management,[44] spasticity,[43] and seating[46]) were also investigated. Studies reported on assessment practices from high- and middle-income countries with comparisons between countries made in two studies (Table I).[39,47]

Reporting of assessment tool use

The extent and type of reporting of assessment use by therapists varied between studies. Two studies[47,48] reported the proportion of therapists using standardized assessment tools generally. Other studies reported the use of specific tools. Tools considered were identified either by the participant therapists or a priori by study investigators. The percentage of therapists using each tool was typically reported. Some studies included a time period which

varied from weeks to years, and other studies used ordinal scales such as always, frequently, rarely, or never. This meant it was not possible to directly compare the amount of use of a tool across studies. Data on the use of assessment tools could not be extracted from three articles as raw data was either not available,[42] had been converted to mean factor scores,[47] or derived T scores were calculated.[48] Authors of one article[43] were contacted to verify reported values, but they were unable to provide original data.

Use of standardized assessment tools

The proportion of each discipline that reported using some form of standardized assessment within specified time periods is shown in Table I. Four articles[26,31,43,45] showed a high but variable percentage of users: 47% of occupational therapists used a standardized test more than half of the time[45] compared to 92% of physiotherapists who used one or more assessments in at least one of four clinical case

Table IV: Characteristics of assessment tools with high level (>50%) use reported

Assessment Tool	Domains assessed	Standardized procedures available	Type of tool	Primary purpose per authors of tool	Age range for tool administration	Acceptable validity for use in CP population	ICF domain focus
AIMS	Gross motor	Y	Norm	Discriminative	Birth–18mo	N	BS & F Activity
BPVS	Verbal comprehension	Y	Norm	Discriminative	3y–16y	N	BS & F
Bracken-BCS	Verbal comprehension	Y	Norm	Discriminative	3y–6y 11mo	N	BS & F
Bus Story	Verbal production	Y	Norm	Discriminative	3y 6mo–6y 11mo	N	BS & F
CCC-2	Communication and interaction	Y	Norm	Discriminative	4y–16y 11mo	N	BS & F Activity
CELF	Verbal comprehension and production	Y	Norm	Discriminative	5y–21y 11mo	N	BS & F
DEAP	Articulation and phonology	Y	Norm	Discriminative	3y–8y 11mo	N	BS & F
DLS	Verbal comprehension and production	Y	NA	Discriminative	Preschool and primary	N	BS & F
GMFCS	Gross motor	Y	Criterion	Descriptive	2y–18y	Y	Activity
GMFM-88 GMFM-66	Gross motor	Y	Criterion	Evaluative	6mo–18y	Y	Activity
Goniometry	Joint range and muscle length	Y	Norm	Discriminative	All ages	Y	BS & F
M-ABC	Gross motor and fine motor	Y	Norm	Discriminative	3y–16y 11mo	N	BS & F Activity
MMT	Muscle strength	Y	Criterion	Discriminative	All ages	N	BS & F
PDMS-2	Gross motor and fine motor	Y	Norm	Discriminative	Birth–5y 11mo	N	BS & F Activity
PLS	Verbal comprehension and production	Y	Norm	Discriminative	Birth–7y 11mo	N	BS & F
PVCS	Communication and interaction	N	NA	No longer available	NA	N	BS & F Activity
RAPT	Verbal production	Y	Norm	Discriminative	3y–8y	N	BS & F
Reynell-DLS	Verbal comprehension and production	Y	Norm	Discriminative	2y–7y 5mo	N	BS & F
STAP	Articulation and phonology	N	NA	Discriminative	NA	N	BS & F
STASS	Verbal production	N	NA	Discriminative	3y–5y	N	BS & F
Talbot Battery	Gross and fine motor, ADL, behaviour and communication	N	Norm	NA	Birth–6y	N	BS & F Activity
TROG	Verbal comprehension	Y	Norm	Discriminative	4y–16y	N	BS & F
VMI	Visual-motor perception and fine motor	Y	Norm	Discriminative	2y–15y	N	BS & F

ICF, International Classification of Functioning Disability and Health; BS & F, Body Structure and Function; NA, not available; Y, yes; N, no; CP, cerebral palsy; ADL, activities of daily living. Tool abbreviations used in this table are provided in full in Appendix S2 (online supporting information).

studies.[31] Standardized assessments were rarely documented in some studies[41,46] and low rates were noted within a specific practice area.[39]

Specific assessment tools in use

Eighty-eight assessment tools were identified from 11 articles[26,31,39–41,43–46,49,50] that reported their use by allied health practitioners working with children with CP. Table III documents the tools reported. We emphasize that care is needed when comparing levels of use between studies due to the different time periods used for each study. Approximately 25% of tools were reported in more than one study. The most widely reported assessment tools were goniometry, Gross Motor Function Measure (GMFM), Paediatric Evaluation of Disability Inventory (PEDI), Manual Muscle Testing, and the Developmental Test of Visual-Motor Integration (Table III).

Frequency of assessment tool use and characteristics

The proportion of therapists using identified assessment tools varied from 0% (not used) to 92% (Table III and Appendix S2, online supporting information). Twenty-three discrete tools were used by more than 50% of therapists. Characteristics of these high use tools are detailed in Table IV (for tool abbreviations list see Appendix S2, online supporting information). These tools typically addressed the body structure and function domains of the ICF-CY.[19] Of the 23 high use tools, four were non-standardized and 15 were discriminative norm-referenced tools.

Although goniometry, the GMFM, and Gross Motor Function Classification System (GMFCS) were reported in high use in some studies, they were also reported to be used infrequently. Use levels ranged from 6% to 64% (goniometry), 0% to 86% (GMFM), and 19% to 92% (GMFCS). Of all assessment tools reported, 70% (*n*=62)

were used by <20% of therapists. Other low use tools (<20%) included individualized assessment tools (e.g. Canadian Occupational Performance Measure [COPM]) and Goal Attainment Scaling, generic criterion-based assessments (e.g. PEDI), pain measures, classification tools (e.g. Manual Abilities Classification System), and evaluative tools validated for children with CP (e.g. Assisting Hand Assessment and Shriners Hospital Upper Extremity Evaluation). Validated tools for assessing quality of life and participation were rarely used.

DISCUSSION

Assessment practices of the three disciplines were documented with many assessment tools reported. Most of the assessment tools frequently used were age-standardized, norm-referenced discriminative tools that focussed on ICF-CY domains of body structure and function. Only a few evidence-based assessment tools were used a lot; a lot were used a little or not at all. The focus of the evidence-based tools that were used frequently was on gross motor function. Available evidence-based tools to assess other areas of activity, participation, quality of life, and pain were rarely used.

The primary purpose of norm-referenced discriminative tools is to identify the presence and extent of impairments and activity limitations. These tools were developed from normative samples that typically do not include children with physical disabilities. With the exception of goniometry,[51] these tools do not yet have validity studies to support their use for children with CP. Use of norm-referenced tools is problematic because standardized procedures for administration may not be possible when assessing children with CP, thus possibly compromising the assessment results.[18,52] Floor effects can be encountered if used to determine the extent of impairment,[52] and small and real changes in function may not be detected when used to assess change over time or outcomes of interventions. Although therapists' rationale for the choice of tool was not collected during this review, the high levels of use of norm-referenced discriminative tools warrants further consideration. Norm-referenced tools have a role in initial screening; however, their usefulness in planning and evaluating outcomes of interventions in the CP population is limited. If employed for their stated purpose it is likely these tools were only used during the initial diagnostic phase. This suggests that the outcomes of interventions for children with CP were either not being evaluated, or that outcomes of therapy were being evaluated using tools not validated for this purpose or target population.

Gross motor function was the focus of all three frequently used assessment tools validated for use in the CP population–GMFCS, GMFM, and goniometry (the '3Gs'). Recent definitions of CP have emphasized the range of disorders that accompany disturbances in movement and posture.[53–55] Children with CP and their families consider gross motor and neuromusculoskeletal-related functions as important, but they also rank self-care, upper limb func-

tion, speech, general health, participation, assistive technology, and quality of life of similar importance.[22,23] Evaluation of outcomes in these domains was not evident in practice. Even though clinicians' conceptual understanding of CP management has broadened,[56,57] this was not reflected in the assessment tools being used in practice. This lag between current understanding and clinical practice may in part be because of the slow uptake of assessment tool use by clinicians but may also reflect a lack of supply. Validated tools with items that adequately capture elements relevant to these important and culturally specific domains may not yet have been developed.[58]

The use of tools was variable across settings. This may reflect the broad populations of children with CP (type, age, severity, and range of settings) and the countries and health care systems of the included studies. It could be expected that the '3Gs' were reported at high levels because of their applicability to all children with CP. However, they were also reported in low use in some settings. Higher levels of use were generally reported in the country of tool development,[26,31,40] where their clinical use was also studied more extensively. Pockets of best practice no doubt exist in many settings and few studies overall have fully addressed the extent of use of validated tools in specific settings for specific subgroups of children with CP. However, these findings suggest that evidence-based assessment practices are not being integrated into the management of children with CP in some settings.

Although the diverse presentation and lifelong impacts of CP are widely considered through the ICF-CY framework, the primary focus of the most frequently used tools was impairments in body structure and function and a limited range of activity performances (Table IV). The School Function Assessment, used by a small percentage of therapists, was the only tool reported that evaluated aspects of participation.[26] Similarly the validated PEDI[59] – used to evaluate activity performance in self-care, mobility, and social functions – was used minimally. Neither generic nor more recently developed condition-specific quality of life tools, such as the Cerebral Palsy Quality of Life Questionnaire for Children,[60] were used by any disciplines. It is also concerning that the validated Paediatric Pain Profile tool[61] was used by <10% of therapists given it has been known for some time that pain is a common problem among children with CP[15,62,63] and is a known determinant of participation and quality of life.[15] Recent findings by Horridge et al.[64] in an audit of paediatricians' file entries from several districts of the UK showed highly variable rates in the documentation of pain (17–100%). This raises the question of who within the rehabilitation team is evaluating therapy outcomes in relation to the important domains of self-care, participation, quality of life, and pain.

Only one classification assessment tool, the GMFCS, was frequently used by one discipline and in only some settings and countries. When used together the validated classification tools (GMFCS, Manual Abilities Classification System,[65] Communication Function Classification

System,[66] and Eating and Drinking Abilities Classification System[67]) illustrate, though do not evaluate, a child's functional performance across discrete but interacting areas of activity performance. Their combined use by all members of the rehabilitation team and family provides a common platform for communication.[68] Furthermore, use of this classification toolset enables therapists to specifically select and apply research findings relevant to the children they see in clinical practice.[68,69] Focus on the single classification tool that relates only to a discipline's traditional area of practice discourages a holistic view of the child with CP.

Use of individualized goal-setting tools, such as the COPM[70] and Goal Attainment Scaling,[71] ensures that assessment is aligned with the best practice framework of Family-Centred Practice.[21,72] The collaborative and individualized characteristics of these tools ensures outcome measures are generated in areas meaningful to each child and family.[73] Their complementary use with generic and condition-specific tools is recommended.[11,74–76] Use of the COPM and Goal Attainment Scaling was identified in only one study[26] and at a low level. It is surprising and concerning that in contrast to its established use in research, the COPM did not feature strongly in surveys of practice.

Known barriers to using standardized assessment tools identified by clinicians include lack of time, knowledge, and confidence in tool selection administration and interpretation,[77] and perceived value in using existing assessment tools.[77,78] Practical issues such as ease-of-use, access to validated tools, and the cost are also reported. In this review the use of norm-referenced tools at high levels predominated where children with CP were part of a mixed caseload.[26,45] In contrast, where all data referred to children with CP, more CP-specific tools were used when available.[31,40,44] In keeping with this finding, Watson and Pennington[50] found that speech therapists with less than five children with CP on their caseloads were less likely to assess augmentative communication skills.

Given the large number of existing and emerging tools, each requiring familiarization and practice to effectively administer, it is understandable that therapists find it difficult to stay abreast of the range of tools available[3,78] when managing diverse caseloads. Although several simple validated, quick to administer, and inexpensive tools (e.g. Manual Abilities Classification System, Shriners Hospital Upper Extremity Evaluation,[79] Timed Up and Down Stairs[80]) and generic tools validated for use with all children with disabilities (e.g. COPM, PEDI, and School Function Assessment) were available, these were used either infrequently or not at all. Similarly basic goniometry was used variably across settings despite its importance in the early detection of secondary musculoskeletal deformity. Although these tools have been identified by expert clinicians as preferred tools for use with children with CP,[22] their uptake by clinicians working with children with CP appears slow and low overall.

The factors influencing the use of assessment tools in practice are likely to be complex.[81] Several studies have reported potential determinants of use of standardized assessments by allied health professionals.[6,24–78,82] Determinants are thought to exist at multiple levels and to be influenced by factors related to the clinician, the tool itself, existing electronic systems for data collection, storage and retrieval, workplace setting and culture, managerial and organizational supports, and the wider health context.[83] A variety of knowledge translation interventions aimed at changing evidence-based practice behaviours among health practitioners have been trialled in different clinical settings.[84] Systematic reviews show that outcomes from single and multi-component interventions are inconsistent and variable.[85,86] Recent studies of knowledge translation interventions specifically targeting clinicians' use of outcome measures with CP populations[40,48,49] have shown positive results. However, uptake was variable between organizations and within sites across organizations. The relative importance and interaction of contextual factors has not yet been identified[81] with the possibility that multiple factors may interact uniquely within an organizational setting.[48,87]

Limitations

This review determined what assessment tools are used by allied health practitioners working with children with CP. More research is warranted to confirm or explain the review findings of low levels of use by investigating the extent of use of validated tools relevant to specific subgroups of children with CP (including type, severity, or age group) and different clinical settings. Factors influencing use within specific workplace environments were not examined but warrant further research. Validation studies for some tools may have occurred since this review was conducted, thus some tools may now have acceptable levels of validity for use with children with CP. The time frame to ascertain the frequency of tool use was short in some studies and may have missed therapists' use of tools that were administered less frequently. This review was limited to studies published in English thereby potentially excluding relevant studies. The search methods were comprehensive and followed prescribed PRISMA-P guidelines for the conduct of systematic reviews.

Recommendations

The findings of this review should encourage clinicians, teams, and service organizations to review existing assessment practices, how tools are being used and for what purpose, the outcomes being evaluated, and how they align with best practice. Use of the full classification toolset (GMFCS, Manual Abilities Classification System, Communication Function Classification System, and Eating and Drinking Abilities Classification System) by all team members would provide immediate benefit for children with CP by ensuring clarity of communication. A coordinated team approach to the use of validated tools to assess pain, quality of life, and participation is needed to ensure that outcomes in these important areas are assessed for each child with CP.

Future research should aim to understand the real world factors that drive assessment practices within different organizational settings. Identification of specific factors that facilitate the routine use of evidence-based assessment tools by therapists will facilitate implementation of targeted and cost-effective knowledge translation activities. Such activities should assist allied health practitioners with the selection of 'the right tool, for the right purpose at the right time'.

CONCLUSION

This review found only a few evidence-based tools that relate to gross motor function were used a lot, and a lot of tools were used a little or not at all in clinical practice by allied health practitioners for children with CP. Consequently therapy and programme outcomes in other important areas of functioning e.g. self-care, pain, upper extremity function, participation, and quality of life were either not evaluated or routinely documented by therapists using validated assessment tools. Contrary to current frameworks for best practice, evidence-based assessment tools are not embedded in clinical practice for children with CP in many settings. There is a need to further investigate the extent of use of assessment tools for children with CP within specific settings and to understand the unique real-world factors that influence individual clinicians' capacity to routinely use evidence-based assessment tools.

SUPPORTING INFORMATION
The following additional material may be found online:

Appendix S1: Example of database search history.

Appendix S2: Tool abbreviations for Table III and Table IV in alphabetical order.

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2.3 Update of systematic review evidence 2015–2019

Further studies examining allied health professionals' use of assessment tools for children with cerebral palsy have been published since conducting the database searches for the original systematic review (O'Connor et al. 2016a). The original search strategy (Appendix A1) was re-run in CINAHL, Medline, ERIC, PsycINFO, and Web of Science databases for the period May 2015 to April 2019. The search identified 861 citation records that were screened by title and abstract. Full-text review was conducted on 15 articles, of which six papers were excluded on the basis of non-allied health practitioner study population (n=5) and non-defined child caseloads (n=1).

Nine articles met the inclusion criteria and thus are included in this update (Adeniyi, Lagunju, Abdus-salam, Sidebotham, & Lesi, 2015; Anaby et al., 2017; Auld & Johnston, 2018a, 2018b; Bailes, Gannotti, & Fenchel, 2017; Deville et al., 2015; Obembe, Dada, Balogun, Ojo, & Johnson, 2018; Stewart, Tavender, Rice, & Harvey, 2018; Walmsley et al., 2018). Of the nine studies, six were cross-sectional surveys; four used a quantitative approach (Adeniyi et al., 2015; Deville et al., 2015; Obembe et al., 2018; Walmsley et al., 2018), and two used a mixed method approach (Anaby et al., 2017; Stewart et al., 2018). The remaining three studies adopted a mixed methods research design (Auld & Johnston, 2018b), a retrospective audit of electronic files (Bailes et al., 2017), and a pre-post observational design (Auld & Johnston, 2018a).

Five of the nine studies related to knowledge translation: three studies collected data on the use of specific tools and barriers to inform future knowledge translation strategies (Auld & Johnston, 2018a; Stewart et al., 2018; Walmsley et al., 2018); one was a knowledge translation study (Auld & Johnston, 2018a); and one was a review of the effectiveness of

previous knowledge translation (Deville et al., 2015). The assessment practices of allied health practitioners and other health professionals were investigated from a range of workplace settings and countries in the nine studies. A summary of the study characteristics and main findings of the included studies are provided in Table 2.1.

Table 2.1. Description of studies included in updated systematic review May 2015 – April 2019

First Author (Year)	Purpose	Design	Sample	Workplace Setting	Country	Percentage (%) data referring to children with CP & GMFCS: age	% therapists using standardised assessments			Conclusions/Findings
							OT	PT	SP	
Adeniyi et al. (2015)	Describe awareness, use, and merits of the GMFCS system	Cross-sectional survey quantitative	24 PT; 2 OT 6 nurses; 46 doctors working in hospital referral centres	3 teaching hospitals.	Nigeria (south-western)	100% ND: ND	58% use overall in routine care Individual hospitals-100%; 50%; 23% NA		NA	• Therapist aware of GMFCS high but less used in practice • Use varied widely between hospitals
Anaby et al. (2017)	Describe current therapy practices by OTs and PTs in management of school-age children with CP	Cross-sectional survey mixed	62 OT; 61 PT Caseload of 2-5 children with CP week	Schools (41%); outpatient clinics (38%); community (7%); hospitals (6%)	Canada	100% ND:5–10 years	Case 1: 44% Case 2: 27%	Case 1: 56% Case 2: 39%	NA	• A "know-do" gap was observed for therapists' use of standardised assessments • Most commonly used assessments relate to body structure and functions domains of ICF particularly among PTs
Auld and Johnston (2018b)	Examine current practices of paediatric therapists, barriers and facilitators to implementation of tactile assessments	Mixed methods	18 PT; 17 OT	State-wide service providers for individuals with CP	Australia	100% ND: ND	55% therapists do not use (monthly) 90% of therapists assess tactile function in less than 25% of children		NA	• Barriers identified: lack of knowledge about how to assess, lack of confidence and access to equipment and organisational processes. • Time not a perceived use barrier

NA data not collected in study for discipline group; ND Characteristic of interest not described in paper; OT, occupational therapists; PT, physiotherapists; SP, speech pathologists; CP, cerebral palsy

Table 2.1. *(continued)*

First Author (Year)	Purpose	Design	Sample	Workplace Setting	Country	Percentage (%) data referring to children with CP & GMFCS: age	% therapists using standardised assessments			Conclusions/Findings
							OT	PT	SP	
Auld and Johnston (2018a)	Investigate Knowledge to Action frame-work guided interventions to improve PTs knowledge, skills, and implementation of tactile assessments	Pre–post observational study without control-mixed	5 OT; 7 PT	State-wide service for children with CP	Australia	100% ND: ND	Tactile assessments used with <25% of children by 11/12 therapists		NA	• 12-month knowledge translation study significantly increased therapist knowledge and addressed clinician level barriers and some organisational barriers • Resolution of all clinician-level barriers and less obvious organisational-level barriers tactile assessment however use improved only slightly
Bailes et al. (2017)	Describe PT interventions in a paediatric outpatient setting according to the ICF, and identify factors associated with the total amount of service within each intervention type	Retrospective audit over one year	PT electronic data set 2008	Single paediatric tertiary hospital - OT and PT outpatient divisions	USA	425 children and adults GMFCS I-III (64%); GMFCS IV-V (37%); 91% < 18y	NA	7% of electronic record entries related to examination; PT evaluation, re-evaluation, test and measures	NA	• Small percentage of assessment records, suggests therapists not evaluating patients with standardised assessment tools frequently within a year • 47% of PT intervention directed toward activity followed by body structure and function. Less services directed toward environmental adaptations and examination
Deville et al. (2015)	Learn more about where PTs in the United States are in the knowledge translation of the GMFCS	Cross-sectional survey quantitative	283 PT Worked with children with CP for at least 6 months	Schools (38%); hospital (27%); community (21%; other (14%)	USA	100% ND: ND	NA	42% (consistently use in decision-making)	NA	• PT training needed on how to incorporate GMFCS into decision making with families • PTs use GMFCS independently more than with families. • PTs unsure of role in providing prognostic information

NA data not collected in study for discipline group; ND Characteristic of interest not described in paper; OT, occupational therapists; PT, physiotherapists; SP, speech pathologists; CP, cerebral palsy

Table 2.1. *(continued)*

First Author (Year)	Purpose	Design	Sample	Workplace Setting	Country	Percentage (%) data referring to children with CP & GMFCS: age	% therapists using standardised assessments			Conclusions/Findings
							OT	PT	SP	
Obembe et al. (2018)	Investigate the level of awareness, use, barriers and facilitators for outcome measure use by PTs for children with CP	Cross-sectional survey quantitative	138 PT	Eight tertiary hospitals-inpatient and outpatient PT services	Nigeria (south-western)	100% ND: ND	NA	NA	NA	• Awareness of outcome measures for children with CP among PTs was higher than utilization, irrespective of educational status or years of work • PTs had a positive attitude toward the use of outcome measures
Stewart et al. (2018)	Investigate knowledge and barriers to identification & measurement of dyskinesia in children with CP; explore educational needs to identiy and assess dyskinesia	Cross-sectional online survey mixed	163 healthcare professionals 58% PT; 24% OT; 2.4% SP; 12.7% medical; 2.8% other	Hospital 39%; Not for profit 35%; other 26%	Australia and New Zealand	100% ND: ND	14% (used the tools frequently) 96% (used rarely i.e. less than twice or not at all)			• Clinical knowledge and available but small percentage of therapists and tools used clinically • Reported to be only somewhat useful or not useful at all • Barriers included limited training opportunities, limited knowledge of scales, and lack of confidence in use • greater understanding of tools perceived as extremely or very beneficial clinically
Walmsley et al. (2018)	Identify current practice and perspectives related to assessment of somato-sensation in children with neurological disorders	cross-sectional survey quantitative	79 OT; 44 PT	Workshop attendees and hospital OT and PT depart-ments	Australia	70% ND: ND	30%	32%	NA	• Majority of therapists' rate assessment of somatosensation as important • Few therapists confident in their ability to assess. • Therapists use non-standardised and/or informal assessments of somatosensation

NA data not collected in study for discipline group; ND Characteristic of interest not described in paper; OT, occupational therapists; PT, physiotherapists; SP, speech pathologists; CP, cerebral palsy

2.3.1 Risk of bias

The quality assessment of the nine studies is summarised in Table 2.2. The external validity (as assessed through the Oxford Centre for Evidence-Based Medicine 2011 Levels of Evidence (Howick et al., 2014), response rate, and sample size) was strong in two studies (Anaby et al., 2017; Deville et al., 2015) and adequate in five studies (Auld & Johnston, 2018a, 2018b; Bailes et al., 2017; Stewart et al., 2018; Walmsley et al., 2018). It was not possible to ascertain response rates in three studies (Adeniyi et al., 2015; Obembe et al., 2018; Walmsley et al., 2018) although external validity was strengthened in the study by Walmsley et al. through use of extensive recruitment methods. The two studies with strong external validity also had strong internal validity (Anaby et al., 2017; Deville et al., 2015). External review of survey questionnaires was not reported in four studies (Adeniyi et al., 2015; Auld & Johnston, 2018a; Obembe et al., 2018; Stewart et al., 2018), although triangulation and additional data sources were used in the mixed methods study by Auld and Johnston (2018a). Bailes et al. (2017) used electronic medical record billing data in 15-minute time 'units' to ascertain the amount of physiotherapy service time dedicated to evaluation, re-evaluation, tests and measurement.

Table 2.2. Study quality for updated systematic review May 2015 – April 2019

First Author (Year)	Oxford CEBM level	Sampling method	Response rate/ usable response rate with strength rating¥	Sample size allied health practitioner	Data Collection tool	Tool validity and reliability	Data Collection methods
Adeniyi et al. (2015)	Level 3 (prevalence)	Health professionals from 3 randomly selected hospital referral centres. Eligible centres and AHP populations not defined	ND/ND*	26	Questionnaire developed for study	Validity* Reliability*	Hand delivered self-report survey
Anaby et al. (2017)	Level 1 (prevalence)	Total population sample of 123 OT's and PT's from across Canada located via provincial and territorial licensing bodies and professional associations and snowballing techniques. Nine of 13 PT organizations and 10 of 12 occupational therapy organizations agreed to participate (response rate between 69% and 83%)	44%/44%**	123	Questionnaire developed for study	Validity*** Reliability*	Online self-report survey using 2 hypothetical case-based vignettes
Auld and Johnston (2018b)	Level 3 (prevalence)	Convenience sample of PT's and OTs subset from state-wide service provider for individuals with CP and conference workshop attendees.	67%/67%**	35	Questionnaire developed for study	Validity* Reliability*	Anonymous self-report survey
Auld and Johnston (2018a)	Level 4 (treatment benefits)	Convenience sample of PT's and OTs subset from state-wide service provider for individuals with CP	[b]36%**	12	Questionnaire developed for study	Validity* Reliability*	Self-report survey; self-monitoring record sheet
Bailes et al. (2017)	Level 3 (prevalence)	Convenience sample of electronic medical records of 425 children with cerebral palsy over one year (2008) from large pediatric tertiary care hospital OT and PT outpatient division	NA	(100% of child records)	Pre-existing checklist criteria	Validity NA Reliability*	billing code data from electronic medical records

Table 2.2. *(continued)*

First Author (Year)	Oxford CEBM level	Sampling method	Response rate/ usable response rate with strength rating[a]	Sample size allied health practitioner	Data Collection tool	Tool validity and reliability	Data Collection methods
Deville et al. (2015)	Level 1 (prevalence)	Total population of paediatric PTs in the United States located via professional associations and snowball techniques to reach non-members.	[c]ND*/ (49 non-useable responses)	283	Questionnaire developed for study	Validity*** Reliability**	Online self-report survey
Obembe et al. (2018)	Level 3 (prevalence)	Convenience sample of PTs from 8 tertiary hospitals, with inpatient and outpatient physiotherapy services. Eligible number of hospitals and PTs not defined	ND*/ (42 non-usable responses)	138	Questionnaire developed for study	Validity* Reliability*	Hand delivered self-administered survey
Stewart et al. (2018)	Level 3 (prevalence)	Convenience sample of healthcare professional members of the Australasian Academy of Cerebral Palsy and Developmental Medicine and affiliated sub-group organisations.	30%/30%** estimated	138	Questionnaire developed for study	Validity* Reliability*	online, anonymous, self-report survey
Walmsley et al. (2018)	Level 3 (prevalence)	Convenience sample of workshop attendees, 52 paediatric OT and PT hospital departments and paediatric OT professional association subgroup (300 members). Eligible OT and PT population not defined.	ND*	135	Questionnaire developed previously for adult stroke population.	Validity** Reliability*	Online self-report survey

[a]Strength rating criteria for usable response rates. Benchmark for mean response rate for surveys taken from Baruch & Holtom (2008): individual=50%; organization=37% with standard deviation 20%. [b]Criteria applied to baseline data. [c]Power analysis determine sample size of 289 needed to acceptable margin of error. Self-report questionnaire: a pro forma completed by the respondent (Sitzia & Wood, 1998). Interview questionnaire: an interview with a fixed set of questions (Sitzia & Wood, 1998). Response rate=total returned questionnaires used as numerator in calculating response rate (Baruch & Holtom, 2008). Usable response rate=useable questionnaires used as numerator in calculating response rate. ND, not able to determine usable response rate for allied health practitioners. *Low: usable response rate below 1 standard deviation of the benchmark, or usable response rate within 1 standard deviation of benchmark with no explanation provided for refusals or unusable responses or not able to determine usable response rate. **Medium: usable response rate within 1 standard deviation of benchmark with explanation provided for refusals or unusable responses OR response rate at or above the benchmark without explanation provided for refusals or unusable responses. ***High: usable response rate at or above the benchmark with explanation provided for refusals and/or unusable responses. Tool validity criteria: NA, not available; *no detail or minimal external review reported on tool development; **evidence of revision after single pre-test in sample similar to study group; ***evidence of revision after at least two rounds of pre-testing in sample similar to study group or tool with known validity established. Tool reliability criteria: *no preliminary reliability testing provided; **pre-existing tool with results of preliminary reliability testing reported; ***developed or pre-existing tool with acceptable reliability statistics. CEBM, Centre for Evidence-Based Medicine; AHP, allied health practitioner; OT, occupational therapists; PT, physiotherapists; SP, speech pathologists; CP, cerebral palsy.

2.3.2 Participants and settings

All studies reported on the assessment practices of physiotherapists and six studies reported on the practices of occupational therapists (Adeniyi et al., 2015; Anaby et al., 2017; Auld & Johnston, 2018a, 2018b; Stewart et al., 2018; Walmsley et al., 2018). Speech pathology assessment practices were reported in one study that included a small number of speech pathology participants (n=4) (Stewart et al., 2018). Medical and allied health professionals were included in two studies (Adeniyi et al., 2015; Stewart et al., 2018). Participants were recruited from professional registration bodies, membership lists of professional associations and cerebral palsy-specific academies, and conference workshops (Anaby et al., 2017; Auld & Johnston, 2018b; Deville et al., 2015; Stewart et al., 2018; Walmsley et al., 2018), hospitals (Adeniyi et al., 2015; Bailes et al., 2017; Obembe et al., 2018; Walmsley et al., 2018) and state-wide service providers (Auld & Johnston, 2018a, 2018b). Assessment practices of therapists working in schools, healthcare and community settings were reported, with hospital-based services reported most often (Adeniyi et al., 2015; Anaby et al., 2017; Bailes et al., 2017; Obembe et al., 2018; Stewart et al., 2018; Walmsley et al., 2018). Almost all studies investigated assessment tool use only in relation to children with cerebral palsy; one study reported on a mixed group where 70% of data referred to children with cerebral palsy (Walmsley et al., 2018).

2.3.3 Reporting of assessment tool use

A large proportion of studies (n=6) investigated therapists' use of specific assessment tools: the GMFCS (Adeniyi et al., 2015; Deville et al., 2015); a suite of somatosensory (Auld & Johnston, 2018a, 2018b; Walmsley et al., 2018) and dyskinesia assessment tools (Stewart et al., 2018); and a pre-defined group of activity-level assessment tools (Obembe et al.,

2018). The remaining studies examined therapists' assessment practices more broadly through use of case vignettes (Anaby et al., 2017) and electronic medical records (Bailes et al., 2017). The publication rate of studies reporting therapists' use of assessment tools for children with cerebral palsy has increased. Fourteen articles were identified between 2000 and 2015 (O'Connor et al., 2016a) and nine articles between 2015 and 2019.

2.3.4 Use of standardised assessment tools

The proportions of therapists from each discipline reporting that they used standardised assessments are documented in Table 2.1. Use rates varied among disciplines, setting and area of practice. Slightly greater proportions of physiotherapists than occupational therapists reported using assessment tools, although this difference may not be significant (Anaby et al., 2017; Walmsley et al., 2018). Low rates of standardised tool use were found among therapists in the assessment of somatosensory function (Auld & Johnston, 2018a, 2018b; Walmsley et al., 2018) and dyskinesia (Stewart et al., 2018). A small proportion of time (7%) was allocated by physiotherapists to using standardised assessments (Bailes et al., 2017). The study by Anaby et al. (2017) identified that 27% to 56% of physiotherapists and occupational therapists typically used standardised assessments as part of their therapy management for children with cerebral palsy.

2.3.5 Specific assessment tools in use and frequency of use

Table 2.3 documents the 40 standardised assessment tools used by allied health practitioners reported across the nine articles. Twenty-six of the assessment tools reported in the update were not identified in the original systematic review (O'Connor et al., 2016a). Eleven of the newly reported tools related to somatosensory assessment, of which six were non-standardised, and five were assessments of dyskinesia. Assessment tools related to

participation and the environment were also newly reported, although used rarely (Anaby et al., 2017).

The most widely reported assessment tool was the Gross Motor Function Classification System (GMFCS); (Palisano et al., 1997) (Adeniyi et al., 2015; Deville et al., 2015; Obembe et al., 2018). Three assessment tools related to gross motor structure and function (GMFCS, goniometry and GMFM) were most highly used—that is, used by more than 50% of therapists in studies reporting their use (O'Connor et al., 2016a). Use of the GMFCS was, however, highly variable, with proportions of therapists using the tool ranging from 'rarely used' to 100%. Goniometry was used more frequently by physiotherapists than occupational therapists while occupational therapists used the COPM more often. Two norm-referenced discriminative tools—the Beery-Buktenica Developmental Test of Visual Motor Integration (Beery, 2006) and Bruininks-Oseretsky Test of Motor Proficiency (Bruininks & Bruininks, 2005)—were among the tools used most frequently by occupational therapists. Non-standardised assessments were used by occupational therapists and physiotherapists in the evaluation of somatosensation. Studies of assessment tool use by speech pathologists for children with cerebral palsy were under-represented, with only one study identified in the updated search (Stewart et al., 2018). The tools reported on and used most often across disciplines addressed body structure and function, and activity domains of the ICF.

Table 2.3. Proportion of therapists using identified assessment tool as reported in each included study in updated review

Use Level	Proportion (%)	Occupational Therapists	Physiotherapists
High Use	>80		**GMFCS[1]**
	70 – 79		**GMFCS[3]**
	60 - 69		**Goniometry[2]**
	50 – 59		**GMFM[2] GMFCS[1] GMFM[4]**
	40 – 49	*Proprioception[6] Stereognosis[6] Light touch[6]*	
	30 - 39	Beery VMI[2] **Goniometry[2]** *Pressure[6]*	*Light touch[6]* **HAT[5]**
	20 - 29	*Texture discrimination[6]* **COPM[2]** BOT-2[2]	MMT[2] **GMFCS[1] PODCI[4]** WeeFIM[7] **FAQ[4] CP-QOL[4]** *Proprioception[6]*
Low Use	10 - 19	*Two-point discrimination[6]* **QUEST[2] Monofilaments[6]**	**Berg Balance Scale[2]** BOT-2[2] **PEDI[4] BADS[5] BFMDRS[5] DIS[5] ASAS[5]** *Two-point discrimination[6] Pressure[6]*
	01 - 09	**Tactile discrimination test[6]**	**COPM[2] MAS[5] Mod Tardieu Scale[5]** Wrist position sense test[6] Tactile discrimination test[6] *Texture discrimination[6] Stereognosis[6]*
	Reported not (0%) in use.	Nottingham sensory assessment[6] Rivermead assessment of somatosensory[6]	**Nottingham sensory assessment[6] Rivermead assessment of somatosensory[6]**
	Reported as "rarely used"	Functional tactile object recognition test[6] Manual form perception test[6]	**GMFCS[4] MAS[4] FMS[4] MACS[4] CAPE[2] PEM-CY[2] CHIEF[2] LIFE-H[2] PACS[2]** Functional tactile object recognition test[6]

Note. This table displays the proportion of a therapy discipline using each tool as reported in each of the studies eg the GMFCS was reported in three studies and is repeated in three cells in this display. Only studies with extractable data on therapists' use of identified assessment tools are included. [1]Adeniyi et al. 2015 (data from three different hospital centres in south-west Nigeria reported); [2]Anaby et al. 2018 (frequency: cited use in case scenario); [3]Deville et al. 2015 (frequency: <90% of the time); [4]Obembe et al. 2018; [5]Stewart et al. 2018; [6]Walmsley et al. 2018. Emboldened tool abbreviations demonstrate tools with acceptable validity for use with cerebral palsy population. Italicised type denotes non-standardised assessment tool. No data were reported on assessment tool use for Speech Pathologists.

Tool Legend (by appearance): GMFCS, Gross Motor Function Classification System; GMFM, Gross Motor Function Measure; Beery VMI, Beery Visual Motor Integration; HAT, Hypertonicity Assessment Tool; COPM, Canadian occupational performance measure; BOT-2, Bruininks-Oseretsky Test of Motor Proficiency; MMT, Manual Muscle Testing; PODCI, Paediatric Outcomes Data Collection Instrument; Wee FIM, Functional Independence Measure for Children; FAQ, Functional Assessment Questionnaire; CP QOL-Child, Cerebral Palsy Quality of Life for Children; PEDI, Pediatric Evaluation of Disabilities Inventory; QUEST, Quality of Upper Extremity Skills Test; BADS, Barry Albright Dystonia Scale; BFMDRS, Burke-Fahn-Marsden Dystonia Rating Scale; DIS, Dyskinesia Impairment Scale; ASAS, Australian Spasticity Assessment Scale; MAS, modified Ashworth Scale; FMS, Functional Mobility Scale; MACS, Manual Abilities Classification System; CAPE, Children's Assessment of Participation and Enjoyment; PEM-CY, Participation and Environment Measure for Children and Youth; CHIEF, Craig Hospital Inventory of Environmental Factors; LIFE-H, Assessment of Life Habits; PACS, Paediatrics Activity Card Sort.

2.3.6 Discussion

An update of therapists' use of assessment tools and outcomes from the quality assessment of included studies is reported. Almost all studies relied solely on self-report questionnaire surveys to collect data from self-selecting participants about their assessment behaviours. Self-selection bias may have contributed to an overestimation of actual practice, as self-reported behaviours typically overestimate actual performance (Adams et al., 1999). It is not possible to know in what way self-selection bias may have influenced the review findings, as response rates and non-responder characteristics were not available in almost half of the studies. Two studies addressed issues of questionnaire validity; the remaining studies did not report on external review processes for the questionnaire used or preliminary reliability testing. Use of electronic medical records, when available, or case file audits are potentially more objective methods of data collection. Overall, the strength of external validity of the studies in the updated review was similar to the original review. Internal validity was less strong with only three of the nine studies achieving a two-star rating or more for tool validity, in contrast to 12 of the 14 studies in the systematic review (O'Connor et al., 2016a). As with all systematic reviews an inherent 'reporting bias' needs to be considered alongside data interpretation. Published data reflects researcher interests, professional disciplines and/or funding and may mean aspects of therapist assessment use will be missed.

Norm-referenced discriminative tools and non-standardised tools were used to a moderate extent by therapists. The original systematic review (O'Connor et al., 2016a) identified high levels of use of norm-referenced discriminative tools and non-standardised tools among therapists. The positive shift in the types of tools reported in this update may reflect the

greater focus of studies on therapist's assessment practices specifically for children with cerebral palsy. Nearly all studies included in the updated review reported assessment tools used for sole populations of children with cerebral palsy. This contrasted with surveys of practice in the original systematic review that included children with a range of disabilities and variable proportions of children with cerebral palsy (O'Connor et al., 2016a). The ongoing use of norm-referenced discriminative tools and non-standardised tools is, however, of concern. As previously discussed, use of norm-referenced discriminative tools suggests assessment tools are being used primarily for diagnosis and identification of impairments and that outcomes of therapy interventions are not being evaluated by therapists, that is,—unless tools not designed or validated to evaluate therapy outcomes for children with cerebral palsy are being used out of context.

The updated review identified that the assessment tools used most frequently related to gross motor function: GMFCS; goniometry; and Gross Motor Function Measure (GMFM) (Russell, Rosenbaum, Avery, & Lane, 2002). Tools that assess daily-related activities and pain were reported, but used only at moderate to low levels. All assessments being used evaluated ICF domains related to body structure and functions and activity. Validated tools assessing participation and the environment were rarely used, a finding that is consistent with the original review (O'Connor et al., 2016a). An increase in the use of the broader activity performance measure, the COPM, may exist among Canadian occupational therapists. The shift from low to moderate levels of use of the COPM over the decade may reflect an increase in actual use, albeit slow (Anaby et al., 2017; Hanna et al., 2007). The consistent finding that the '3G's (GMFCS, GMFM and goniometry) remain the only assessment tools used frequently by therapists suggests that important domains, such as

pain, quality of life, participation, self-care and communication that have previously been identified as important by families, are not being assessed (Vargus-Adams & Martin, 2009).

Use of specific assessment tools is highly variable across geographical and organisational settings. Therapists from Canada and the United States reported high levels of use of the GMFCS and GMFM across a range of workplace settings. More recent studies of practice in hospital sites in Nigeria identified very high and very low levels of use. The GMFCS is reported as the most highly used assessment tool (Adeniyi et al., 2015; Anaby et al., 2017; Obembe et al., 2018). However, a gap between therapists' knowledge and use of the GMFCS is also reported (Deville et al., 2015; Obembe et al., 2018). The nation-wide survey of physiotherapists in the United States by Deville et al. (2015) found all physiotherapists were aware of the GMFCS, but it was used consistently by only 42% of therapists. Similarly, Adeniyi et al. (2015) found the majority of therapists (81%) in Nigeria were aware of the GMFCS, but only 54% of therapists used the tool in patient care. As 'baseline' levels of GMFCS use in these two settings are not available, it is not clear if this knowledge-practice gap closes with time or persists. Studies investigating use of the GMFCS across different settings provide a picture of wide dissemination but variable uptake within settings.

The suite of classification tools used in cerebral palsy (GMFCS, MACS, Communication Function Classification System (CFCS) (Hidecker et al., 2011), Eating and Drinking Abilities Classification System (EDACS) (Sellers, Mandy, Pennington, Hankins, & Morris, 2014) describes a child's functional performance across a range of areas. Individually, each classification tool provides discrete information about a child's functioning. When combined, these classification tools provide an important holistic overview of the child that

can facilitate communication between families, therapists and researchers in relation to therapy and service provision. Use of the GMFCS was reported as high in both the original review and the updated review; however, use of the MACS is seldom reported and no studies were identified that reported therapists' use of the CFCS and EDACS. The CFCS and EDACS have, however, been published only more recently, whereas the GMFCS has been freely available for two decades. Consistent with the findings from the original review, the updated review findings suggest the GMFCS is being used in isolation, rather than as part of a suite of tools. Further investigation is needed to determine if this is the case.

The 'know-do' gap between therapists' awareness and actual use of assessment tools was evident in the updated review. Therapist characteristics such as age and qualifications were significantly associated with use in some settings (Deville et al., 2015) but not in others (Obembe et al., 2018). Well known organisation-level barriers to use were identified that included time (Obembe et al., 2018), resources (Auld & Johnston, 2018a), prescribed professional roles and complex processes (Auld & Johnston, 2018a). Clinician-level barriers related to knowledge, skills, confidence and clinical utility of tools were also identified (Adeniyi et al., 2015; Auld & Johnston, 2018a; Stewart et al., 2018; Walmsley et al., 2018). Several authors speculated on the possible reasons for the gap between knowledge and practice and concluded further investigation was needed (Adeniyi et al., 2015; Auld & Johnston, 2018a; Bailes et al., 2017; Deville et al., 2015). In keeping with the original review, this update highlights factors related to the clinician, the tool, data collection processes, organisational setting and health context as important considerations for knowledge translation of assessment tools into practice.

2.4 Conclusions

The overall purpose of this thesis is to understand what is needed for allied health practitioners to more easily embed evidence-based assessments in therapy practice for children with cerebral palsy and their families. The aim of the systematic review (and update) was to determine whether evidence-based assessment tools were used by allied health practitioners when working with children with cerebral palsy, and if so, what assessment tools were used, by whom and how often. Necessary consideration was also given to the study design and quality of studies included in the review.

The original systematic review (O'Connor et al., 2016a) concluded that levels of use of standardised assessments were variable but low overall and, of the assessment tools used frequently, many were not validated for children with cerebral palsy. The focus of the most frequently used and validated assessment tools was gross motor function. The assessments evaluated body structure, function and activity domains of the ICF. Validated assessments for other important domains were rarely used by therapists, for example, participation, environment, quality-of-life, and pain. Findings from the systematic review update (2015–2019) report variations in child participants, tools used and study quality, but findings overall are consistent with those of the published systematic review (O'Connor et al., 2016a). Within the limited available published data and practice settings reported the systematic review and update conclude that:

1. Norm-referenced discriminative tools and non-standardised tools are used by therapists for children with cerebral palsy;

2. The ICF foci of the most frequently used tools relate to body functions and structures, and mobility related activities;

3. The '3G's (GMFCS, GMFM and goniometry) are the assessment tools used most frequently;

4. Areas such as pain, quality of life, participation, self-care and communication that have previously been identified as important by families are not being assessed;

5. The GMFCS is widely disseminated but used variably, and potentially in isolation rather than as part of a suite of tools;

6. Factors related to the clinician, the tool, data collection processes, organisational setting and health context are important considerations for knowledge translation of assessment tools into practice.

Thus, the use of evidence-based assessment tools in therapy management for children with cerebral palsy varies between and within countries and remains low overall, despite therapists having knowledge of assessments and resource availability. These findings suggest a more in-depth understanding of the contextual drivers of therapists' assessment behaviours is needed. This could be successfully achieved by combining a qualitative investigation of therapists' experiences alongside measures of actual practice across different organisational contexts. Therefore, the objective of the next study in this thesis was to design and conduct a study to understand in-depth the contextual and personal influences on allied health practitioners' use of evidence-based assessment tools and the extent of use of such tools, within two community organisations (one large, one small) in Victoria, Australia.

Chapter 3 Understanding allied health practitioners' use of evidence-based assessments for children with cerebral palsy

3.1 Introduction

This chapter presents the research undertaken to meet the second objective of this thesis. The aim and research questions addressed in Study 2 are stated initially, followed by two sections that provide: 1) the rationale for the mixed methods research design chosen for Study 2 and 2) the methodological approach chosen for the qualitative component of the study. The two sections on research design are followed by the published paper from Study 2. The supporting materials for Study 2 can be found in Appendix B. A summary of the study implications and direction taken for subsequent work in the thesis is then outlined. Study 2 was nested within a larger multifaceted knowledge translation project aiming to increase allied health practitioner implementation of research in practice (Imms et al., 2015). Ethical approval for the current study was obtained through the larger study – *CP Check Up: providing the best service at the best time* (Appendix B1).

The aim of Study 2 was to develop an in-depth understanding of allied health practitioners' experiences, perceptions and use of evidence-based assessment tools for children with cerebral palsy, within two different community organisations (one large, one small) in Victoria, Australia. The following research questions were developed:

1. What are allied health practitioners' experiences and perceptions of using evidence-based assessments in clinical practice for children with cerebral palsy?

2. To what extent are evidence-based assessments used by allied health practitioners in two community organisations in Australia for children with cerebral palsy?

    a. What assessment tools are used, and how often?

3. Are differences in allied health practitioners' experiences of assessment reflected in practitioners' use of assessments in different organisational contexts?

3.2 Mixed methods research design

Mixed methods research sits as the third major research paradigm alongside traditional qualitative (interpretivist) and quantitative (positivist) paradigms (Johnson, Onwuegbuzie, & Turner, 2007). While the 'unique paradigm' status of mixed methods continues to be debated (Baškarada & Koronios, 2018), the mixed methods approach remains a highly relevant and applicable approach to investigating healthcare practice. Mixed methods research is informed by the philosophical tradition of pragmatism developed by Pierce (1839–1914), James (1842–1910) and Dewey (1859–1952) that focusses on "the practical nature of reality" (Shaw, Connelly, & Zecevic, 2010, p. 514). Multiple viewpoints are viewed as necessary to acquire meaningful knowledge and truths about real-world problems. Mixed methods research seeks to understand real-world transactions by integrating results from qualitative and quantitative theoretical perspectives (Johnson et al., 2007). Novel inferences or conclusions can potentially be drawn that would not have been possible if each theoretical perspective was considered in isolation (Herbert & Higgs, 2004; Tashakkori & Creswell, 2007). This pragmatic approach to acquiring knowledge aligns theoretically with the reality of clinical practice. Social (qualitative) and practical

(quantitative) sources of knowledge need to be integrated during therapy (Shaw et al., 2010). Mixed methods research can generate meaningful results that reflect the complexity of clinical practice (Creswell & Plano Clark, 2007).

Morse and Niehaus (2009) define mixed methods as:

> the incorporation of one or more methodological strategies, or techniques drawn from a second method, into a single research study, in order to access some part of the phenomenon of interest that cannot be accessed by use of the first method alone (p. 14).

The first two research questions for Study 2 reflect the different social and practical dimensions of clinical practice, with the third question seeking to understand practitioners' assessment behaviours in different contexts. A mixed methods research design was considered most suitable to encompass the different theoretical approaches required to address these research questions. An inductive approach was best suited to Question 1 that sought to understand allied health practitioners' experiences of assessment; in contrast, a deductive approach was needed to capture the extent of tool use sought through Question 2. By integrating these different perspectives, it was possible to generate an understanding of how different therapists' experiences with using assessment tools in different contexts might impact assessment tool use.

The rationale for choosing a mixed methods approach (as described above) for Study 2 can be substantiated from the literature; however, guidance on how to conduct mixed methods research is less clear. Critical appraisal frameworks and tools for mixed methods research were in the early stages of development when this thesis commenced (Heyvaert, Hannes, Maes, & Onghena, 2013; Shaw et al., 2010). Without guidance, the term 'mixed' can lend

itself to a 'pudding bowl' approach that threatens study validity (Baškarada & Koronios, 2018; Morse & Niehaus, 2009). The latter argue it is not possible to 'mix' qualitative and quantitative methods and remain valid; rather, they recommend a systematic approach where the two methods are conducted separately (either simultaneously or sequentially) and "meet at the point(s) of interface" (Morse & Niehaus, 2009, p. 11). It is also important that conventional quality criteria are met for the qualitative and quantitative study components, particularly in the absence of published critical appraisal tools for mixed methods research (Shaw et al., 2010). 'Mapping' the steps taken and points of interface identified for integrating data components can also improve transparency and reproducibility of the study methods (Morse & Niehaus, 2009).

Morse and Niehaus (2009) emphasise the importance of clarifying the theoretical drive of the study. The theoretical drive determines the methods used for the core component of the study. The core component can typically stand alone as an independent study, but is further enriched by the supplementary component(s) (Morse & Niehaus, 2009). Supplementary components are merged with the core component when data analysis is sufficiently developed—that is, data are ready to be meaningfully combined. The exploratory nature of this project's aim—to develop an in-depth understanding of real-world assessment practices—aligned with an inductive approach to enquiry and formed the basis for the theoretical drive of this mixed methods study. The core component of Study 2 used qualitative research methods to explore therapists' experiences. Quantitative supplementary components related to: the extent of assessment use; perceived supports and barriers; and contextual characteristics of the organisations and participants. The two components were collected and analysed simultaneously, but separately, until the point of

interface. A 'map' of the methods adopted for Study 2 is provided in Figure 3.1 to illustrate the sequence of steps taken and points of interface where core and supplementary components were integrated during analysis and writing up of the study.
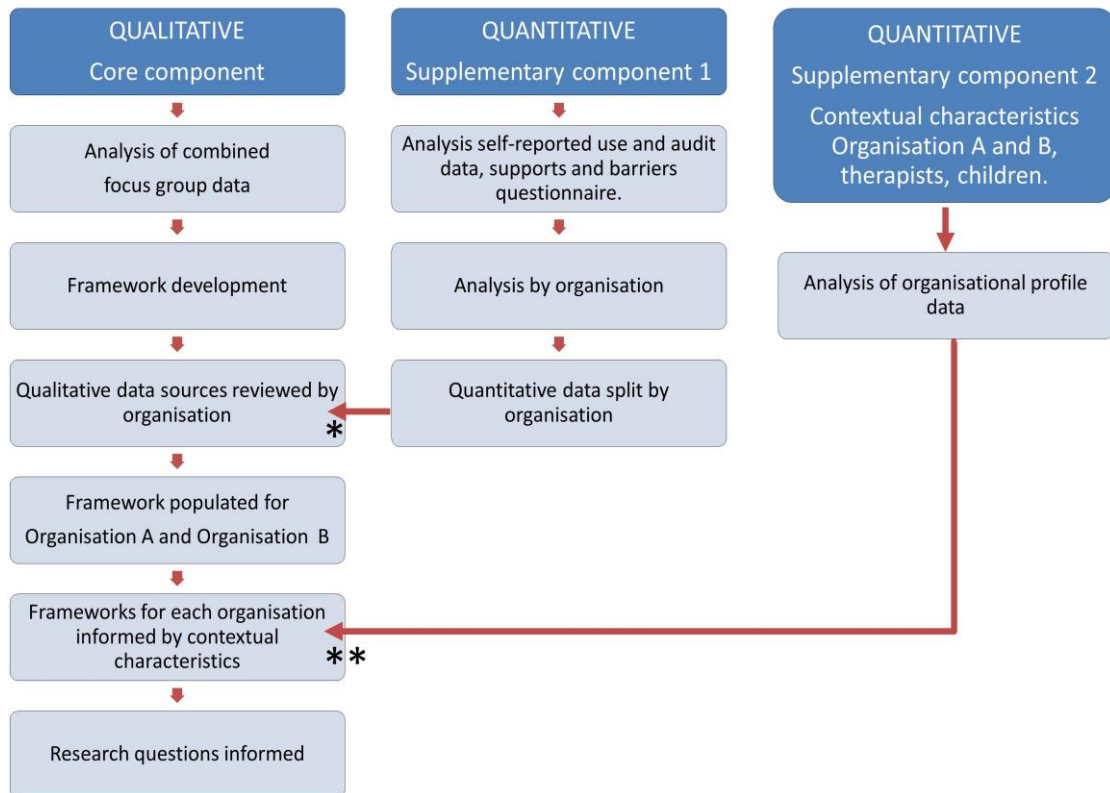
Figure 3.1. Integration of core (qualitative) and supplementary (quantitative) data components. *first point of interface **second point of interface

3.3 Interpretive description as the core qualitative method

The core component of Study 2 adopted a qualitative approach to understanding allied health practitioners' experiences of using evidence-based assessment tools. The purpose of the study was to understand what is needed to make it easier to use evidence-based assessment tools in clinical practice. The focus of qualitative research is on understanding the meaning and interpretation people give to what they do and how people "make sense of their experiences and the world in which they live" (Liamputtong, 2013a, p. xii). Most

qualitative research in the health sciences aligns with a constructivist (rather than subjective) stance to inquiry, where truth, meaning and knowledge arise from our engagement with the world (Crotty, 1998). Different theoretical perspectives shape research. Traditional qualitative research methodologies developed through the social sciences, such as grounded theory, phenomenology and ethnography are informed by an hermeneutic interpretivist perspective that strives to interpret and understand how meaning is attributed to a particular phenomenon (Crotty, 1998). To understand therapists' assessment behaviours an interpretivist perspective was taken. Such a perspective reflected a personal position and inclination as a clinician and researcher, possessing a keen interest in the meaning attributed to evidence-based assessment and how use of assessment tools with families can be interpreted within different organisational contexts.

The knowledge products from theoretically driven traditional methods are, however, often not suited to the pragmatic clinical problems that are peculiar to healthcare practice (Thorne, 2016). A need for credible knowledge that was less theoretically driven, and applicable to the 'messiness' and complexity of clinical practice was identified (Thorne, Kirkham, & MacDonald-Emes, 1997). The focus of the thesis was in developing knowledge that was usable in clinical practice. Interpretive description is a qualitative research method that is consistent with the study aim. Interpretive description aims to develop "a form of understanding that is of practical importance to the applied disciplines within the context of their distinctive social mandates" (Thorne, 2016, p. 29). Consistent with an interpretivist theoretical perspective, interpretive description positions the researcher alongside the participants to take on their view of the world in order to

understand their experience as fully as possible. Interviews or focus groups are commonly used methods for data collection.

Data analysis strategies used in interpretive description borrow strongly from the traditional inductive approaches, often found in grounded theory (Hunt, 2009). However, interpretive description differs in its approach to analysis by asking broad questions of the data, for example, 'What is happening here?', rather than very detailed focus on small segments of textual data (Thorne et al., 1997). Inductive data analysis is conducted through an iterative process of comparison and interrogation of data sources beyond the "self-evident" that enables patterns, relationships and thematic insights to be developed (Thorne, 2016). Themes are then reconfigured by the researcher(s) to form an interpretive description of the findings that shifts how we traditionally view a specific clinical event—in this case, the clinical use of evidence-based assessment tools.

Interpretive description was chosen as the qualitative component method for Study 2 as this approach specifically addresses the complexity and pragmatic demands of practice, with the potential to generate clinically relevant findings in new areas of investigation. Furthermore, the contribution of the researchers' clinical expertise is made explicit and used to orientate: the research; define the boundaries of the topic; structure and interrogate data; and reconfigure thematic findings in a way that makes the research relevant to clinical practice (Hunt, 2009). The next section presents Study 2 of the thesis.

3.4 Paper 2. Understanding allied health practitioners' use of evidence-based assessments for children with cerebral palsy: A mixed methods study.

Due to publishing requirements the Word version of the accepted manuscript will be presented, rather than the PDF format. For reasons of text consistency some alterations in punctuation may exist between the published paper and accepted manuscript.

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Understanding allied health practitioners' use of evidence-based assessments for children with cerebral palsy: A mixed methods study.

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Abstract

Purpose: Evidence-based assessment tools for children with cerebral palsy are not widely used by healthcare professionals in day-to-day practice. This study aimed to examine allied health practitioner experiences, perceptions and use of assessments for children with cerebral palsy.

Method: A mixed methods study was conducted in two rehabilitation organisations. Three focus group interviews explored therapists' assessment experiences with data analysed using interpretive description. Assessment practices of therapists (n=55) were assessed through self-report questionnaire and case-file audit of children with cerebral palsy (n=44).

Results: Emergent themes described therapists' motivation to use of assessment tools on a behavioural continuum of *I don't; I can't; I try; I do; We do;* influenced by assessment satisfaction, child and family collaboration, organisational expectation, research fit, and dedication of time. Only two of fifteen audited assessment tools were documented in more than 50% of files. Use was higher where assessments positively connected therapists, children and parents, and use was organisationally endorsed. The 'Cultural Cone for Evidence-based Assessment' was conceptualised.

Conclusion: Engagement in assessment appears to require a conceptual shift by therapists and organisations to understanding assessment as part of, not an adjunct to, therapy. The Cultural Cone framework may assist therapists and services with designing site-specific strategies to promote evidence-based assessment behaviours.

Implications for rehabilitation

- Therapists' can reflect on where they are positioned on the *use continuum* in the Cultural Cone framework, and consider the contextual influences contained in this framework to understand their motivation to use evidence-based assessment tools.

- Routine use of evidenced-based assessment tools for children with cerebral palsy by allied health practitioners remains generally low and therapists and service organisations need to consider ways to increase use.

- Where possible, therapists should choose assessment tools that fully engage children and families and themselves in the assessment process.

- The Cultural Cone framework may be used to assist therapists and organisations identify and design site specific strategies to increase evidence-based assessment use in day-to-day practice.

3.4.1 Introduction

Assessing children with cerebral palsy in a therapeutic context requires information to be gathered from a range of sources that can inform clinical decision making and goal setting, and evaluate outcomes of therapy interventions. Over the past two decades many clinically relevant and psychometrically robust assessment tools have been developed for children with cerebral palsy (King, Wright, & Russell, 2011; Law & Darrah, 2014; Wright & Majnemer, 2014). Use of these assessment tools is now considered integral to evidence-based practice (Duncan & Murray, 2012; Green, 2014; Grimmer-Somers, 2007; Law et al., 1999) and collaborative decision making in the field of childhood disability (Brewer, Pollock, & Wright, 2014; King et al., 2011; Majnemer, 2010; Palisano, 2006; Wright & Majnemer, 2014).

Within an evidence-based practice framework, findings from valid and reliable assessment tools are integrated with findings from informal methods of assessment, clinician and family expertise, and child and family aspirations, within the resources available and their context (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). Including evidence-based assessment tools in clinical practice has been promoted by educational and professional health bodies for many years. In spite of these efforts, adoption of the tools in day-to-day clinical practice has been slow (Copeland, Taylor, & Dean, 2008; Duncan & Murray, 2012; Jette, Halbert, Iverson, Miceli, & Shah, 2009; Piernik-Yoder & Beck, 2012; Stapleton & McBrearty, 2009) and their limited use in the field of cerebral palsy is no exception (King et al., 2011; McConnell, Johnston, & Kerr, 2012; Saleh et al., 2008; Watson & Pennington, 2015). A recent systematic review of allied health practitioners' use of evidence-based assessment tools for children with cerebral palsy highlighted that only a limited number of validated tools were used, and not in all practice settings (O'Connor, Kerr, Shields, & Imms, 2016).

Many studies have explored potential barriers to and supports of the use of evidence-based assessment tools in clinical practice (Duncan & Murray, 2012; Garland, Kruse, & Aarons, 2003; Skeat & Perry, 2008). Barriers have been identified at multiple levels—organisation, practitioner, assessment tool and patient. Commonly perceived barriers include low levels of organisational commitment and support, diminished knowledge and confidence in tool selection and administration, and low perceived value and fit of assessment tools in the clinical setting. Practical issues related to tool availability, cost and time are also reported as factors influencing use in the clinical setting (Duncan & Murray, 2012).

To date, the effectiveness of knowledge translation interventions to increase and embed assessment tools into clinical practice has been inconsistent or modest (Colquhoun et al., 2016; Käll, Larsson, & Bernhardsson, 2016). A recent systematic review investigating the effectiveness of knowledge translation interventions to increase allied health practitioners use of standardised assessment tools (Colquhoun et al., 2016) reported only a few studies using interventions tailored to known barriers - instead relying on less effective traditional educational strategies (Forsetlund et al., 2009). Multifaceted interventions (Boaz, Baeza, & Fraser, 2011) tailored to identified barriers (Baker et al., 2010) across multiple levels (Duncan & Murray, 2012; Grol & Wensing, 2004) are more likely to be effective in changing health professionals' behaviours.

Clinical practice is complex and multiple factors are likely to interact to influence a clinicians' decision to use assessment tools (Nilsen & Bernhardsson, 2013; Yano, 2008). Direct causal links between identified barriers to assessment use and eventual uptake of assessment tools cannot be assumed. Even when barriers are identified, it is not clear which barriers to target, their relative importance, and whether all barriers have been identified (Nilsen & Bernhardsson, 2013).

Effective knowledge translation also requires an in-depth understanding of behaviour and how to bring about optimal behaviour change for therapists working in complex clinical environments. Two theoretical frameworks can be considered in relation to changing practitioner behaviours (Ryan, 2013): motivational readiness for change based on the trans-theoretical model, (Prochaska & Norcross, 2014; Prochaska, Redding, & Evers, 2008b); and concepts of autonomous motivation founded on self-determination theory (Ryan & Deci, 2000a). The trans-theoretical Model (Prochaska et al., 2008b) describes how

individuals move towards initiating and sustaining a new behaviour through readiness-based stages of change: pre-contemplation, contemplation, preparation, action and maintenance. Action is preceded by a decisional balance point where a conscious decision is made to pursue goals around changing behaviour (Gale & Skouteris, 2012). Self-determination theory describes motivation states and their accompanying degrees of 'ownership' of the intent to act (Ryan, 2013; Ryan & Deci, 2000b). When amotivated, intent is absent or lacking, the activity is not valued, and low levels of competence and autonomy, or self-determination are often present. Extrinsically motivated behaviours satisfy external rewards or demands and carry low degrees of autonomy and "ownership". More autonomous forms of motivation see increasing degrees of internalised value and ownership of the behaviour and diminished external regulation. When intrinsically motivated, the behaviour is accompanied by high degrees of competence and autonomy and pursued for its inherent value, satisfaction and enjoyment. A growing evidence base exists for behaviour change interventions derived from these theoretical frameworks, for example, health coaching (Gale & Skouteris, 2012) and cognitive orientation to daily occupational performance (Polatajko & Mandich, 2004).

Understanding the social and contextual influences on therapist's decision to use, or not to use, evidence-based assessment tools is essential to enable design of more effective behavioural change interventions to increase evidence-based assessment use for children with cerebral palsy (Baker et al., 2010; Colquhoun et al., 2016; Dannapfel, Peolsson, & Nilsen, 2013; Käll et al., 2016; King et al., 2011; Nilsen & Bernhardsson, 2013; O'Connor et al., 2016; Yano, 2008). Therefore, the aim of this study was to develop an in-depth understanding of allied health practitioners' real-world practices—their experiences,

perceptions and use of standardised assessments for children with cerebral palsy in different clinical contexts. The social and practical dimensions of this phenomenon called for a multi-dimensional research paradigm that could describe *what* tools were used to what extent, the social and cultural context for use *(when, where* and *how)* and identify potential interacting factors, both external and internal to the health professional, that could help explain *why* practitioners may or may not use assessment tools in practice. Thus, a mixed methods research approach (Johnson, Onwuegbuzie, & Turner, 2007), that integrates quantitative (positivist) and qualitative (interpretivist) theoretical perspectives was chosen.

We wanted to specifically determine;

a) What were allied health practitioners' experiences and perceptions of using evidence-based assessment tools in clinical practice?

b) To what extent were evidence-based assessment tools used by allied health practitioners for children with cerebral palsy?

c) Are differences in allied health practitioners' assessment experiences reflected in practitioners' use of assessment tools in different organisational contexts?

3.4.2 Methods

This study formed part of a larger project (Imms et al., 2015) evaluating the effectiveness of a multifaceted knowledge translation intervention to improve allied health practitioners' research implementation behaviours. The larger study was conducted in five Australian-based organisations that provided community-based rehabilitation services to children with cerebral palsy.

Study Design

A concurrent, qualitatively driven (Morse & Niehaus, 2009) mixed methods study design (Crotty, 1998) was adopted that enabled between-method triangulation, elaboration of results from each method, and enhanced contextual validity (Johnson et al., 2007). Although standardised instruments, have been developed to assess organisational contextual factors—as examples, Alberta Context Tool (Estabrooks, Squires, Cummings, Birdsell, & Norton, 2009) and the Barriers and Facilitators Assessment Instrument (Peters, Harmsen, Laurant & Wensing, 2002), these tools are in their early stages of development and are not yet transferable between contexts (Jung et al., 2009), nor are they psychometrically robust (Chaudoir, Dugan, & Barr, 2013); thus, they were not used.

Study Setting

The study focussed on two of the five organisations participating in the larger study; Organisation A and Organisation B. Both organisations were situated within the same Australian state. Organisation A, a large service, was based in a metropolitan city (population of 4.4 million) and provided school-based and early intervention therapy services to children and adults with a wide range of disabilities. Organisation B, a small service, was situated in a regional city (population of 225,000) and provided centre-based and outreach services to children with cerebral palsy. Sites were chosen for their contrasting size and locations, common state legislature and convenience. Organisational characteristics such as size and number of sites, profiles of children attending the service, staffing and geographical location, were gathered using a study-specific Organisational Profile questionnaire completed by each organisation. The characteristics of each setting are shown in Table 1.

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Table 1. Organisational profiles

Characteristic	Organisation A	Organisation B
Number of sites		
Centre	0	1
Early Childhood	6	0
School	2	0
Service model	Trans-disciplinary & Educational	Multi-disciplinary & Centre based
Funding source	Government 76% Other 24%	Philanthropic 90%
Total Staff (no./EFT)	127/75.0	12/5.3
Occupational Therapists	22/13.1	2/0.8
Physiotherapists	16/11.1	5/2.0
Speech Pathologists	26/13.0	2/0.7
Total AHP	64/37.2	9/3.5
Other Allied Health	5/4.3	0
Other Professional staff	14/8.7	1/0.4
Administrative staff	NS	1/0.6
Senior Executives	NS	1/0.8
Children		
Age group	EI-School	EI- School
Diagnoses	CP and other	CP and other
Total children in service (no.)	630	58
Children with CP 3-<6 years	20	25
Children with CP 6-18 years	85	26

no., number; EFT, equivalent full time; AHP, Allied health practitioner; NS, not specified; CP, cerebral palsy; EI, early intervention; School-school aged (6-8years); Other Professional staff - e.g. recreational officers, team leaders.

Study participants and recruitment

Eligible participants from the two organisations included: i) allied health practitioners, physiotherapists, occupational therapists and speech pathologists, who worked with, or had the potential to work with, children with cerebral palsy; and ii) children aged 3 to 18 years diagnosed with cerebral palsy and their families. Organisation-specific recruitment strategies included on-site information sessions held for staff and families by the research team, word-of-mouth advertising; and distribution of posters, newsletters and email advertisements. In addition, allied health practitioners received a letter containing project information and an invitation to participate. Voluntary, written informed consent was obtained to complete two questionnaires and to enable participation in an audio-recorded focus group. Families, whose children with cerebral palsy received therapy services from the participating organisations, were provided with information about the study via the research team or the child's therapist. Participant families provided voluntary written consent to collect and securely store relevant clinical information from their child's file. Children with cerebral palsy, enrolled in the first phase of the larger study before 22nd January 2014, were included in the current study.

Ethics

Ethics approval was obtained from the Australian Catholic University Human Research Ethics Committee (2012 309V), the Department of Education and Early Childhood Development (2013_001962), and the Cerebral Palsy Alliance Human Research Ethics Committee (2013-04-02) as part of the larger study, *CP Check Up: providing the best service at the best time.*

Data collected

Allied health practitioners' experiences and perceptions of evidence-based assessment use were obtained through focus group interviews. The extent to which evidence-based assessment tools were used by allied health practitioners (frequency of use) was assessed using two sources: a) the Evidence Based Practice Competencies Questionnaire-CP (EBPCQ-CP), a psychometrically evaluated self-report measure of allied health practitioners' evidence-based practice behaviours (test-retest reliability ICC = .94) (Kerr, Bowe, Miyazaki, & Imms); and b) a case-file audit. A second questionnaire (Supports and Barriers Questionnaire (Rivard et al., 2010)) was used to ascertain allied health practitioners' perceptions of known factors (Fleuren, Wiefferink, & Paulussen, 2004) influencing the routine use of assessment tools. Data reported here were collected during the baseline period of the larger project. Questionnaires were administered to AHP participants during scheduled in-service days at each organisation.

1) Focus groups were held at each site, two at Organisation A, and one at Organisation B. Focus groups were guided by the same experienced and independent moderator using an interview topic guide developed by the investigators (see Box 1). Due to the small number of therapists in organisation B, individual details of focus group participants were not recorded to protect individual therapist identity. Between four and seven AHPs' participated in each group with all therapy disciplines represented. Member checking was instigated periodically throughout each focus group to confirm facilitator understanding and enhance confirmability of the data. Interviews were audio-recorded and lasted 1 to 1.5 hours. Recorded data were transcribed verbatim by a professional transcription service and

imported into QSR NVivo version 10 (QSR International Pty Ltd., Melbourne, Australia) for data management.

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Box 1: TOPIC GUIDE: Allied health practitioner experiences of evidence-based practice and assessment.

- What is your understanding of evidence-based practice?
- Considering the definition of EBP that I have just given you, what do you think is the relevance of evidence-based practice in your day-to-day work?
- What is your experience of using evidence-based assessment tools within your workplace?
- Can you expand on why you use, or don't use, evidence-based assessment tools with the children and families you see?
- What do you take into consideration when selecting an assessment tool for use with a child and family?

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2) The following data were extracted: participant information (profession, years of clinical experience, postgraduate qualifications, continuing education and level of clinical expertise); and Evidence-Based Practice Competencies Questionnaire-Cerebral Palsy items, which assessed therapists' self-rated frequency of use (0-5%, 6-24%, 25-49%, 50-74%, 75-100% of the time) of three validated assessment tools for children with cerebral palsy. They are as follows: (1) functional classification tools (Gross Motor Function Classification System, Manual Abilities Classification System and Communication Function Classification System); (2) Canadian Occupational Performance Measure; and (3) Goal Attainment Scaling. These individualised, non-discipline specific tools are well known, freely available, and recommended for children with cerebral palsy (Palisano, 2006).

3) Children's case files were audited during March – April 2013. Audit 'data capture periods' were selected to reflect best practice in routine surveillance for children with cerebral palsy: a 6-month period for children under six years of age; and a 12-months data capture period for children six years or older (Hägglund et al., 2014). The audit period preceded implementation of the larger study to avoid contamination. The following case-file data were extracted: age, gender, cerebral palsy type and distribution, and the presence or absence of results from 15 validated assessment tools (see Table 4 legend). Decision making by the research team in relation to which assessment tools to include in the audit was based on the following criteria: whether or not they were validated for children with cerebral palsy; their importance in surveillance of progressive musculoskeletal deformity; and generic availability and applicability across types, age, severity of cerebral palsy, and important ICF-CY (2007) domains of functioning (Vargus-Adams & Martin, 2011). A data collection form was developed for the case-file audit and data were extracted by an independent research assistant and the primary author.

4) Supports and Barriers Questionnaire (Rivard et al., 2010) used an 11-point Likert Scale (-5 to +5) to ascertain the allied health practitioners' perceptions of the extent to which five factors—organisational structures and resources, therapists, assessment tools and children, and families—were perceived as barriers to routine assessment tool use.

Qualitative data analysis

Focus group data transcripts were analysed inductively using an interpretive description approach (Thorne, Kirkham, & MacDonald-Emes, 1997) Interpretive description focuses on generating new knowledge through understanding "complex experiential clinical phenomena within nursing and other health disciplines concerned with applied health

knowledge or questions [from the field]" (Thorne, 2016, p. 27). It aims to make sense of the variability that accompanies practice in the real-world of healthcare (Thorne, Kirkham, & O'Flynn-Magee, 2004). Themes and patterns within subjective perceptions of a clinical phenomenon are captured, interpreted, conceptualised and presented in new ways that can inform clinical understanding (Thorne, 2016; Thorne et al., 2004).

Initial immersion in the combined focus group data by the first author generated categories reflecting broad areas of therapist interaction with evidence-based assessment tools. Categories were cross checked for authenticity by the co-authors. Textual data were further interrogated by the first author for thematic relationships, patterns and linkages through an iterative process of labelling and conceptual development. A reflective journal was kept during thematic development with questions posed in relation to the data such as: *In what practical and social contexts are assessment tools used? How do therapists view and decide to use standardised assessments? How do therapists use assessment tools?* and *What social, intellectual or emotional interactions accompany therapists' use of assessments?* Emergent sub-themes were condensed into overarching themes that captured the timbre and context of therapists' interactions with assessment tools in the clinical setting.

Quantitative data analysis

Descriptive data were analysed using frequency counts and descriptive statistics. Allied health practitioners were categorised as High-user, Moderate-user or Low-user on the basis of self-reported use of the three assessment tools included in the Evidence-Based Practice Competencies Questionnaire-Cerebral Palsy. High-users were allied health practitioners who reported using functional classification tools *AND* an individualised tool (Canadian Occupational Performance Measure, or Goal Attainment Scaling) more than 50% of the

time. A moderate-user used some tools to some extent; i.e., functional classification tools *OR* an individualised tool more than 25% of the time, but did not meet high-user criteria. Low-users did not use any tools to any extent; that is, they used functional classification tools, or an individualised tool less than 25% of the time.

Individual child case-file audit data were converted to a Use Index Score, calculated as: (number of assessments completed/total number of assessments possible) x 100. A Use Index Score of 0% indicated no audited assessments were completed; conversely, a Use Index Score of 100% indicated all audited assessments were used. The Use Index Score enabled comparison of the number of assessments documented per child during the audit period. Responses to the Supports and Barriers Questionnaire were analysed using descriptive statistics, with Likert scores of less than -1 categorised as a Barrier, Ambivalent if between -1 and +1, or a Support if greater than +1.

Data synthesis occurred in three phases. Initially, qualitative findings were examined by the primary author, looking for potential relationships across themes and sub-themes. Secondly, a framework illustrating the interactive elements and processes inherent in allied health practitioners' assessment behaviours was developed and reviewed for authenticity by the co-authors. This framework was considered in relation to, and then situated within, current theories for understanding motivation and behaviour change. Finally, analysed quantitative data were merged with the qualitatively derived framework and considered in relation to each organisation: the experiences and perceived barriers (focus group and questionnaire data); the amount and types of assessment tools used by therapists (self-report and audit data); and organisational, therapist and child characteristics.

3.4.3 Results

Participant characteristics

Of 73 eligible allied heath practitioners from both organisations, 55 (75%) completed both questionnaires (see Table 2). Sixteen allied heath practitioners participated in three focus groups; nine from Organisation A and seven from Organisation B. Proportionally, Organisation A had fewer physiotherapists and a greater spread in staff experience than Organisation B. The characteristics of the children with cerebral palsy are displayed in Table 3. Overall, the children with cerebral palsy from Organisation B were younger (pre-school age) with higher levels of functional mobility than those from Organisation A.

Table 2. Allied health practitioner participant characteristics

AHP Characteristic	Organisation A (n=47)	Organisation B (n=8)	Combined n=55 (%)
Discipline			
Occupational Therapists	16	2	18
Physiotherapists	15	4	19
Speech Pathologists	16	2	18
Years since graduation			
< 5years	10	0	10 (18)
> 5 years	37	8	45 (82)
Years in disability sector			
< 5years	16	4	20 (36)
> 5 years	31	4	35(64)
Years with organisation			
< 5years	29	6	35 (64)
> 5 years	18	2	20 (36)
Self-reported expertise level[a]			
novice	13	0	13 (64)
intermediate	27	5	32 (58)
expert	7	3	10 (18)
Further formal education			
Degree level	32	3	35 (64)
Post-grad certificate or diploma	12	3	15 (27)
Masters degree	2	2	4 (7)
Doctorate	1	0	1(2)

[a] taken from King et al. (2007) definitions of expert, intermediate and novice

Table 3. Child participant characteristics

Characteristic	Organisation A n=21	Organisation B n=23	Combined N=44
Age (years) at start of extraction			
2-<6	4	15	14
6-11	7	4	11
>11-18	10	4	19
Gender			
female	6	14	20
male	15	9	24
GMFCS Level			
I	1	1	2
II	2	8	10
III	3	4	7
IV	5	7	12
V	10	3	13
Distribution			
Bilateral	17	17	34
Unilateral	1	4	5
Unknown	3	2	5

GMFCS: Gross Motor Function Classification System

Allied health practitioner experiences and perceptions of using evidence-based assessments

Focus group discussions centred on how allied health practitioners experienced and used standardised assessment tools in their practice. The following key themes and sub-themes emerged from the data:

1. Assessment Tool Use

Motivation and Accessibility: I don't, I can't, I try, I do, We do.

Within the Assessment Tool Use category, therapists reported their rationale, approach and subsequent use of evidence-based assessment tools. Responses ranged from those who reported not using tools (*I don't*) to those that did (*I do* and *We do*). Tool use related to motivation and tool accessibility.

I don't therapists could not justify using standardised assessments, instead preferring to draw on informal methods.

> *It's not applicable to assess every single child due to cognition, due to various different reasons...unless there's actually relevance for doing an assessment, I wouldn't. (Organisation A)*

I can't therapists were unable to use standardised assessments due to constraints in availability; tools were either unavailable in their setting or they perceived that tools had not yet been developed for the children with complex needs on their caseload.

> *With a lot of the students [children with CP] here, trying to do some of the more formalised assessments our students don't always fit into the categories or the assessments that we have available. (Organisation A)*

Other therapists recognised the need for using standardised assessments. *I try* therapists actively pursued ways to use assessments in spite of identified constraints.

> *It was like, well, how do I assess this girl who's come on a boat from Christmas Island? What do I use? Like I asked around and we did the GMFM on her but that was my first assessment tool and it was driven by me wanting to get a baseline of something from somewhere. (Organisation A)*

I do therapists adopted an individualised and unplanned approach in their settings where assessment use did not appear embedded.

> *Whether it's just a Six Minute Walk test or a Timed Up and Go there's always something I can use somewhere. (Organisation A)*

We do therapists reported using selected tools routinely, in a way that was collaborative, systematic and planned.

> *That's built into our practice for every child - we do GAS [Goal Attainment Scaling] every term. (Organisation B)*

2. Assessment Activity

Satisfaction: Value, Enjoyment, Authenticity

Through therapists' descriptions of the activity of using assessment tools, it was possible to ascertain a sense of satisfaction with assessment that was linked to concepts of value, enjoyment and authenticity. Using tools was valued highly when additional insights and foci for interventions were provided, and the tool enabled collaboration with the child, family and the team in relation to life's real needs. There was a deep sense of satisfaction in capturing a child's progress.

I love that we're now using the COPM [Canadian Occupational Performance Measure] prior to them choosing a GAS goal. I love that it gives you this holistic view and as there are changes we're like, yep this is what we're talking about. (Organisation B)

It keeps you in focus too…because you get all sorts of other ideas and you can go all over the place but it's like these are the two that I need to measure. So it keeps me really focused. (Organisation B)

For other therapists, findings from assessment tools did not add further value to the information they gathered through informal methods of assessment.

I find there is so much value in discussions and informal observation, more so sometimes than using my standardised assessments. (Organisation A)

When the tool was fun to use adjustments were made to overcome practical challenges associated with use. Satisfaction however was influenced by tools being too complex and thus quite stressful for therapists to use.

For my Assisting Hand Assessment—I did six videos before the group and six videos afterwards. You know, it's great fun when you do the assessment but I've now got eight videos to score and I'm just trying to drip away, like I need cancellations. (Organisation B)

I still use it to guide my practice, but the complexity and availability, like I did my research on one of the assessment tools, and I'm still confused about it a lot of the time. I mean, and I did it for a year. (Organisation A)

It's still a really complex tool, like writing GAS goals is hard and you really have to think about it - you can never jot down a GAS goal - I can't. (Organisation B)

Writing GAS goals is stressful and difficult. (Organisation B)

Therapists valued tools that were authentic; that is, they accurately reflected a child's capabilities within real-world contexts and could be widely applied.

> *I think ones that you can do with a variety of kids, not just kids that are willing to sit down at a table and do task after task after task… But can you employ it in a more natural way and actually feel like you're capturing an accurate picture of the kid. (Organisation B)*

> *I'm not going to use that [Peabody assessment] anymore because it's just not really useful for me in that situation, as in it's probably a useful tool if you work with children who have perfect cognition and language, but I don't have any of these [children] on my caseload. (Organisation B)*

3. Research

Congruence: Critique, Affinity

Evidence-based assessment was discussed within the context of therapists' interaction with research and evidence-based practice. Therapists grappled with "finding a fit", or congruence, between research, the child and family and their own personal intervention preferences. Therapists with a strong affinity for research endeavoured to find evidence to endorse their practice but were, however, very careful and critical in their application of this evidence to individual children and families. Using evidence-based assessment tools was seen as necessary to evaluate the impact of interventions.

> *The biggest concern to me is when someone says Green Light bi-manual training, fantastic, so you send your kid off for bi-manual training and it's a disaster because it's a Green Light so they just do it, but they're not*

measuring, they're not thinking, they're not applying it to the right child. (Organisation B)

It's important to us as an organisation that we do monitor what we're doing and that we are measuring what we're doing. (Organisation B)

Other therapists talked of the tension they felt between evidence, and their personal preference for practices they enjoyed using and that they felt were effective. Therapists seeking to align evidence with the child and family's needs referred to using objective methods of outcome measurement to support their practice. In contrast, therapists with less affinity for research-informed practice preferred to adopt interventions based on personal preference and talked of "seeing" and "feeling" the benefits of their interventions.

I can see the benefits of this, but the research isn't matching up. I really want to use it, but my senior is going to tell me not to use it, but I can see the clinical benefits of it. (Organisation A)

I know a lot of the stuff that I personally enjoy using, that I feel works for the kids from here isn't rated very highly. (Organisation A)

4. Families and children

Collaboration: Understanding and Involvement

In the context of families and children, collaboration was perceived to be influenced by both family and therapist understanding and involvement in the assessment process. Therapists perceived that families liked assessment, but that parents often did not have sufficient information. Therapists found it difficult to explain assessment results in ways that families could understand.

I think families like assessment. It's just they don't necessarily know that they can ask for it, and what we can provide. (Organisation A)

You write up the results to explain to the parents, what this assessment means, what's involved in it...you give them the report, it's very difficult for them to understand the interpretation, the language."(Organisation A)

Some therapists did not see a role for standardised assessments to inform goal setting with families.

As a key worker in our service, it's not about actually sitting down and doing an assessment. You work at the level that they're at and set goals. (Organisation A)

In contrast, other therapists perceived the use of assessment tools as a powerful means of involving and enhancing collaboration with families. In these instances, families were also seen as informed and receptive to assessment.

I would have said we did it really well, we listened to families and did the goals, but since we've done the COPM it's just taken on a whole new level. (Organisation B)

Reflection is a really positive thing, to have that time to reflect and discuss with the parents and the families and the children what your goal is going to be, what their goal is, but then to actually write that [GAS goal] takes a lot of reflection and it helps you capture what you want to. It guides you there. (Organisation B)

We've got families on board, you know, it's all there ready for the taking really. (Organisation B)

5. Organisational setting

Expectation: Opportunity, Encouragement, Systems

Therapists perceived varying levels of expectation to use formalised assessments within their organisation. This was influenced by factors related to opportunity, encouragement and systems. Structural processes and service delivery methods directly affected therapists' opportunity to use formalised assessments. In the school setting, therapists found it difficult to access children and families for individualised assessment and goal setting. School therapy services were focussed on providing overall classroom support, with therapists' input guided by day-to-day observations rather than individualised assessment. Education goals were perceived as different from therapy goals.

> *…here we don't tend to do the formalised assessments. It's more observation, informal I guess, the goals aren't really made – they're more around education. They're not traditional therapy goals that I'm used to because we're not putting formal interventions into place. (Organisation A)*

> *We don't do one-on-one. I don't say Joe Blogs has got this or we need to work on that. I haven't got the capacity to do that. I'm supporting the classroom. (Organisation A)*

> *When I first started we did a lot more formal kind of gross motor and range of motion…we had more specific key goals, physio goals and speech goals …but then the school changed their reporting system and so we had to fit into that. The school management completely changed as well and so that completely changed what their priorities were. It's hard to work in an environment where you're still trying to do therapy but it's not therapy. (Organisation A)*

Similarly, the dual role of caseworker and therapist in the key worker service delivery model, created a tension for therapists between the professional expectation to use assessment tools and limited capacity and expectation of use within the organisation's service delivery model. Perceived opportunity to shape the therapy service within the organisation also varied.

> *That's probably one of the constraints in the key worker model that you may never see – you can spend five years with a family and you're just really the consistent person that comes into the home. You become the person that families vent all their life stuff to. I would say about 60:40, 60% around the case manager and then 40% you're probably like a speechie. (Organisation A)*

Expectation to use evidence-based assessment tools was strongly influenced by the encouragement and perceived value of assessment by management. Where use was actively promoted by management, therapists reported assessment use as a presumed and unquestioned part of practice. Goal setting was viewed as a collaborative process between family and therapist, informed by assessment. When positively encouraged, therapists felt compelled to meet the organisation's expectation to use assessments, with a sense of guilt prevailing if this expectation was not met.

> *It's really nice because there's that backup because our manager goes, 'Now I've looked at all your GAS goals and that's good.' So that accountability. (Organisation B)*

> *You're really motivated to get them [COPM] done and you feel really bad when you don't. (Organisation B)*

> *Outcome measures are just built in…you don't have a choice - it's just*
> *what you do. (Organisation B)*

In contrast, other therapists described being actively discouraged and questioned in their use of formalised assessments. Therapists perceived that standardised assessment was viewed by their organisation as unrelated to family centred practice and goal setting, and therefore unnecessary.

> *For where I work– there kind of needs to be a purpose. We're sort of told,*
> *unless the family requests an assessment what's the point, like what are*
> *you going to use that information for? …you're trying to be guided by the*
> *family's goals. (Organisation A)*

Therapists reported on the systems in place to support the use of formalised assessment. Some settings had a planned schedule to ensure assessments were completed. In other settings, assessments were performed on an *ad hoc* basis in spite of therapists' desire for a systematic approach.

> *In the first two weeks, we all went in pairs and visited kids. We did the*
> *COPM in the home with two of us. It was a pretty full on couple of weeks,*
> *but it's made a difference. (Organisation B)*

> *We haven't had that [Dysphagia Severity Scale] and I think it's something*
> *that has been needed because no one standardly does the same practice.*
> *(Organisation A)*

> *Participant: We are getting better at it- but we do it as a, oh, hang on, it's about*
> *time…*
> *Participant: I do agree they [assessments] should be regular.*
> *Participant: Yeah, but there's some [children] that just drop off the radar.*

Participant: It's three years, and they haven't been reviewed.

Participant: Well they are reviewed but we don't do a formal assessment.
(Discussion thread between Organisation A participants)

6. Use of time

Availability and Dedication: Not the time, If time, Making time.

Therapists across all settings reported limited time for activities related to using formalised assessments. Therapists varied, however, in how they dedicated time to assessment activities. Therapists reported "making time" by opportunistically squeezing in assessment related tasks.

> *I've got eight videos to score and I'm just trying to drip away, like I need cancellations. The videos are done so just it's a matter of getting the scores done. But trying to fit them in is hard. (Organisation B)*

Others reported assessment activity as a low priority and doing assessments only "if time" was available. Others felt there was "not the time". They were either not able to, or not prepared to, allocate time to evidence-based assessment activities, and that these activities were unlikely to happen at any time.

> *In a setting like this, we don't have the time often to do formalised assessments– other things get prioritised. (Organisation A)*

> *I think we do value it [research], but yes, it's the same thing as for using standardised assessments, I sort of go, I don't have time to do that. (Organisation A)*

Frequency of evidence-based assessment use

Actual and self-reported use of assessment tools are shown in Table 4. The median Use Index Score was 13% in Organisation A and 20% in Organisation B. Two of the 15 tools audited were documented in more than 50% of children's case files. Collectively, 16/55(29%) of allied heath practitioners reported using classification tools (GMFCS, MACS or CFCS), 6/55(11%) used the COPM and 8/55(15%) used the GAS, more than 50% of the time. Overall, higher levels of assessment use were reported in Organisation B; 5 of the 8 AHPs (63%) in Organisation B reported using at least one of the tools more than 50% of the time compared to 11/47 (23%) of allied heath practitioners from Organisation A.

Table 4. Frequency of assessment tool use (actual and self-reported) in each organisation and combined: Actual number of children's case files with completed individual assessments documented during audit period; and allied health practitioners' self-reported rates of use of functional classification tools (Gross Motor Function Classification System, Manual Abilities Classification System, Canadian Occupational Performance Measure and Goal Attainment Scaling)

	Organisation A	Organisation B	Combined
Assessment tool* completed	Child case files n=21	Child case files n=23	(%)
GMFCS	18	19	37/44 (84)
FMS	18	12	30/44 (69)
MACS[a]	0	9[b]	9/39 (23)
COPM	0[c]	8[d]	8/38 (21)
Hip x-ray	6	3	9/44 (20)
GMFM	1[c]	6[d]	7/38 (18)
Pain-tool undefined	2	4	6/44 (14)
Goniometry-Lower Limb[e]	3	3	6/44 (14)
Goniometry-Upper LImb[f]	3	2	5/44 (11)
ASAS	1	1	2/44 (5)
HAT[a]	1	1[b]	2/39 (5)
CFCS	0	2	2/44 (5)
PEDI	0	1	1/44 (2)
DSS	0	0	0/44 (0)
mHouse	0	0	0/44 (0)
Proportion of time tool* used	AHPs n=47	AHPs n=8	AHPs n=55 (%)
GMFCS, MACS or CFCS			
75-100%	8	4	12 (22%)
50-74%	3	1	4 (7%)
25-49%	3	1	4 (7%)
6-24%	6	0	6 (11%)
0-5%	27	2	29 (53%)
COPM			
75-100%	0	6	6 (11%)
50-74%	0	0	0 (0%)
25-49%	0	1	1 (2%)
6-24%	1	1	2 (4%)
0-5%	46	0	46 (84%)
GAS			
75-100%	0	7	7 (13%)
50-74%	0	1	1 (2%)
25-49%	1	0	1 (2%)
6-24%	1	0	1 (2%)
0-5%	45	0	45 (82%)

*Tool legend; ASAS, Australian Spasticity Assessment Scale; COPM, Canadian Occupational Performance Measure; CFCS, Communication Function Classification System; DSS, Dysphagia Severity Scale; FMS, Functional Mobility Scale GAS, Goal Attainment Scaling; GMFCS, Gross Motor Function Classification System; GMFM-66 or GMFM-88, Gross Motor Function Measure-66 or 88; HAT, Hypertonicity Assessment Tool; MACS, Manual Abilities Classification System; modHouse, Modified House; PEDI, Paediatric Evaluation of Disability Index; n=total number of files audited; [a]validated for 4-18 years only. [b]n=18 as 5 children aged <4 years; [c]n=18 as unable to retrieve 3 archived files; [d]n=20 as unable to retrieve 3 archived files; [e]wrist and elbow measures documented; [f]ankle measure documented. AHPs, allied health practitioners.

Perceived barriers and supports for evidence-based assessment use

High, medium and low-user ratings of the extent to which organisational structures and resources, therapy colleagues, children and families and assessment tools acted as a support or a barrier to routine assessment tool use is shown in Table 5. Therapy colleagues were not viewed as a barrier to use (i.e. a support or neutral). High-users rated all items as supportive to some extent. Low and medium-users rated items similarly, although approximately one third rated organisational structures and resources as barriers to some extent.

Table 5. Number of therapists from high (HU), medium (MU) and low user (LU) allied health practitioner groups that rate a) organisational structure b) organisational resource c) therapists d) child and family and e) tools on a -5 to +5 Likert scale as either a support (-5 to -2), ambivalent (-1 to +1) or barrier (+2 to +5), to routine assessment tool use

		Barrier (-5 to -2)	Ambivalent (-1 to +1)	Support (+2 to +5)
a) Organisational Structures	HU n=5	0	0	5
	MU n=16	5	3	8
	LU n=30	9	5	16
b) Organisational Resources	HU n=5	0	0	5
	MU n=17	7	3	7
	LU n=31	8	9	14
c) Therapists	HU n=5	0	0	5
	MU n=17	0	3	14
	LU n=31	0	13	18
d) Child and Family	HU n=4	0	0	4
	MU n=17	2	6	9
	LU n=31	2	12	17
e) Tools	HU n=5	0	0	5
	MU n=17	2	6	9
	LU n=31	1	13	17

High user (HU): Uses tools consistently: Reports use of GMFCS, MACS or CFCS, AND the COPM and GAS, as more than 50% of the time. Moderate user (MU): Uses some tools to some extent. Reports use of GMFCS, MACS or CFCS, OR either the COPM or GAS, or both, more than 25% of the time but High user criteria not met. Low user (MU): Tools not used to any extent. Reports use of GMFCS, MACS or CFCS, AND the COPM and GAS, less than 25% of the time.

3.4.4 Synthesising the findings:

The 'Cultural Cone framework for Evidence-based Assessment Behaviours'.

The analysed qualitative data informed the development of a conceptual framework, the Cultural Cone, which describes the salient elements and relational processes that interact to influence individual behaviour—in this instance, allied heath practitioners' use of evidence-based assessments. We propose the Cultural Cone in order to visually represent the dynamic interplay between unique (but not always explicit) content and context specific processes that support an individual's beliefs, emotions and action, at any point in time. It is unique to the setting, never exactly replicable, although similarities in component processes are likely to exist across settings.

Our Cultural Cone for evidence-based assessment behaviours', seen in Figure 1, is characterised by the central behavioural element in focus, that of *Assessment Tool Use*, that emerges from the interactions between it and the remaining elements, arranged as five segments of the cone. The overarching concept, A*ssessment as Therapy,* transpires when all relational processes interact at the highest level; the point where assessment and therapy are coupled and assessment is conceptually and practically integrated as therapy. '*We do*' therapists, situated towards the top of the cone, embed evidence-based assessment tools in therapy, whereas '*I don't*' and '*I can't*' therapists conceptually de-couple assessment and therapy. Evidence-based assessment tools may be used but are not viewed as inherently therapeutic. '*I try*' and '*I do*" therapists' may view standardised assessment similarly to '*We do*' therapists i.e. assessment and therapy are coupled, but practically assessment is unable to be or has not yet been embedded in therapy.
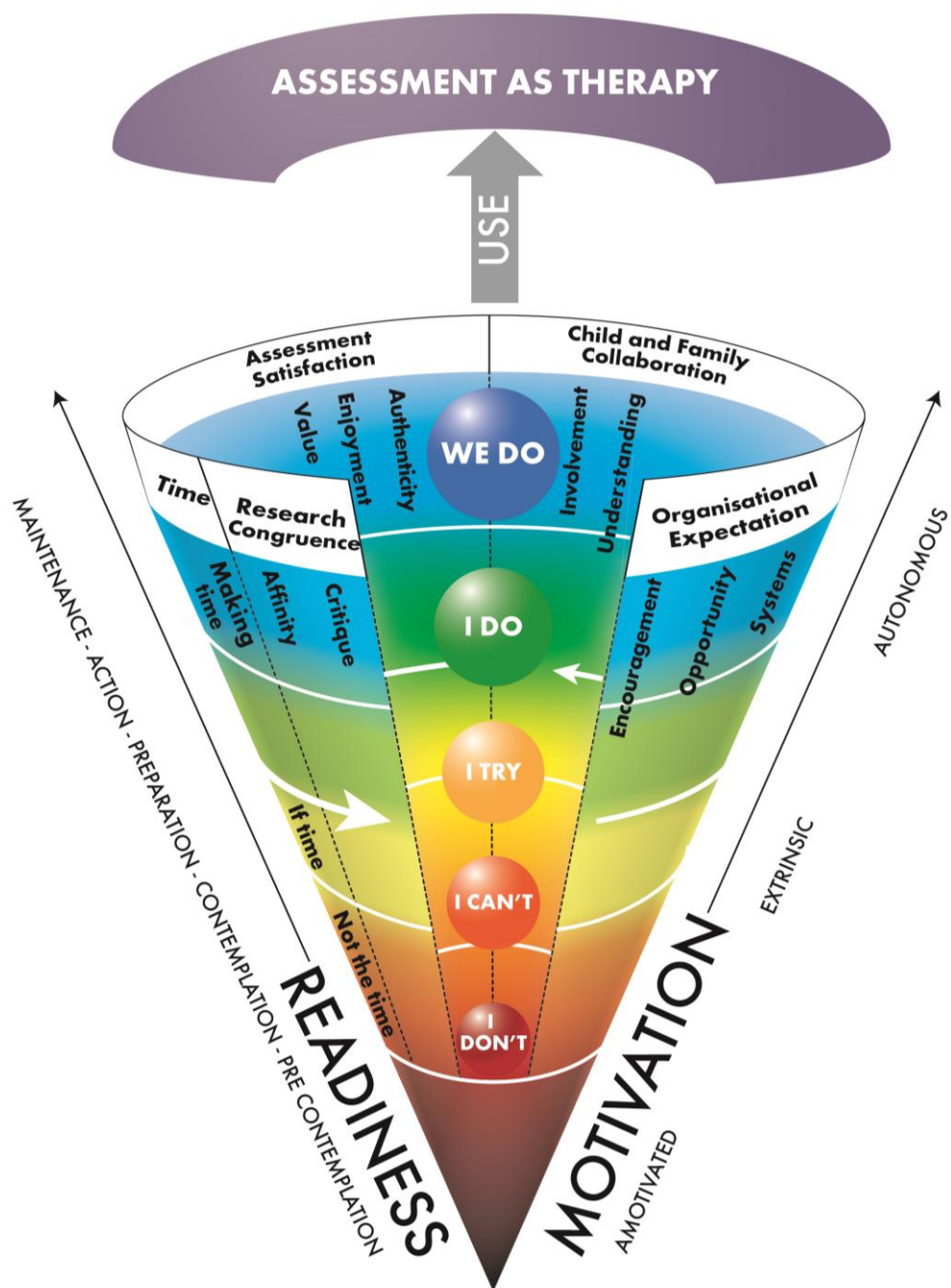
Figure 1. Cultural Cone for Evidence-based Assessment Behaviours, in which themes and sub-themes are represented as cone segments whose interaction influences allied health practitioners' motivation and readiness (*I don't, I can't, I try, I do, We do*) and ultimate engagement in evidence-based assessment practice. Reprinted with permission.

Using the theoretical frameworks of the trans-theoretical model (Prochaska & Norcross, 2014; Prochaska et al., 2008b) and self-determination theory (Ryan & Deci, 2000a), we can interpret the *I don't*, *I can't*, *I try*, *I do*, and *We do*, findings of the Cultural Cone. Levels of motivation and use equated broadly to therapists' readiness to change. '*I don't*' therapists could be considered at the pre-contemplative stage; '*I can't*' therapists are contemplating use but not acting, while '*I try*' therapists are hovering on the decision point of action; ready to act, but may be heavily influenced by their situation (Gale & Skouteris, 2012). '*I do*' therapists use standardised assessments when individual circumstances allow, however use is not embedded into individual or team practice. '*We do*' therapists in contrast, collectively embed standardised assessment into day-to-day clinical practice. Use is maintained over time across the organisation, and assessment use is organisationally endorsed. Within self-determination theory (Ryan & Deci, 2000b) '*I don't*' therapists may be amotivated with little interest in formalised assessment. '*I can't*' therapists may be largely motivated by external factors while '*I try*' and '*I do*' therapists, who may highly value assessment, are still influenced by external factors - such as professional and organisational expectation. '*We do*' therapists may be both intrinsically and extrinsically motivated with high degrees of autonomy, with assessment pursued largely for its inherent value and enjoyment.

The qualitative and quantitative data were combined to determine if therapists' experiences of assessment, as represented in the Cultural Cone framework, reflected therapists' use of assessment tools in different settings. This enabled a representational Cultural Cone for Evidence-based Assessment structure to be generated for each organisation (see Figure 2(a,b)). Textual data from Organisation A fell predominantly into the categories of *I don't, I can't, I try*, and to a lesser extent, *I do*. In contrast, all *We do* textual data originated from

Organisation B. Organisational processes were described and perceived more strongly as barriers to assessment use in Organisation A. Similarly, opportunities for family collaboration through assessment, time dedication, research and assessment fit, and satisfaction with assessment were described less positively overall in Organisation A. The frequency of assessment use by both organisations during the case-file audit period was low overall; however, differences in use existed between settings. Organisation B's higher assessment use was consistent with the higher level *We do* category of the Cultural Cone framework. Conversely, the lower level of assessment use in Organisation A was accompanied by lower level use categories in the Cultural Cone.

 The individualised Cultural Cone for Evidence-based Assessment for each organisation also needs to be considered in relation to the organisation, therapist and child characteristics. All therapists in the smaller organisation, Organisation B, had intermediate or greater levels of expertise, and managed a cerebral palsy specific caseload within a multi-disciplinary service delivery model. In contrast, over one quarter of practitioners in Organisation A reported themselves as novice practitioners with less than 5 years of experience in the disability sector. Therapists from Organisation A managed a mixed caseload of children that included a higher proportion of children with cerebral palsy classified GMFCS level IV or GMFCS level V within either a trans-disciplinary or school-based model of service delivery.
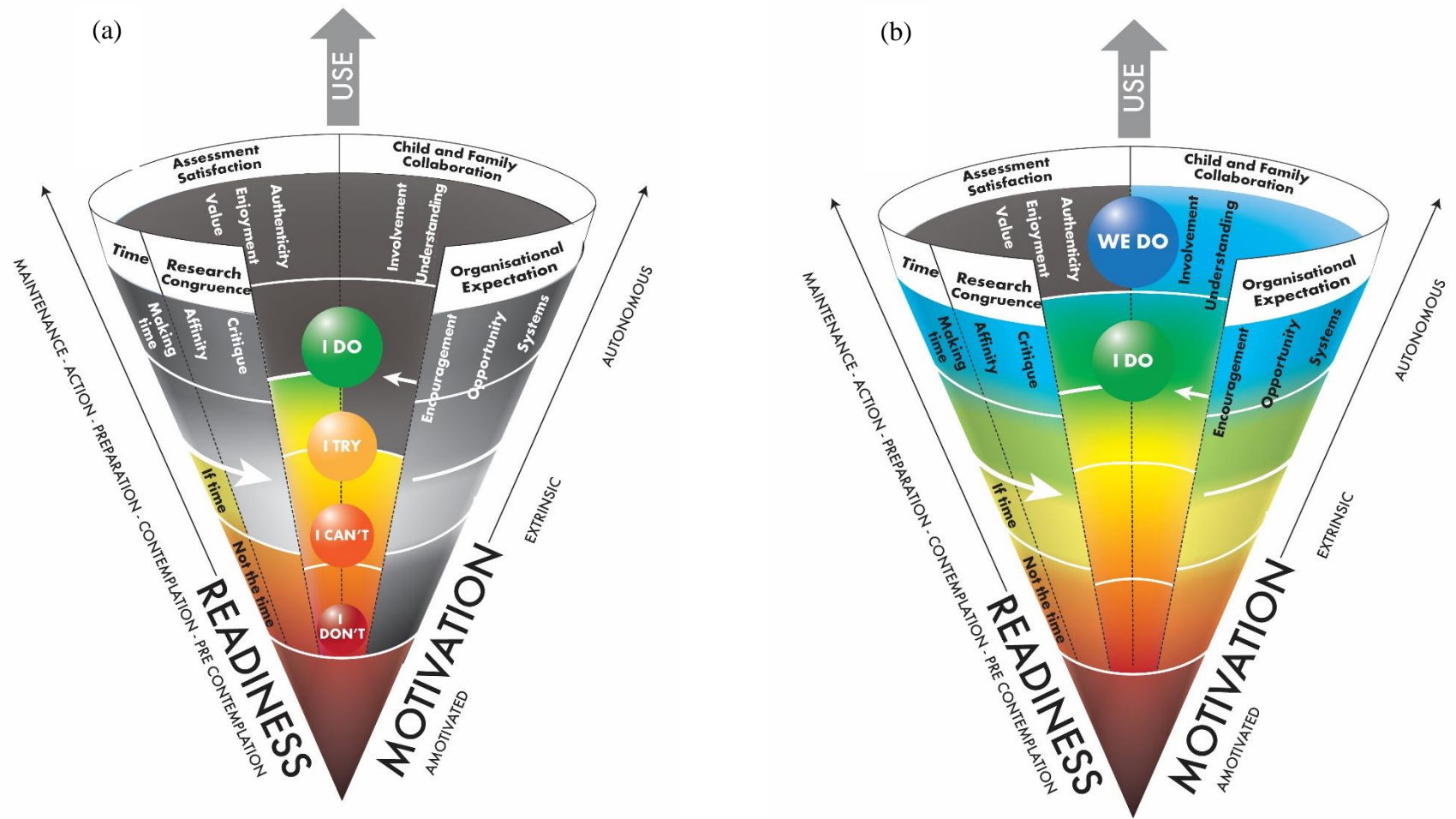
Figure 2. Cultural Cone for Evidence-based Assessment Behaviours, showing mapped performance for cone segments, motivation and assessment use for (a) Organisation A and (b) Organisation B. Reprinted with permission.

3.4.5 Discussion

The Cultural Cone for Evidence-based Assessment provides a new framework for conceptualizing the influences on allied heath practitioners' use of assessment tools for children with cerebral palsy in paediatric community rehabilitation settings. The framework illustrates the salient cultural ingredients that interact to influence the evolution of allied health practitioners' readiness and autonomous motivation to use evidence-based assessment tools within a clinical setting. These process interactions— across assessment activity, the child and family, organisational setting, research and time —culminate in evidence-based assessment tool use. Motivation to use evidence-based assessment tools was higher when therapists, children and parents were able to connect positively through using assessment tools, and use was endorsed and supported by the organisation. Therapists were both intrinsically and extrinsically motivated to use assessment tools. Where use was well established, assessment was viewed positively and positioned practically and conceptually as therapeutic, rather than as separate or optional. Consistent with the findings from a recent systematic review (O'Connor et al., 2016), use of individual tools in two Australian community settings was low overall, with gross motor function remaining the primary focus of tools used frequently. However, differences in assessment tool use between settings can be further understood and uniquely represented through the Cultural Cone. This may provide a meaningful framework to design organisational, practitioner and family-focused knowledge translation interventions aimed at increasing the use of evidence-based assessment tools.

This study suggests the process of '*engaging with*' assessment arises from the co-dependent interaction between the therapist, the assessment tool, the assessment activity itself,

research, the child and family, the organisational setting and time. This is consistent with the idea proposed by Bright, Kayes, Worrall, and McPherson (2015) that engagement in healthcare is a "co-constructed process and state" where a connection gradually develops between the client and the provider that enables both to become active, committed and invested collaborators in healthcare. The state of '*engaged in*' evidence-based assessment occurs when therapist, child and family believe in, enjoy and dedicate time to the evidence-based assessment process. Conceptually and practically evidence-based assessment becomes part of, not an adjunct to, therapy. For assessment to become embedded in day-to-day practice a conceptual shift by the organisation, therapists, and families, needs to occur. When assessment tool use was not perceived as therapeutically beneficial overall, formalised assessment was fitted-in only "if time" and not at the expense of "doing therapy" (King, 2000). While limited time may have contributed to low levels of use overall in this study, it does not account for all differences. When the assessment process was understood by all parties — organisation, therapists and families — to add value to therapy, then time was 'found' to use evidence-based assessment tools.

Assessment tool use was situation dependent. In our study, where systems and supports existed for using assessment tools, experiences were recounted using the collective pronoun "We do". Where organisational support for use was absent, individual therapists found it difficult to use assessment tools consistently. Individual therapists were left to decide if, when and what tools to use, and were unsure about how assessment would be perceived by families. Even autonomously motivated therapists found it difficult to consistently use assessment tools without wider organisational support. Therapists and families from the smaller single site service, predominantly for children with cerebral palsy, appeared to fit

more closely with the definition of being 'engaged-in' evidence-based assessment. In contrast, therapists in the larger multi-site organisation servicing a mixed caseload of children within different service models were either in the process of 'engaging with' or, in some instances, 'dis-engaged with' evidence-based assessment. This suggests that, in addition to organisational support, service delivery model and caseload breadth may also influence therapists' use of evidence-based assessment tools.

Central to paediatric therapy practice is the formation of a positive therapeutic relationship between the child, parent and therapist (King et al., 2007; King et al., 2011). Currently this relationship is situated within best-practice frameworks of family-centred and evidence-based care: Therapists endeavour to develop a clear understanding of the child and family's priorities alongside skilful selection, administration and sharing of assessment findings to promote collaborative goal setting, intervention planning and objective measurement of meaningful outcomes to the child and family (Wright & Majnemer, 2014). Inclusion of formalised assessment is integral to the care process but appears contingent on both parental and child understanding and involvement, as well as therapists' ability and confidence to use and discuss findings from the assessment tool in a way that enhances, rather than jeopardises, their relationship with the child and family.

The clinical utility of existing and future assessment tools also requires consideration in relation to their influence on the therapist-child-parent relationship. Therapists reported that using tools was deeply satisfying when the assessment tool was uncomplicated, the process was fun and engaging for themselves and the child, and the tool could easily capture meaningful changes in the child. Fun and engagement for both child and therapist during a tool's administration is also important for obtaining a child's optimal performance (Wilson

et al., 2011). The recently developed Challenge assessment tool (Wilson et al., 2011), that has explicitly incorporated fun, engagement and children's opinions during development (Mistry, Gibson, & Wright, 2016) has been reported to be perceived by children and parents to engender a sense of achievement and pride in the child (*V.Wright personal communication 16/12/2016*). Other recently developed tools e.g. DISABKIDS Chronic Generic Measure (Petersson, Huus, Åkesson, & Enskär, 2016) and Perceived Efficacy and Goal setting (Tam, Teachman, & Wright, 2008), contain child and parent friendly visuals and colour schemes that may facilitate discussion and improve motivation and communication between the therapist and child (Petersson et al., 2016). An assessment tool's capacity to engage, promote communication, efficiently assess and easily document changes relevant to everyday life may be important tool characteristics needed to support the therapist-child-parent relationship, and be adopted in practice. Including clinical end-users early in the tool design phase, particularly children, families and therapists from across different clinical, geographical and cultural settings, may be critical for adopting an assessment tool in the longer term.

The importance and benefits of using evidence-based assessment tools has been widely documented (Brewer et al., 2014; Colquhoun, Letts, Law, MacDermid, & Missiuna, 2012; Majnemer, 2010, 2012; Wright & Majnemer, 2014). However, the low levels of use and engagement in formalised assessment found in this study suggests many therapists and their organisations are yet to be convinced of their direct benefit or value to themselves or the child and family (Kay, Myers, & Huijbregts, 2001). Studies evaluating the immediate and long-term benefits, non-benefits or harms of using standardised assessments with children and families are sparse (Brewer et al., 2014; Brogren Carlberg & Löwing, 2013; Garland

et al., 2003; Wallen & Hoare, 2014). Routine surveillance programmes (incorporating standardised assessments) for children with cerebral palsy have demonstrated improved bio-mechanical and pain outcomes (Hägglund et al., 2014; Wawrzuta et al., 2016). Individualised client-centred tools such as DISABKIDS and Canadian Occupational Performance Measure have been associated with increased motivation with activity-focused interventions and improved therapy practice (Colquhoun et al., 2012; Petersson et al., 2016). Further research, however, is warranted to demonstrate if inclusion of appropriately selected evidence-based assessment tools adds more to enablement of the child and family, than informal and observational assessment only.

Implications for practice

A multi-faceted approach, combining wider organisational support systems with individualised evidence-based behaviour change techniques to support therapists' use of selected tools, is recommended. The Cultural Cone provides a framework to assess the relative strengths of modifiable elements influencing therapists' use of assessment tools within an organisation; and provides a potential basis for choosing behavioural interventions to increase use. This framework proposes interventions that specifically address individual therapists' motivation through the lens of the therapist-parent-child relationship within a supportive organisational context. In practice, interventions grounded in motivational interviewing and self-determination theory (Markland, Ryan, Tobin, & Rollnick, 2005) that support therapists autonomous motivation may be beneficial (Baker et al., 2010; Deci & Ryan, 2000; Friederichs, Oenema, Bolman, & Lechner, 2016; Markland et al., 2005; Poulsen, Rodger, & Ziviani, 2006). Individual goal identification and ownership, developing 'just right' challenges for skill development within the practice

setting are needed. This approach aligns with recommendations for tailored knowledge translation interventions to bring about change in clinical practice (Baker et al., 2010). Individualised support on how to involve families and children in the assessment process using carefully chosen, easily administered, engaging and relevant tools may assist therapists to initially 'engage-with' assessment. A highly individualised approach may assist therapists to progress from "I don't" to "I do", while concurrent organisation-wide adjustments that address gaps in opportunity, expectation, and efficient systems (Lowes et al., 2016; Oeffinger, 2016) and promotion of assessment value among families are likely to be important for embedding assessment use to the "We do" level, where assessment is therapy and *"just what you do."*

Implications for future research

Future research is needed to validate the Cultural Cone framework against existing tools and across other paediatric settings and contexts, and to investigate its potential clinical application in designing intervention strategies to increase assessment use. Consideration of tool characteristics in terms of their capacity to enhance therapists' engagement with assessment for children and families is also warranted. Further research into the experiences and benefits of evidence-based assessment use in optimizing meaningful outcomes for children and families, is also needed.

Limitations

The study design enabled an in-depth exploration of allied health practitioners' assessment use and the development of a conceptual framework, but this exploratory study draws evidence from a limited number of settings within one cultural context. Therapists interviewed came to this study with similar experiences and understandings of evidence-

based practice through professional education and training programmes. This may limit the transferability and applicability of these findings to settings where the concepts of evidence-based healthcare have been introduced more recently.

3.4.6 Conclusions

Therapists' use of assessment tools for children with cerebral palsy and their families in the clinical context is complex. Therapists' experiences of evidence-based assessment tools can be represented through the Cultural Cone framework which conceptualises assessment use on a behavioural continuum of; *I don't, I can't, I try, I do, We do*. Motivation to use evidence-based assessment tools appears related to organisational expectation and support systems, therapist perceived satisfaction with assessment, affinity for research and dedication of time, along with family and child involvement with the assessment process. Promoting the use of 'any old assessment tool' however is not enough. Tools that are fun and engaging, add value to goal setting and communication with parents and children, and positively support the therapeutic relationship are more likely to be used.

Consistent with previous studies, low levels of assessment use overall were identified in this study. To address this the Cultural Cone framework advocates knowledge translation interventions that firstly identify the relative strengths of the Cultural Cone elements, and then employ individualised evidence-based behaviour change techniques and organisational supports related to the therapist's context. This may spur a conceptual shift towards 'assessment as therapy' and help address the low level and scope of assessment tools used across some paediatric rehabilitation settings.

Declaration of Interest

The authors state that they have no interests which might be perceived as posing a conflict or bias.

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3.5 Extended discussion and conclusions

The findings from Study 2 were used to derive a framework for understanding the evidence-based assessment behaviours of allied health practitioners for children with cerebral palsy in community paediatric settings. Frameworks are useful as they identify a set of variables and relationships that should be examined in order to understand a phenomenon (Kitson et al., 2008). The Cultural Cone for Evidence-Based Assessment framework proposes therapists' motivation to use assessment tools is on a behavioural continuum that is influenced by: assessment satisfaction; child and family involvement and understanding; organisational expectation; research alignment; and dedication of time. Motivation to use assessments was higher when assessment tools were viewed positively; that is, they were authentic, enjoyable to use and seen as having therapeutic value; they were able to positively connect with children and parents when using an assessment tool; and use was endorsed and supported by the organisation (O'Connor et al. 2019).

The Cultural Cone presentation — the segments, central spheres and colour scheme — was developed as an interpretation of the qualitative and quantitative study findings. Qualitatively derived themes informed the cone segments while the spheres captured the analysed interview and self-reported assessment use data. The colour sequence - red, orange, yellow and green - and additional blue, is an 'extended' traffic light system with colours merged to show the culture of engagement with evidence-based assessment as a continuum. Red aligns with a culture of disengagement; orange - low engagement; yellow – emerging engagement; and, green – 'engagement with' assessment. Blue reflects organisation wide 'engagement in' assessment as part of a "blue sky" and innovative assessment-as-therapy culture.

Individual segments of the cone and the AHP motivation spheres were populated for each organisation with the colour scheme sequence. It was not possible to directly link high, medium and low assessment users to an organisation or AHPs to individual client files for reasons of confidentiality. Hence the Cultural Cone figures for each organisation (Figure 2, p105) are currently notional but, with further research, could potentially be quantified.

Actual use of assessments appeared to be linked to therapist perceptions of parent and child understanding and uncertainty with how to involve parents. Therapists' confidence with introducing formal assessment and discussing assessment outcomes in a way that sustained a positive therapeutic relationship was identified by therapists as difficult. Limited time was reported as a factor impacting levels of use, however time availability related more closely to satisfaction with the assessment process, family involvement and understanding, and affinity with research, rather than lack of time itself. When the assessment process was understood by all parties (organisation, therapists and families) to add value to therapy, then time is 'found' to use evidence-based assessments. These findings suggest it may be more feasible for evidence-based assessment tools to become part of day-to-day practice when and if assessment can be viewed conceptually and experienced practically as part of, not an adjunct to, therapy.

Consistent with the findings from Study 1 (O'Connor et al., 2016a), evidence-based assessment tool use in two Australian community settings was generally low, with gross motor function most frequently assessed. Assessment tool use was also organisation dependent. Where organisational support for use was lacking, even motivated therapists found it difficult to consistently implement assessments. This study suggests therapists in smaller services with narrower caseloads and managerial expectation to use evidence-based

assessment tools may find it easier to apply and maintain diagnostic-specific evidence-based assessment skills.

Organisational structures and resources were the most frequently perceived barriers to assessment use. However, almost half of medium-low users also rated structures and resources as supportive to some extent. A small difference in actual use was found between settings (7%), however the amount of use was low in both settings (13% Organisation A; 20% Organisation B). Differences in expectation to use assessments were identified between settings through the focus group interviews. While differences in setting expectations may help explain the small differences in use it does not explain the low levels of use overall. Even when resources, structures existed and expectations to use were high, tools were still used infrequently. The two cone themes related to therapists' interactions with assessment tools and the parent and child —*Assessment satisfaction* and *Family and child collaboration* — were raised across both settings as influential suggesting investigation of therapists' use of evidence-based assessment tools through the lens of the parent-therapist-child relationship may be a valuable line of enquiry. The theme describing therapists' relationship with time (*No time; If time; Making time*) was also an influencing factor in assessment use however therapists' relationship with time may also be a by-product of use, making exploration of this theme more appropriate to later phases of this work. Adding the perspective of parents was also considered very important in understanding therapists' use of evidence-based assessment tools at the clinical interface, particularly within the prevailing framework of family-centred care.

The following two chapters (Chapters 4 and Chapter 5) pursue this line of enquiry to further understand what is needed for therapists to more easily embed evidence-based assessment tools into practice.

Chapter 4 Caregiver experiences of evidence-based assessment for children with cerebral palsy: A scoping review

4.1 Introduction

Chapter 4 addresses the third objective of the thesis: to identify what is known from previous studies about parents' experiences of formal assessment for their child with cerebral palsy. The body of this chapter comprises a scoping review of published studies of parents' experiences of formal assessment for their child with cerebral palsy. Prior to the review, a rationale for the choice of review methodology is provided. The chapter ends with a concluding summary.

4.1.1 Background

Assessment is a fundamental part of a family's early encounter with a health service and its providers. Consequently, assessment may play an important role in setting the tone of the relationship and subsequent collaboration between the parent, child and therapist (Simeonsson, Edmondson, Smith, Camahan, & Bucy, 1995). Understanding how assessment influences collaboration between parents, therapists and children can potentially provide further insight into understanding of therapists' evidence-based assessment behaviours.

There has been increased interest in understanding the extent and quality of collaboration within paediatric rehabilitation services for children with disabilities (Dunst & Trivette, 2009a; Nijhuis et al., 2007). Collaboration as part of service delivery has been evaluated quantitatively and qualitatively. Parent perception of the family-centeredness of services

has been evaluated widely using the quantitative Measure of Processes of Care tool (Almasri, An, & Palisano, 2017; Bjerre et al., 2004). Parents' experiences have been also explored qualitatively in relation to specific interventions for children with cerebral palsy and parent needs for allied health therapies (Burton et al., 2017; Jackman, Novak, Lannin, & Froude, 2017; Kruijsen-Terpstra et al., 2016; Wiart, Rosychuk, & Wright, 2016). Parents' desire for specific and general information, transparent communication and partnerships in healthcare decision making are consistently highlighted (Almasri et al., 2017; Kruijsen-Terpstra et al., 2016; Resch et al., 2010). However, the role and influence of assessment, specifically evidence-based assessment tools, on family-centred collaboration, has not been explored in these studies.

Study 2 explored therapists' experiences of evidence-based assessment in-depth, for children with cerebral palsy in different community settings (O'Connor et al., 2019). Areas influencing therapists' motivation to use evidence-based assessment tools in day-to-day practice were identified and represented in segments of the Cultural Cone framework. Two areas—*Child and family collaboration* and *Assessment satisfaction*—occurred at the clinical interface between the therapist, caregiver, child, and assessment tool. Using assessment tools was viewed positively by some therapists, but not others. Therapists were uncertain about parents' understanding and feelings about their child being formally assessed (O'Connor et al., 2019). Therapists described feeling unsure how to involve, use, and communicate assessment results in ways that promoted and preserved the therapeutic relationship. Concern was expressed that some of the available assessment tools did not capture the child's abilities or reflect performance in different contexts. The finding in Study 2 (O'Connor et al., 2019) that therapists may find it difficult to integrate the use of

evidence-based assessment tools with maintaining effective relationships has been suggested by others but not investigated empirically (King et al., 2011; Russell et al., 2010).

During Study 2 (Chapter 3), therapists also raised concerns about the authenticity (face-validity) and clinical utility of assessment tools, particularly for children with complex needs. Criteria for reviewing the clinical utility of assessment tools has traditionally related to practical issues for the assessor and the-assessed, such as: clarity of instructions; format; time to administer; cost and availability; and ease of use (Law et al., 1999). The uptake of evidence-based assessment tools may also relate to the subjective experience of being assessed with a specific tool or the experience of being assessed more broadly. The less visible impacts of assessment tools and the assessment process on parent-therapist relationships warrant further exploration.

Information about parent and therapist assessment interactions in Study 2 (Chapter 3) was gathered from the therapists' perspective. To gain a deeper understanding of evidence-based assessment interactions identified through the Cultural Cone themes of *Child and family collaboration* and *Assessment satisfaction,* the parent perspective of assessment was needed. A study designed to understand the experiences of parents of children with cerebral palsy was considered a necessary step to provide insight into the more subtle influences on therapists' behaviour in relation to evidence-based assessment tools.

Prior to conducting Study 3, a scoping review of the literature was undertaken with the primary purpose of determining: 1) the extent of published studies of parents' experiences of formal assessment; 2) current knowledge about the formal assessment experiences of parents' of children who have cerebral palsy vis-a-vis specific assessment tools and

assessment generally; and 3) the research methods used to understand parent's experiences of evidence-based assessments.

4.2 Method

4.2.1 Rationale for review method

Scoping reviews sit alongside narrative and descriptive reviews with a shared primary goal of summarising prior knowledge on a topic area (Paré et al., 2015). An evidence overview can outline concepts, theories and gaps to inform directions for new research. Specifically, the purpose of a scoping review is to assess the potential breadth and nature of available published literature, both conceptual and empirical, on a proposed topic of interest (Grant & Booth, 2009). Other possible purposes are to determine "the value of undertaking a full systematic review; or, identify research gaps in the extant literature." (Paré et al., 2015, p. 186). Like narrative and descriptive reviews (but unlike systematic reviews), scoping reviews pose questions that tend to be broad; however a scoping review is distinguished from a descriptive review by a systematic, and hence more comprehensive, search strategy (Paré et al., 2015). Debate exists about whether scoping reviews require formal quality appraisal of the included sources (Paré et al., 2015). Practically, quality appraisal can be difficult when sources are not limited to peer-reviewed materials. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews Checklist (PRISMA-ScR) (Tricco et al., 2018) has been published to address a lack of clarity in the methods and reporting of scoping reviews. The PRISMA-ScR was published after the scoping review for this programme of research was conducted.

A scoping review method was chosen to segue into the new area of exploration for this thesis that related to parents' experiences of formal assessment. The purpose was to develop

an overview of the breadth of the field and determine if and where research gaps existed in understanding parents' perspectives of assessment. While the review needed to be comprehensive in terms of breadth, the depth of synthesis provided by a systematic review was not warranted or appropriate at this early stage of investigation.

The review was conducted in four steps

1. development and conduct of a search strategy;

2. development of criteria for selection of articles;

3. application of selection criteria;

4. analysis of retrieved articles in relation the purpose of the review.

Step 1: Development and conduct of the search strategy

A search strategy was developed in consultation with the supervising research team and reviewed by the university librarian at Australian Catholic University (see Appendix C). Free text terms for 'parent', 'assessment', 'cerebral palsy' and 'experience' were combined with their related subject headings and adapted to the electronic databases (CINAHL, Medline, ERIC, and PsycInfo). To ensure parent evaluations of specific tools were located, each search was re-run after replacing free text terms for 'assessment' with the names of all assessment tools used by allied health practitioners identified in Study 1.

Step 2 Criteria for selecting studies

Criteria for identifying relevant articles were established a priori. Articles were included if:

1. The study reported caregiver perspectives, in the clinical setting or as part of assessment tool validation, about assessment using standardised measures generally or in relation to specific assessment tools;

2. Participants were caregivers of children with a disability inclusive of cerebral palsy;

3. Assessment administrators included allied health practitioners (occupational therapists, physiotherapists or speech pathologists);

4. Articles were peer reviewed primary English-language journal sources or conference abstracts of any study design, published between 1995 and 2018. The publication period was chosen to coincide with the period of raised awareness of family-centered care, evidence-based practice and clinical availability of validated assessments for children with cerebral palsy (Arango, 2011; Rosenbaum, King, Law, King, & Evans, 1998).

Articles were not included if they described caregiver experiences of assessments contributing to their child's initial diagnosis of cerebral palsy, due to the greater emphasis on the medical practitioner role at this time.

Step 3: Application of selection criteria

Searches were conducted between November 2017 and January 2018, with regular citation alerts until February 2018. Databases were selected for coverage of research across healthcare, education, psychological and social services. Reference lists of included full-text articles were manually searched to check for additional relevant articles. Retrieved citations were reviewed by the author (BO) in two phases against the inclusion criteria: initial screening by title and abstract within the database followed; by full-text review of

the remaining articles where a decision could not be made, or confirmation of inclusion was required.

Step 4: Analysis of the literature

A tabular and narrative review of the study findings was undertaken. Study characteristics were tabulated by the author (BO) to provide an overview of the literature that included the study aim, participants, type of formal assessment investigated, study design and methods used to investigate parent's experiences of standardised assessment. Findings relevant to the review purpose were extracted from each study and summarised as dot points in the table. Studies were then considered together to identify commonalities and differences between studies. A narrative review including study design and methods was structured according to the extent of the parents' perceived benefits and challenges in relation to assessment with specific tools and with assessment generally.

4.3 Results

Database searches identified 943 citation records that were screened by title and abstract, leaving 25 citations retained for full-text review, with an additional four citations sourced through citation alerts and reference list searches. The PRISMA flow diagram in Figure 4.1 provides sequence and reasons for exclusion. Nine articles met the inclusion criteria: eight full-text journal publications and one conference abstract.
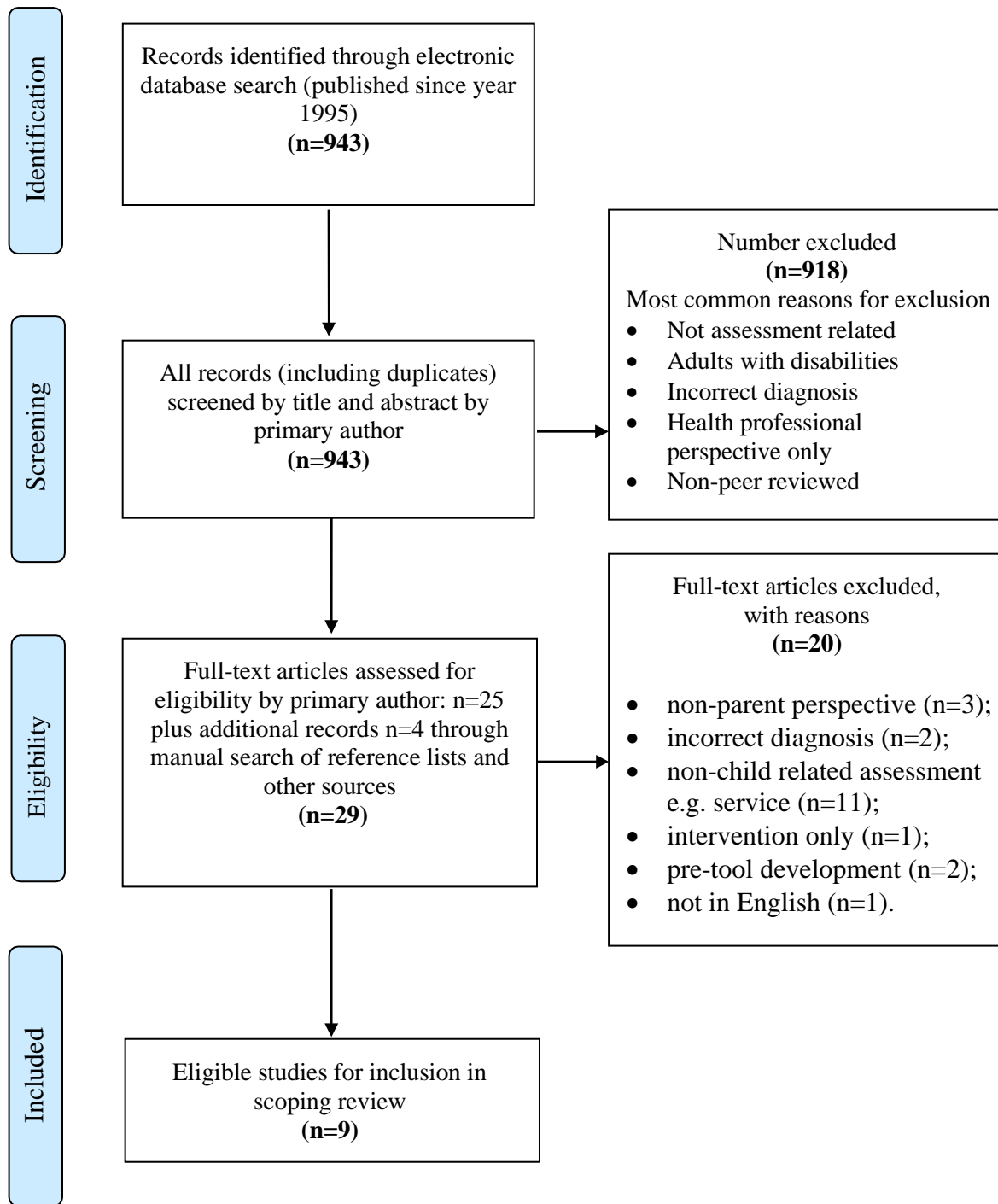
Figure 4.1. PRISMA flow diagram

The flow diagram contains the following text:

Identification

Records identified through electronic database search (published since year 1995)
(n=943)

Screening

All records (including duplicates) screened by title and abstract by primary author
(n=943)

Number excluded
(n=918)
Most common reasons for exclusion
- Not assessment related
- Adults with disabilities
- Incorrect diagnosis
- Health professional perspective only
- Non-peer reviewed

Eligibility

Full-text articles assessed for eligibility by primary author: n=25 plus additional records n=4 through manual search of reference lists and other sources
(n=29)

Full-text articles excluded, with reasons
(n=20)

- non-parent perspective (n=3);
- incorrect diagnosis (n=2);
- non-child related assessment e.g. service (n=11);
- intervention only (n=1);
- pre-tool development (n=2);
- not in English (n=1).

Included

Eligible studies for inclusion in scoping review
(n=9)

4.3.1 Extent of published studies and reporting of parents' experiences of formal assessment

Six studies reported parents' experiences of assessment with a specific assessment tool validated for children with cerebral palsy (Gibson, Mistry, & Wright, 2017; Kerr et al., 2016; Öhrvall & Eliasson, 2010; Øien, Fallang, & Østensjø, 2010; Rich, Rigby, & Wright, 2014; Scime, Bartlett, Brunton, & Palisano, 2017). Three studies reported on the overall experience of formal assessment for parents of children with disabilities, of which some of the latter had cerebral palsy. Of these three studies, one reported the parents' experiences of their child's assessment (Bjorbaekmo & Engelsrud, 2011), one focused on parent perceptions of assessment processes in relation to family-centred care (Crais, Poston Roy, & Free, 2006), and the focus of the other was in relation to multidisciplinary team assessments (Simeonsson et al., 1995). A summary of study characteristics and relevant findings of each of the included studies is provided in Table 4.1. The shaded citations in the author-year column in Table 4.1 differentiate studies related to specific assessment tools from studies of formal assessment overall.

Table 4.1 Study aim, assessment type, method and findings

Author & Year	Aim	Participants	Assessment type	Study design	Method	Analysis	Findings relevant to review
Bjorbaekmo et al. 2011	Explore testing practices from interviews and participant observations among children with disabilities and their parents	20 children, parents one adult living with disabilities; 5 children with cerebral palsy; 2 with spina bifida; 2 with hereditary spastic paraplegia; 11 other	Generic testing	Qualitative phenomenology	Interviews Participant observation	Critical discussion	Parent perspective • Emotional impact on relationship with daughter • Concerns about effects of testing on child • Impacts of repeated testing Author interpretation • Impact of repeated testing on self-consciousness and body confidence • Discussion about the personal cost of testing,
Crais et al. 2006	Determine degree to which professionals & families agreed on whether family centred practices were implemented in assessments and which practices important for future assessments	134 health professionals and 58 parent-carers of children with disabilities, 0-5 years	Generic testing	Cross sectional survey quantitative	Questionnaire following therapist assessment	Frequency statistics	Parents infrequently involved in pre- assessment planning Post assessment • Infrequent sharing of results • Parents not asked if they agreed with recommendations or diagnosis • No preview of report Author interpretation • >90% families satisfied with participation however half of family centred practices not implemented. • Important to gather actual practice data not only parent satisfaction

Gibson et al. 2017	Produce child-centred guidelines for administration of a measure of children's advanced gross motor skills, the Challenge	31 children with cerebral palsy and their parents	Challenge	Qualitative Social constructivist stance	Interview following assessment tool use	Group analysis technique	• Diverse parent interpretations of test and how it can benefit them or child
							• Parent and child invest in doing well
							• Even enjoyable assessments can invoke anxiety
							• Utility -parents mostly found useful applications
							Author recommendations
							• Inquire first strategy
							• Create space for carer and child to talk about:
							  o Experiences of being tested
							  o Balance fun and therapeutic activity
							  o Focus on score change not actual score

Table 4.1 (*continued*)

Author & Year	Aim	Participants	Assessment type	Study design	Method	Analysis	Findings relevant to review
Kerr et al. 2016 (conference abstract)	Evaluate parent perceptions of routine assessment screening for their child with cerebral palsy received from allied health professionals	61 parents of children with cerebral palsy	Suite of assessments for routine surveillance	Cross-sectional survey mixed	Questionnaire-open and closed questions	Content analysis and frequency statistics	• Assessment process valued to a moderate or greater extent by 80% of parents • 70% reported assessment process encouraged collaboration. • 14% reported no opportunity to discuss child's findings with assessor • 20% no written report • Parents desired annual assessment, at least
Öhrvall & Eliasson 2010	Investigate content validity related to parents' and therapists' descriptions of children's ability to use their hands in daily manual tasks, choice of MACS level and comprehension of MACS concept	Therapists and parents of 25 children with cerebral palsy	MACS	Qualitative Description	Short interview following assessment tool use	Content analysis (qualitative)	• Differences between MACS levels were meaningful • Choosing appropriate level easy for most parents • All parents positive about 'can do' focus rather than limitations
Øien et al. 2010	Explore parents' and professionals' perceptions of setting and implementing goals within a family-centred programme for pre-schoolers with cerebral palsy	Parents and service providers of 13 pre-school children with cerebral palsy, GMFCS I-III	GAS; COPM	Qualitative multi-case study within participating action research	Focus group interview	General thematic analysis	• Goals enhance competence, direct attention and activated within everyday settings • Active involvement in setting and implementing goals increased parent feelings of competency and professional partnership

(Continued over page)

Table 4.1 (*continued*)

Author & Year	Aim	Participants	Assessment type	Study design	Method	Analysis	Findings relevant to review
Rich et al. 2014	To identify parents' experiences associated with completing the PEDI, as well as their views of the PEDI	12 mothers of children with a primary diagnosis of cerebral palsy or developmental disabilities	PEDI	Qualitative Description	Interviews	Content analysis (qualitative)	Benefits • Insight into child's abilities in relation to typical development. • Assist with goal setting and ways to involve child Emotional challenges • Feeling "overwhelmed" when unable to perform most items • Child "in-between" scores • Child capable but unwilling. • Gains not captured - not responsive enough Recommendations • Clarify scoring and relevance of measure to goal setting • Caution when child unlikely to be able to perform many items
Scime et al. 2017	Investigate the experiences and perceptions of parents of children with cerebral palsy when classifying their children using the GMFCS, MACS and CFCS	7 parents of children with cerebral palsy	GMFCS; MACS; CFCS	Qualitative Pragmatic stance	Interviews	Interpretive description approach	Variable reaction • Less positive for parents of children greater involvement. • Not capturing other aspects of the child Utility • Useful for securing resources, communication, advocating, • Informing future expectation and risks of complications • Not useful in day-to -day life Recommended practice • Acknowledge parent reactions • Recognise limitations of classification systems
Simeonsson et al. 1995	Examine parental perceptions about their child's assessment and involvement in multi-disciplinary team evaluation	39 parents and 81 healthcare professionals mixed caseload	Generic testing	Cross sectional survey mixed	Questionnaire open and closed questions	Frequency statistics and quantitative content analysis	• Parents expectation for involvement vary greatly • Therapists inaccurately perceived family's emotions - therapists perceived more negative feelings than parents themselves • Few therapists endorsed parent involvement with test validation or sharing emotional aspects of assessment Recommended practice • Increase in sharing information gathering and decision making • Individualised approach

Note. Sources listed alphabetically. Highlighted studies denote qualitative studies investigating parents' experiences of assessment tools validated for children with cerebral palsy. Tool abbreviations and references: CFCS, Communication Function Classification System; COPM, Canadian occupational performance measure; GAS, Goal Attainment Scale; GMFCS, Gross Motor Function Classification System; MACS, Manual Abilities Classification System; PEDI, Paediatric Evaluation of Disabilities Inventory.

4.3.2 Parents' experiences of specific assessment tools

Parents' experiences of assessment for their child were explored in relation to the use of specific assessment tools. These included: three classification tools (GMFCS (Palisano et al., 1997), MACS (Eliasson et al., 2006), and CFCS (Hidecker et al., 2011)); a suite of impairment and function-based assessment tools as part of a routine clinical assessment programme examples of which included, goniometry, Dysphagia Severity Scale, Hypertonicity Assessment Tool, two individualised goal setting measures, the GAS (Kiresuk, Smith, & Cardillo, 1993) and COPM (Law et al., 1990); the daily activity performance tool, the Paediatric Evaluation of Disabilities Inventory (PEDI) (Haley, Coster, Ludlow, Haltiwanger, & Andrellos, 1992); and, the Challenge measure of advanced motor skills for children with cerebral palsy (Wilson et al., 2011).

Parents' described their experience of specific tools often in pragmatic terms of usefulness (Gibson et al., 2017; Kerr et al., 2016; Öhrvall & Eliasson, 2010; Øien et al., 2010; Rich et al., 2014; Scime et al., 2017; Simeonsson et al., 1995). Specific tools, for example the Challenge, provided parents with increased insight into their child's abilities, while other tools highlighted their child's difficulties, for example the PEDI (Gibson et al., 2017; Øien et al., 2010; Rich et al., 2014; Simeonsson et al., 1995). Parents used information from specific assessment tools in different ways. Parents of children undertaking the Challenge tried new activities with their children that they had previously thought too challenging (Gibson et al., 2017; Simeonsson et al., 1995). Others reported that use of the COPM and GAS increased competency and focus with therapy (Øien et al., 2010), while the PEDI highlighted areas for parents to make changes to enable greater involvement of their child with self-care (Rich et al., 2014). Parents perceived that specific assessment tools provided

more informed expectations (Rich et al., 2014; Scime et al., 2017) and increased competency with planning (Øien et al., 2010; Rich et al., 2014), tailoring home activities (Gibson et al., 2017; Simeonsson et al., 1995) and securing resources (Scime et al., 2017). Assessment tools were also perceived by parents to facilitate communication (Scime et al., 2017) and collaboration with therapy providers (Kerr et al., 2016; Øien et al., 2010). Perceptions of how the assessment benefitted them or their child varied across studies, but overall these studies suggested assessments were considered useful and valued by parents (Gibson et al., 2017; Kerr et al., 2016; Öhrvall & Eliasson, 2010; Øien et al., 2010).

Parents' emotional responses to specific assessment tools were also reported; however, these responses were more variable. Two studies investigated parent experiences of classification tools (Öhrvall & Eliasson, 2010; Scime et al., 2017). Öhrvall and Eliasson (2010) found parents valued the MACS for its focus on their child's abilities and performance instead of usual discussions about their child's limitations. In contrast, Scime et al. (2017) found parents' responses ranged from ambivalence to feeling overwhelmed and frustrated when using the GMFCS, MACS and CFCS. Rich et al. (2014) also reported parents feeling discouraged when using the PEDI, whereas Gibson et al. (2017) noted that parents' emotional responses to the Challenge varied from delight (most common) to ambivalence. Gibson et al. (2017) noted, however, that even enjoyable assessment tools such as the Challenge still provoked parental and child apprehension. Øien et al. (2010) reported that parents felt positive about their involvement in scaling, monitoring and measuring GAS and COPM goals if well supported by therapists during the process.

4.3.3 Parents' experiences related to the assessment tool characteristics

Parents' experiences appeared to be influenced by the design and administration procedures of the assessment tool. Positive emotions of assessment prevailed with the Challenge and individualised measurement tools used to assist goal setting, such as the COPM and GAS. The Challenge (Wilson et al. 2011) assessment is administered in an enjoyable and flexible way that encourages the child to choose and demonstrate their maximum capability. In contrast, the classification tools (e.g. GMFCS, CFCS, MACS) and PEDI focus on usual performance and parents are required to choose category options that most accurately represent their child's typical abilities. Parents found it challenging when using the PEDI and classification tools to fit their child into a category that often did not accurately reflect their child's abilities (Rich et al., 2014; Scime et al., 2017). Parents expressed that their child was able to do some of the assessed tasks, but were often unwilling to perform the required tasks due to a range of other factors not accounted for in the assessment. Parents reported frustration with the inability of the PEDI to 'tell the whole story" (Rich et al., 2014, p. 281). It is possible that individualised measures such as the COPM and GAS were perceived more positively because parents helped to define the categories to be assessed. Nonetheless, if therapist support was not available to help with refining, scaling and evaluating COPM and GAS goals and scores, parents had a negative perception of the assessment process (Øien et al., 2010). Accordingly, flexible and individually administered tools may be perceived more positively by parents.

4.3.4 Parents' experiences of formal assessment generally

Bjorbaekmo and Engelsrud (2011) captured the overall experience of repeated assessment for parents and the child and raised the notion of beneficial and harmful testing practices.

In this study, parents recounted the need for their child to "be brave" (Bjorbaekmo & Engelsrud, 2011, p. 130) and to be able to "put up" (Bjorbaekmo & Engelsrud, 2011, p. 127) with assessment. Parents' in the study by Simeonsson et al. (1995) were asked to rate their feelings about assessment from a predetermined list of feelings; emotions were varied but not mutually exclusive: hopeful (63%); worried (42%); happy (29%); sad (21%); afraid (17%); upset (8%), and angry (8%). The varied but sometimes less positive emotional responses to assessment overall suggest a need for further investigation to understand the impacts of standardised assessment on parents and children, the contextual influences (personal and environmental) on the assessment experience, and implications for the parent-child-therapist relationship.

4.3.5 Parents' experiences of assessment according to their child's physical disability

When studies were considered in relation to the functional motor level of the participants' children, more positive emotional experiences of assessment occurred in those studies where participants' children were classified from GMFCS levels I to III, compared to those with more significant gross motor involvement (Gibson et al., 2017; Øien et al., 2010). In contrast, more negative experiences were reported in the two studies where participants' children were from all levels of gross motor function (GMFCS level I – level V) (Rich et al., 2014; Scime et al., 2017). Parents in these studies were disheartened by only being able to tick the "unable to do" response option with the PEDI and felt discouraged about their child's future when the assessment failed to show a change in their child's abilities (Rich et al., 2014). A parent of a child, classified as GMFCS level V shared similar emotions when the classification tools were being used for her child (Scime et al., 2017). On the other hand, a parent of a child classified as GMFCS level I in the same study did not attribute

negative emotions to their child's classification (Scime et al., 2017). Parents' experiences of current standardised assessments vary widely but appear to be less positive for parents whose children have more significant and complex disabilities (GMFCS level IV– level V).

4.3.6 Parents' experiences of formal assessment processes

Parent satisfaction and perceptions of involvement in the assessment process were compared with practitioner perceptions in two studies (Crais et al., 2006; Simeonsson et al., 1995). Crais et al. (2006) noted that, although most families rated their satisfaction with their participation in assessment highly, all families agreed that nearly half of the listed family-centred assessment practices were not implemented as often as preferred; for example, assessment purpose was not explained beforehand, opportunity to comment on assessment results did not occur, or they were not able to review the written report. Furthermore, families and practitioners agreed less than half the time on whether specific assessment practices had occurred. The study by Simeonsson et al. (1995) examined the congruence in practitioner and parent perceptions of the occurrence of specific components of assessment and perceived emotional impact of the assessment process. Large differences were found in perceptions of assessment practices. Parent recollections about whether a classification tool had been explained were also identified as an issue (Scime et al., 2017). These findings suggest a lack of explicit processes regarding assessment tool use for both parents and practitioners.

4.3.7 Research methods used to understand parent's experiences of assessment

Of the nine studies, six studies used qualitative research designs to investigate parents' experiences of assessment. Three studies used a survey design: two mixed response surveys (Kerr et al., 2016; Simeonsson et al., 1995), and one quantitative survey (Crais et al., 2006).

The studies using a survey design were able to gather the perspectives of many parents (n= 234) through the use of questionnaires. The types of questions developed enabled aspects of the assessment experience to be quantified, such as: the percentage of parents who valued the assessment process (Kerr et al., 2016); the number of parents experiencing specific types of negative or positive emotions (Simeonsson et al., 1995); and the prevalence of assessment processes (Crais et al., 2006). Two studies included open questions to gather additional information to assist interpretation of questionnaire data (Kerr et al., 2016; Simeonsson et al., 1995). The survey approach provides detailed collective information about pre-determined aspects of a phenomenon, but has limitations in generating in-depth knowledge and understanding from the parent perspective. A qualitative approach on the other hand can delve into the assessment experience from the parent perspective to varying depths, and from different standpoints, depending on the methods used. The qualitative studies identified in this scoping review used a range of methods relevant to the healthcare context: qualitative description (Öhrvall & Eliasson, 2010; Rich et al., 2014); interpretive description (Scime et al., 2017); phenomenology (Bjorbaekmo & Engelsrud, 2011); and social constructivism (Gibson et al., 2017).

The qualitative description approach used in the studies of the MACS tool (Öhrvall & Eliasson, 2010) and PEDI (Rich et al., 2014) typically provide a more descriptive than interpretive account of a phenomenon, for example, the *who*, *what*, and *where* (Bradshaw, Atkinson, & Doody, 2017; Lambert & Lambert, 2012). The interpretive description approach used by Scime et al. (2017) was more 'interpretive' and enabled understanding of the experience of the classification tools to be developed that can be related to the pragmatic realities of clinical practice. Meaning saturation in the study by Scime et al.

(2017) was achieved with seven participants which is less than the 16 to 24 interviews typically expected (Hennink, Kaiser, & Marconi, 2017), and is a possible reason for not generating the 'interpretive turn' or synthesis referred to by Thorne (2016). The social constructivist approach adopted by Gibson et al. (2017) provided the social focus needed to understand how the Challenge tool could be administered more effectively for parents and children. Interviews were conducted with a large number of parents (n=31), with key aspects of credibility (authenticity, trustworthiness) addressed.

All studies discussed so far have explored parents' experiences in relation to specific assessment tools. Only one qualitative study explored the overall experience of assessment (Bjorbaekmo & Engelsrud, 2011). The participant group in this study included adults, parents, and children with a range of disabilities (Bjorbaekmo & Engelsrud, 2011). The phenomenological approach adopted by Bjorbaekmo and Engelsrud focuses on the embodied experience of individuals from a psychological perspective, and less on the social interaction with others (Starks & Brown Trinidad, 2007). This study generated important insights through critical analysis into the personal experience of "being tested". However, from a pragmatic and social perspective, a gap exists in studies of the overall experience of assessment for parents of children with cerebral palsy. The interpretive description study by Scime et al. (2017) achieves this, but only in relation to the specific use of classification tools. When limited previous work exists on a topic area, as identified in this scoping review, interpretive description is proposed as a useful starting place (Hunt, 2009) that can generate new 'usable' knowledge capable of informing and shifting clinical practice (Starks & Brown Trinidad, 2007).

All the qualitative studies included in this scoping review used individual interview techniques to collect data, with the exception of one study that used a focus group method (Øien et al., 2010). One-on-one interviews enable the researcher to gain greater depth of information and understanding. Through the interview format, the researcher is able to see the world from the participants' perspective and subsequently undertake more in-depth analysis of the data (Liamputtong, 2013a). Furthermore, parents may participate more easily than in a focus group when talking about personal experiences related to assessment. Therefore, the research design and data collection method selected to understand parents' experiences overall of formal assessment was an interpretive description research design and individual face-to-face interview data collection method.

4.4 Scoping Review Conclusions

This scoping review identified nine studies that consider the personal experience of evidence-based assessments of parents of children with cerebral palsy. Given the large number of assessments available and promoted for use in the clinical setting, it is surprising the subjective experience of assessment for parents and children has not been well evaluated. This review suggests assessment tools are valued overall by parents, but that parent emotional responses to assessment at an individual level varies (Gibson et al., 2017; Rich et al., 2014; Scime et al., 2017), and may be influenced by: the child's functional motor level (Rich et al., 2014; Scime et al., 2017); the tool (Øien et al., 2010; Rich et al., 2014); and the assessment processes (Crais et al., 2006; Scime et al., 2017; Simeonsson et al., 1995). The finding that parents are aware that their child with disability needs to be braver than others "to put up with" assessment (Bjorbaekmo & Engelsrud, 2011, p127) also highlights the need for a greater understanding of the possible burdens of the assessment

process. The findings suggest more flexible and individually administered tools may be perceived more positively by parents with more explicit processes regarding assessment tool use needed for both parents and practitioners.

An apparent gap exists in the literature concerning studies designed to understand the overall experience of evidence-based assessment for parents, one which can potentially generate usable knowledge for practice. Exploration of the subjective and contextualised assessment experiences of parents from an interpretive perspective and using individual interview methods is recommended from this scoping review to help gain a deeper understanding of the potential parent-related factors influencing therapists' use of evidence-based assessment tools. A qualitative interpretive description research method is proposed to address Study 3 and is presented in Chapter 5.

Chapter 5 Parents experiences of evidence-based assessment for their child with cerebral palsy

5.1 Introduction

This chapter addresses the fourth objective of this thesis: to design and conduct a study to understand parents' experiences of evidence-based assessment for their child with cerebral palsy. The Cultural Cone for Evidence-based Assessment, developed in Study 2 (Chapter 3), and the results from the scoping review (Chapter 4) informed the direction of the study reported in this chapter (Study 3). The purpose of Study 3 was to explore in depth parents' experiences of evidence-based assessment for their child with cerebral palsy.

The core qualitative interpretive description method adopted in Study 2 was carried forward into this study. Interpretive description methods were determined to fit with both the purpose of the current study (Study 3) and the overall orientation of the thesis towards informing clinical practice. The detail of interpretive description and its rationale was discussed in Chapter 3, Section 3.3. Justification for selecting an interpretive description research design for Study 3 and face-to-face interviews for data collection was provided in Chapter 4. The methods for Study 3 are otherwise fully described in the accepted manuscript that forms the body of this chapter.

The accepted manuscript for Study 3 is provided and followed by a short conclusion to the chapter.

5.2 Paper 3 Steering towards collaborative assessment: A qualitative study of parents' experiences of evidence-based assessment practices for their child with cerebral palsy

Due to publishing requirements the Word version of the accepted manuscript will be presented rather than the PDF format. For reasons of text consistency some alterations in punctuation may exist between the published paper and accepted manuscript.

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**Steering towards collaborative assessment: A qualitative study of parents'
experiences of evidence-based assessment practices for their child with cerebral
palsy.**

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Abstract

Purpose: To understand parents' experiences of evidence-based assessment by health professionals for their child with cerebral palsy.

Methods: A qualitative interpretive description study was undertaken. Primary carers of children with cerebral palsy (aged 3–18 years) from south-eastern Australia were invited to participate. Face-to-face interviews were held using a semi-structured topic guide and data analysed inductively. Credibility was ensured through journal reflections, co-author review, audit trail, and, participant member checking.

Results: Fourteen parents of children with cerebral palsy, representing Gross Motor Function Classification System levels I–V, participated. Six themes emerged: (1) Protection; (2) Positively Framed; (3) Bridging the Gap; (4) Involvement; (5) Finding Worth; and (6) Trust. Central to parents' experience was protection of their child's identity and personal self. Assessment can be emotionally confronting, at any stage. Representing the child positively and highlighting possibilities was deemed essential. Parents' involvement ranged from being 'overlooked spectators' to being 'instigators of assessment'. Evidence-based assessment was worthwhile when relevant to parents' direction and family context. The researchers' interpretive description generated a schema and metaphor—the Steering Wheel for Collaborative Assessment.

Conclusions: A strengths-based approach to diagnosis and assessment is essential. The resulting interpretive description may assist health professionals align evidence-based assessment practices with family-centred care.

Implications for rehabilitation

1. Parents of children who have cerebral palsy describe having to protect their child's identity and representation, and their own personal well-being, through evidence-based assessment and diagnostic processes.

2. Involving parents in the process of evidence-based assessment and adopting a strengths-based approach is essential.

3. The interpretive description developed—the Steering Wheel for Collaborative Assessment—may assist health professionals to implement evidence-based assessment tools in ways consistent with family-centred care principles.

5.2.1 Introduction

The number and availability of psychometrically robust assessment tools has increased markedly in cerebral palsy research and practice (Schiariti et al., 2018; Wu, Mehravari, Numis, & Gross, 2015). Information from appropriately selected tools can guide allied health practitioners, children and families with goal setting, planning interventions, predicting resource needs, and can provide objective evaluation for interventions (Bartlett et al., 2018; Palisano, 2006; Wright & Majnemer, 2014). Assessment tools are defined as evidence-based when there are both published instructions on how to administer, score and interpret the assessment, and acceptable levels of reliability and validity when used with the population of interest, in this case children with cerebral palsy (Wright & Majnemer, 2014). Including psychometrically robust assessments (henceforth referred to as 'evidence-based assessment tools') in practice is widely advocated, as health professionals strive to strengthen their evidence-base for practice, and consumers and funders seek greater

accountability from service providers (Ketelaar, Russell, & Gorter, 2008; Unsworth, 2011). The term 'evidence-based assessment' will be used in relation to the overall assessment process i.e. the procedures, actions and interactions involved with using evidence-based assessment tools. Evidence-based assessment is considered to be both the use of research to guide which assessment tool to use, and an assessment process that integrates the use of psychometrically robust assessment tools, when available, with family preferences and clinician expertise.

In the area of childhood disability, use of evidence-based assessment tools needs to be considered within the context of family-centred care (King & Chiarello, 2014; Kuo et al., 2012). An increasing body of research links family-centred care to enhanced parent well-being and optimal child outcomes (Dunst & Trivette, 2009b; Järvikoski, Härkäpää, Martin, Vasari, & Autti-Rämö, 2015). Central to family-centred care is the emphasis on child and family strengths and the formation of collaborative interpersonal relationships between professionals, families and children (King & Chiarello, 2014; Kuo et al., 2012). Collaboration is underpinned by shared decision making, trust and open communication (Kuo et al., 2012). Parents consistently highlight their desire for well delivered, specific information in relation to their child's care (Jackson, Cheater, & Reid, 2008; Kruijsen-Terpstra et al., 2016; Resch et al., 2010). If used collaboratively, evidence-based assessment tools can potentially enhance parent participation in decision making about their child's therapy. However, the implementation of collaborative therapy practices has been identified by allied health professionals and families as an area requiring improvement (An et al., 2018; Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009).

The uptake of evidence-based assessment tools by health professionals (occupational therapists, physiotherapists and speech pathologists, referred to collectively as therapists) remains slow (Bailes et al., 2018; O'Connor, Kerr, Shields, & Imms, 2016), with interventions to increase use showing only modest success (Colquhoun et al., 2016). Uncertainty about parents' perceptions of formally administered assessments and potential impact on the parent-professional relationship has been identified as a "sticking point" by therapists (King, Wright, & Russell, 2011; Krohne, 2013; O'Connor, Kerr, Shields, & Imms, 2019; Reeder & Morris, 2018). Parent perspectives of specific evidence-based assessment tools are variable, with some assessment tools perceived more positively (Gibson, Mistry, & Wright, 2017; Kerr et al., 2016; Öhrvall & Eliasson, 2010; Øien, Fallang, & Østensjø, 2010) than others (Bailes et al., 2018; Rich, Rigby, & Wright, 2014; Scime, Bartlett, Brunton, & Palisano, 2017). Parents' mixed responses and therapists' uncertainty with using evidence-based assessment tools suggests further investigation is needed. Parental experiences may provide valuable insights into the slow uptake and use of evidence-based assessment tools within the paradigm of family-centred care. Therefore, this study, aimed to understand parents' experiences of evidence-based assessment practices by health professionals for their child with cerebral palsy.

5.2.2 Methods

Study Design

A qualitative approach using interpretive description (Thorne, 2016) was chosen. Interpretive description assumes a constructivist view of knowledge where meaning is constructed through social interaction, experience and context (Crotty, 1998). The design of interpretive description generates understanding about the human experience in a way

that is meaningfully applied to clinical practice. This research was approved by the Australian Catholic University Human Research Ethics Committee (2017-257E).

Participants and recruitment

Primary carers of children with cerebral palsy living in south-eastern Australia were invited to participate. Eligibility included: prior experience of formally administered evidence-based assessment tools with an occupational therapist, physiotherapist or speech pathologist; ability to communicate in English; and their child being aged between 3 and 18 years. A heterogeneous sample was sought according to child age, Gross Motor Function Classification System level (Palisano et al., 1997), and geographical home location to encompass a broad range of child-family circumstances (Liamputtong, 2013).

No set rules exist regarding parameters for sample size in qualitative research. Often 'code saturation'—the point at which no further novel information is being added to the data set —is used to justify ceasing recruitment i.e. the researcher has "heard it all" (Hennink, Kaiser, & Marconi, 2017, p. 605). This study aimed for 'meaning saturation' with sufficient data gathered to "understand it all" (Hennink, Kaiser, & Marconi, 2017, p. 605). Sixteen to 24 interviews are recommended to achieve meaning saturation (Hennink et al., 2017).

Participants were recruited between January and May 2018. Interested parents contacted the primary author directly or gave verbal consent for their contact details to be forwarded. Recruitment continued alongside preliminary analyses, until new data did not add further meaning or significantly change the interpretation (Hennink et al., 2017).

Data Collection

Participants provided study consent on entry to an online questionnaire as part of data collection. The online questionnaire was used to collect parent and child information to provide contextual background to the interviews. Information gathered included parent age, income, education and geographical location, and child age, gender, functional classification abilities for mobility, hand function and communication, and therapy service history.

Parents' experiences of their child's assessment with health professionals using evidence-based assessment tools were explored through face-to-face interviews conducted with the primary researcher (an experienced paediatric physiotherapist) at a private location chosen by the parent. A topic guide (see Appendix D7) developed by the research team, all of whom have experience in qualitative research, was employed; assessment was explained broadly and in the context of healthcare, with examples provided of evidence-based assessment tools that parents were likely to have encountered. Initially, parents reflected on their experiences of their child's assessment broadly and then were asked to consider, more specifically, their experiences when evidence-based assessment tools were used. Interviews lasted between 30 and 90 minutes and were audio-recorded and transcribed verbatim by a professional transcription service. Transcripts were cross-checked with the original audio files.

Data Analysis

Interview data were analysed inductively using an interpretive description approach (Thorne, 2016). Analysis was immersive and iterative with stages that included: familiarisation with audio, textual and post-interview summary data; initial coding of

textual data into broad thematic patterns; and, repeated testing and questioning of labels and linkages between and across data elements to clarify and finalise thematic interpretations.

Final synthesis involved looking for potential relationships across themes and subthemes. Personal and discipline-specific critique was provided in relation to the final conceptual understanding and structure, and it's relevance to practice. Iterations developed by one researcher (BO) were reviewed for authenticity by the other researcher team members (CI, CK, NS, BA). The final interpretive description was considered in relation to, and then situated within, current theoretical frameworks.

The influence of the authors' personal and clinical perspectives and experiences during data analysis was recognised and acknowledged. A documented audit trail of decisions during concept development and a reflective journal, were kept by the primary author. Interpretations were documented and questioned throughout data collection and analysis. All co-authors were involved through: regular discussion and critique of evolving thematic descriptions and their interpretations; and, cross-checking of coded textual data against themes and sub-themes with differences resolved through discussion. Finally, study participants were asked to consider the 'authenticity' of the findings, that is, whether or not themes and final conceptual description—the schema and metaphor—'rang true' according to their experiences.

5.2.3 Results

Fourteen parents (all maternal carers) of children with cerebral palsy (child age 3–14 years) participated in the study (see Table 1). Parents were aged 30–54 years; two were sole-carers

and one spoke English as a second language. Children's therapy service histories encompassed all sectors (early intervention, hospital, school, private practice, and community health), with all children having received therapy from two or more therapy disciplines in the past.

Table 1: Parent and child characteristics

Parent			Child		Functional Classification*		
Code	Education	Home location	Gender female (F) male (M)	Age (years)	GMFCS (level)	MACS (level)	CFCS (level)
Parent #1	Postgraduate	Metropolitan	F	14	II	II	II
Parent #2	Degree	Metropolitan	F	14	V	IV	III
Parent #3	Year 12	Metropolitan	M	8	II	II	III
Parent #4	Certificate	Rural	M	8	II	II	III
Parent #5	Certificate	Regional	M	3	IV	IV	IV
Parent #6	Year 12	Rural	F	12	II	II	I
Parent #7	Certificate	Regional	F	14	I	III	III
Parent #8	Certificate	Regional	F	6	V	V	V
Parent #9	Postgraduate	Rural	M	12	III	I	I
Parent #10	Postgraduate	Regional	M	3	V	V	IV
Parent #11	Degree	Metropolitan	M	11	III	II	I
Parent #12	Postgraduate	Metropolitan	M	11	III	III	I
Parent #13	Certificate	Regional	F	7	I	II	I
Parent #14	Certificate	Regional	F	10	I	III	III

*Classification legend; Gross Motor Function Classification System; MACS, Manual Abilities Classification System; CFCS, Communication Function Classification System

Six themes emerged: *Protection*; *Positively Framed*; *Bridging the Gap*; *Involvement*; *Finding Worth*; and *Trust*. These main themes and their associated sub-themes are discussed in detail and illustrated in Figure 1.

Protection

This central theme included the sub-themes *Protecting my Child's Identity* and *Protecting the Self* and was influenced strongly by the *Legacy of Diagnosis* sub-theme. All parents described feeling anxious and some parents fearful with assessments and reported their need to protect the essence of their child through the assessment process. For some parents these feelings "*stemmed from*" distressing diagnostic experiences that subsequently impacted parents' willingness to engage with therapists and assessment.

> *So, yeah, I was just terrified. From that [early hospital experience] - I was*
> *so reluctant to go near hospitals or doctors. Really, at the age of nine, this*
> *is the first time I've taken him, because I don't want to lose control again.*
> *Parent #4*

Parents recounted how assessments often failed to reflect and adequately represent all facets of their child. This generated a strong desire within parents to *Protect their Child's Identity*: an individual in their own right—not as a child defined by the assessment, disability or diagnosis. Parents felt *"quite confronted"* when their child was *"reduced to a number"*. Parents talked about needing to separate assessment terminology, such as "*she's a five*" from their child "*who loves going in a helicopter*".

Parents described ways of *Protecting one's Self* emotionally during the assessment process. Evidence-based assessment triggered visceral emotions in some parents, such as feelings of sadness, and vulnerability in the lead up to, during and when receiving associated

prognoses and reports afterwards. Some parents chose not to "*put themselves through it*" to circumvent "*judgement*" and *"feeling like you're in the principal's office"* or witnessing their child's "*failure because they are low down*" or "*don't fit*" the assessment criteria. The assessment process brought up issues for parents *"that are always under the surface".* Parents drew on different mental strategies to help ameliorate feelings of "*disappointment*" such as focusing on things that were changeable, "*never having high expectations"*, and "*manning up to face these things*".

> *I can't focus on what I can't change, I've just got to go with it. I've got to accept where he is and who he is and what he is, and that makes me a much better person and parent, and happier in myself. Parent #9*

Positively Framed

Providing a positive perspective throughout the assessment process was a strong theme. Assessment needed to: provide positive *Representation* of their child; highlight *Possibilities* (not deficits); and *Support* parents emotionally and practically by highlighting strategies parents could implement to support their child's development.

> *It can make or break your whole attitude toward how you're going to approach it, yeah. So when that physio just said that one thing 'see how he opens his hands, he's not clenching really tightly, that's a good sign' ...I was like, "That's fine. I'll take it." Parent #11*

Negatively framed assessment heightened *Protection* and undermined parents' optimism and motivation "*to get up every day"* and subsequently engage with assessment. Examples of this included negatively based language, pass-fail scoring, prognoses and reports highlighting deficits and limited possibilities, such as those used to secure resources.

They just went, "Therefore, he will never, he will never, he will never." I
get the impression that it's still a very common story. I don't know why
they do that. If you just say, "We expect this, but we don't know," that
leaves some room for possibility or anything. Parent #4

Bridging the Gap

This theme, and associated sub-themes, illustrates parents' evolving understanding and feelings about evidence-based assessment. The Gap refers to the different perspectives of the child during the assessment process—the parent's intimate view and connection with their child's interactions and the therapist's analytical interpretation of the child's presentation. Parents recalled struggling initially to make sense of unfamiliar assessment practices—parents were *Unknowing* of what the assessments were, why they were being done, what the findings from assessments meant for them and their child, and the roles of different health professionals.

What therapists ascertain from those assessments is beyond me, you know.
It's completely foreign. Parent #5

Although many parents wanted to know "*as much as possible in black and white*" early on about their child and their future, parents also recounted their simultaneous desire for retaining some ambiguity.

I think if she had have done that test and said, "Oh, that's where he's going
to get to; let's draw the line there", it would have been really, really
disheartening, and really deflating, and really hard to deal with. Parent
#10

Parents reported becoming more familiar with the assessment process and knowing *"what's expected of us"*. Parents' initially *Complied* with therapists' requests for assessment rather

than wanting to be formally assessed. For many parents, assessment remained linked with underlying feelings of disappointment, sadness and frustration. Some parents felt *Resigned* to the assessment process, deeming it necessary despite its perceived limitations. For other parents, the "*scariest*" early assessments were *Reconciled* and eventually appreciated, if perceived to be beneficial.

> *You do get used to some of the expectations, I guess, but, you know, it's generally, with clothes off, just in a nappy. And already, as a parent, you're ticking —no one wants their child naked. Parent #5*

Involvement

Parents described being involved with their child's assessment in a continuum of ways related to being; *Overlooked, Spectators, Intermediaries, Mentees and Mentors*, and *Instigators* of assessment. Often, involvement with assessment needed to be balanced with the *Personal and Practical Costs* of undertaking the assessment.

When *Overlooked,* parents felt disempowered: they recounted not being informed that assessments had taken place; feeling peripheral to conversations between professionals about their child's assessment; and either, not receiving assessment results, or receiving results that were "*mentioned down the track"* or as an "*off-hand remark"*. Parents often felt overwhelmed by the amount and complexity of information, and consequently found it difficult to interpret and relate assessment information to their child, particularly when the terminology and acronyms carried little meaning.

> *I feel superfluous to be honest. ...I'm just the one that dresses and appropriately points and holds and—yeah, I'm just the one—the 'staff member' that knows the baby best, so that is sort of it really. Parent #5*

Parents described being *Spectators* of assessments in two ways. When relegated, parents stood by as observers or kept out of the way; parents responded to therapists' questions but were not able to "*volunteer*" information easily, particularly in clinic environments that were "*scheduled to the minute*". Parents stepped back voluntarily during assessments with trusted practitioners as their child got older. This was an active choice by parents wanting more independent relationships to develop between their child and their therapist.

Parents performed multiple tasks as *Intermediaries* during assessments to enable therapists to gather information efficiently and accurately. Parents recounted "*interpreting in both directions*" between their child and the therapist and assisting with physical handling to ensure their child's comfort and safety. Parents recalled their difficulty "*preparing my child*" when insufficient information was provided about the assessment procedure beforehand. As children became older, parents increasingly needed to be able to "*backup and reinforce*" information about assessments with their child and adapt information for different family members and friends. To do this, they needed therapists to "*keep it simple*".

Some parents felt they were *Mentees* to therapists who helped to develop their understanding of assessments, whereas other parents felt more support was needed. As mentees, parents reported needing to "*feel comfortable*" asking questions and "*owning a thirst*" for information to support their child. Parents were also *Mentors to* therapists by providing support to novice practitioners in how to interact with their child and to listen and receive guidance from parents. Mentoring therapists was viewed as important not only for their child, but also to benefit other families. As parents became familiar with individual assessments and how they were used, they reported being less reliant on therapists and more proactive *Instigators* of relevant evidence-based assessment for their child.

Parents described how involvement with assessment-related appointments significantly drew on practical, financial, family and emotional resources, and their time for usual parenting activities. Parents needed access to reliable transport, care for siblings, and flexible work options. Mothers reported their partners were rarely able to attend assessments, leaving them to "*hold information*" and deal with the emotional impacts of assessment alone. Parents also described the burden of assessment on their child. While some assessments were fun and viewed as a "*special time*", others were long and draining (for both child and parent) and sometimes physically uncomfortable.

> *So, trying to get Jess to fully bend her knee and actually measure the angle. She didn't like that so much. I mean, she's very, very tolerant of pain and you know, she's so used to people doing these sorts of things to her, or with? - no, maybe 'to her'. She looked visibly uncomfortable. …. She doesn't hold a grudge even though they just straightened her leg out and I didn't want them to. Parent #2*

Finding Worth

This theme captured what made assessment worthwhile for parents and related to tool *Accessibility; An Eye on Things; New Insights; Making Plans;* and, *Relevant and Helpful.* Worth changed as a parent's *Focus changed* for their child.

Parents recounted variable *Access* to assessments in the early years and that there was "*nothing really helpful*" as their child got older. Parents also reported that priority assessments for younger children (e.g. range of movement) became less important over time, as their child's interests and social opportunities took precedence. Parents expressed concerns that this *Change in Focus* could result in physical deterioration, but this needed

to be reconciled as part of the "*constant juggle*" for parents "*between acceptance and cure*".

> *It probably doesn't quite mean as much, because—you know, the first ten years, we're trying to always get better, get better, get better, what can we get out of him? Whereas, you get to a certain point where you know—not that you accept, "Okay, this is how he is going to be," but recently we have kind of made a call. Parent #9*

High value, particularly in the early years, was placed on feedback from evidence-based assessments about their child's development. Parents described vividly their intense joy and motivation from positive *Insights* gained during assessment and felt reassured when their child' progress was being monitored by therapists who kept *an Eye on Things* and detected issues early.

> *I loved that, I loved to see that he was going to go up [on the Gross Motor Function Measure], even if it was a little bit. Every little bit gives hope to parents, and every little bit is positive. Parent #9*

Assessment was accepted as necessary for *Making Plans* and setting goals although some parents felt goals were "*very limiting*" and preferred to just stay "*open to further improvement*". Goal setting was described as unhelpful and disheartening if unrealistic, not revisited, or when outcomes were unusable in day-to-day settings. Parents understood goals were individualised to their child, however rating goal satisfaction "*was tricky*" as parents contemplated the disparity between how things are and how things could be "*if able to do it all on his own*". Parents questioned the expectation by some therapists for parents to set goals without first having detailed assessment information.

They always ask me, "so what would you like to achieve?" and I don't know. Normal life. How do we, you know normal life? I'm suddenly sweating there and like, I need to set a goal now. Oh, um, ah, I want him to ride a bike? Parent #3

Parents described evidence-based assessment as *(ir)Relevant and (un)Helpful* when showing little or no positive change and no options existed to address the issue: parents didn't "*need to be reminded he's not going anywhere*". The process was *Worth It* when the assessment: had "*a clear purpose*"; was aligned with parents' focus and priorities; was "*agreeable*" to their child and themselves; and led to interventions that the "*family can work with*".

Trust

Experiences of evidence-based assessment were shaped by parents' relationship with therapists. This was articulated as *Trust* related to: *Will it work?; Familiarity*; *Openness*; and being *In Good Hands*. Many parents' viewed assessment as "*for the therapist*" and preferred the assessment process to be the therapists' remit so they could "*be a Mum*". Some parents recounted they "*just did them*" and took therapists "*at their word*", while other parents reported feeling they were "*overstepping*" if they asked therapists for assessment information. Others were surprised the assessment process could be shared thereby giving rise to the sub-theme *Assessment for Whom*? Parents talked about needing to feel confident in the therapeutic relationship and described an initial period of determining *Will It Work?* Trust was difficult to establish when therapists were not able to adapt assessment and therapy approaches to parents' therapy ethos.

> *I was really coming from, "We're going to change." And she was really*
> *coming from, "It's inevitable…We're just going to work around and*
> *support" And I believe she would have created a disability. Parent #4*

Parents emphasised it was easier when the assessment process was familiar—that is, knowing where and what was likely to happen—and therapists helped to reduce "*the anxiety that builds*" for the child. Parents' trust in assessment and the parent-therapist relationship was deeply undermined when therapists did not articulate their thoughts openly and parents' felt *"left out in the dark"* and were *"the last to know"*. Parents sensed therapists' awkwardness and reluctance in "*bringing it up*" and sharing assessment information. While parents acknowledged this information was difficult to hear, parents in this study wanted *Openness* with therapists when discussing assessment information.

> *I just asked her, "Could I get a copy of that [AIMS assessment]?" And*
> *like, you know, it wasn't a secret or anything like that; it wasn't something*
> *that I wasn't allowed to have, but I just felt… It wasn't something that she*
> *was doing with me to then hand over. Parent #10*

Parents talked about their relief when feeling "*in good hands*". Parents equated being *In Good Hands* when: therapists were practically and emotionally competent; therapists had a good understanding of child development, and helped set realistic goals; support and guidance was provided as needed; and when parent and therapist expertise was freely exchanged.

5.2.4 Synthesis

Synthesis of the six themes resulted in the interpretive description—the Steering Wheel for Collaborative Assessment (Figure 1). This schema and metaphor illustrate our understanding of parents' experiences of formal assessment. The Steering Wheel for Collaborative Assessment is characterised by a central hub with four radiating spokes to an outer rim. The hub contains two themes: *Protection* and *Positively Framed*. Most central is *Protection* where parents act, during the assessment process, to protect their child's being, representation and identity, and their own psychological well-being. *Positively Framed* wraps around *Protection* and is connected by a dotted 'porous' line to indicate the potential dynamic influence of assessment on parents' need to protect. We propose the way in which assessment, diagnosis and prognosis is implemented and framed strongly influences parents' need to protect, with enduring impacts on collaboration and capacity building with parents.

The rim contains four themes: *Bridging the Gap*; *Involvement*; *Finding Worth*; and, *Trust*. Themes interact around the rim and individually with the central hub via a series of sub-themes in the wheel segment, connecting the hub to the rim and a generic sub-theme in the spoke sitting clockwise to the segment. The sub-themes in each segment are a continuum, where those closest to the hub describe less empowering and collaborative assessment experiences than those closer to the rim.
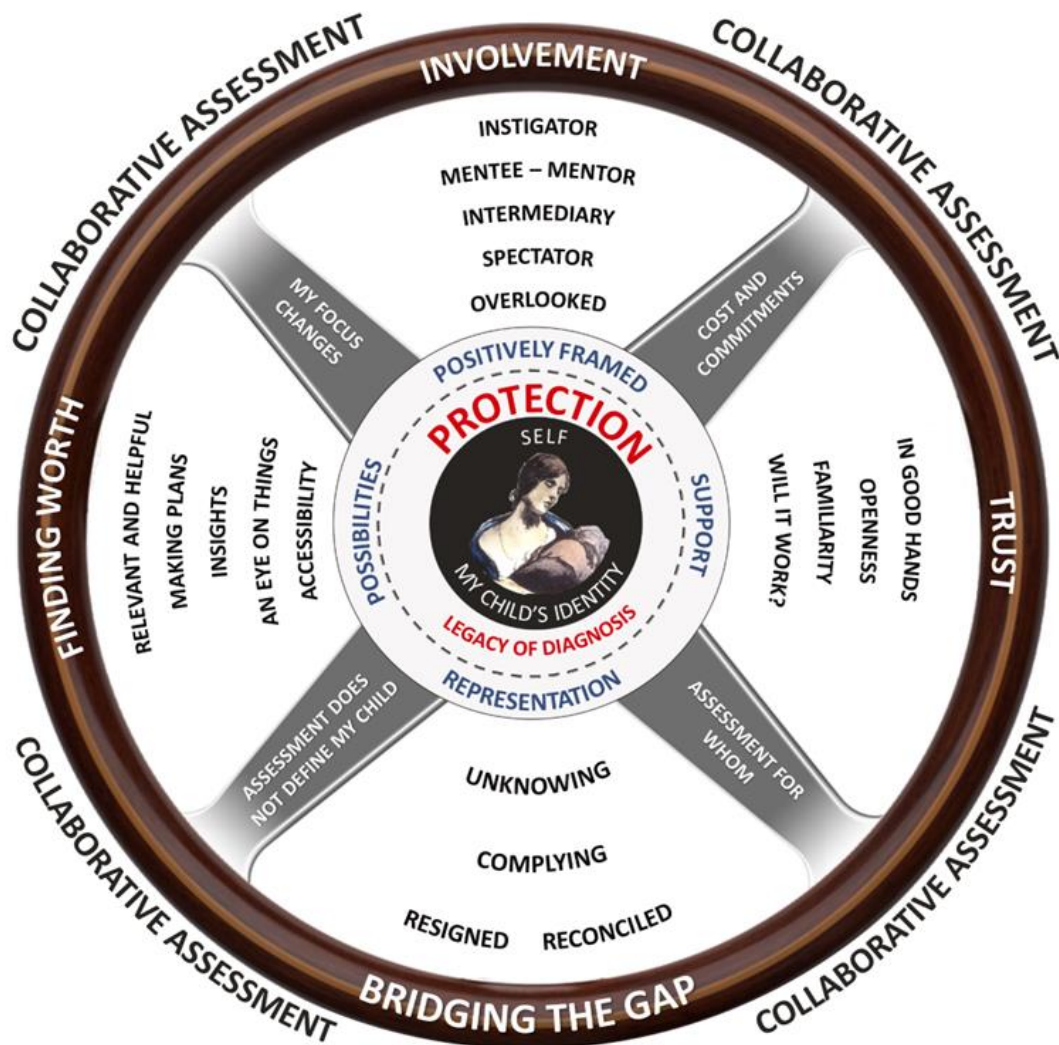
Figure 1. The Steering Wheel for Collaborative Assessment. Themes of Protection and Positively Framed sit in the central hub. The porous line between Protection and Positively Framed denotes the dynamic interaction between formal assessment and parents' need to protect: Protection recedes or expands in response to whether assessment is framed positively or negatively, which consequently impacts on possibilities, support and representation. The central themes in the hub influence the four themes located on the rim of the Steering Wheel: Bridging the Gap; Involvement; Finding Worth; Trust. Sub-themes for each of the rim themes are detailed in the segment connecting the hub to the rim, with more collaborative experiences denoted by closer proximity to the rim. Additional sub-themes, related to those presented in each segment, are presented in the spoke located clockwise to the relevant segment. Central image: Courtesy of People's History Museum (Pryse, c.1919). Central image and figure reprinted with permission (Appendix E1).

A parent's need to protect is magnified by negative assessment interactions, that: focus on deficits; speculate about what may not be possible; threaten child identity and representation; and, revive feelings of grief and erode optimism, making collaboration during assessment difficult. In these instances, the 'gap' between the parent and therapist view of assessment may widen. Parents may avoid evidence-based assessment interactions altogether or feel they can only participate as a resigned spectator of their child's assessment. Consequently, evidence-based assessment may hold little worth and decrease parent motivation to implement associated recommendations.

In contrast, positive assessment interactions that identify and frame assessment and prognostic results in terms of possibilities, and focus on a child's strengths and identity, reduce parents need to protect; thereby enabling parents to be involved in assessment. When framed positively, parents may reconcile the limitations of available assessments, and feel able to choose how, and if they want to be involved according to their circumstances, and priorities. Parents' assessment capacity can develop, enabling parents to instigate assessment that informs therapy relevant to the family's preferences. Assessment in this instance is underpinned by a collaborative therapeutic partnership that builds parent (and therapist) capacity, as represented beyond the rim.

The interactions in the Steering Wheel for Collaborative Assessment can be interpreted through two theoretical frameworks: the capacity-building paradigm (Dunst & Trivette, 2009a) and parent self-efficacy (Bandura, 1977). The capacity-building paradigm (unlike the traditional paradigm of profession-centered and deficit-based models) emphasises family-centred, strengths-based and empowerment models (Dunst & Trivette, 2009a). Therapists act as agents to address parent priorities and concerns in ways that enhance

competence and existing strengths. The themes *Positively Framed* and *Trust* are consistent with the *relational* aspects of capacity-building that involve active listening, empathy and respect, and positive beliefs about strengths and capabilities (Dunst & Trivette, 2009a). Similarly, themes of *Involvement*, *Bridging the Gap* and *Finding Worth* sit consistently with the *participatory* aspects of capacity-building practice that is individualised and responsive to family priorities and actively involves parents in making informed choices about their child's care (Dunst & Trivette, 2009a). Parental self-efficacy is linked positively with parental competence and improved mental health for both parent and child (Dunst & Trivette, 2009b; Jones & Prinz, 2005; Trivette, Dunst, & Hamby, 2010). The Steering Wheel for Collaborative Assessment describes parents' assessment experiences as positive and empowering but also confronting and dis-empowering. These negative assessment experiences may have implications for parent self-efficacy and child well-being, and raises questions about how evidence-based assessment is implemented in practice.

The Steering Wheel for Collaborative Assessment also provides a metaphor for assessment: by illustrating parent experiences of assessment in a Steering Wheel schematic, we align the assessment process with driving, with choices required about whether to and when to drive, where to go, and the route to be taken. Assessment determines the directions for therapy interventions—a process driven traditionally by the therapist or rehabilitation team. Within the paradigm of capacity-building, one can ask who is holding the wheel and how tightly—the therapist, the parent and child, or both?

Assessment is a learning process for parents and their child that may require therapists to loosen their grip on the wheel if wanting parents to come on board. By viewing themselves as a co-driver, therapists might hold the steering wheel initially but then move across into

the passenger seat, so the parent can hold the wheel. The therapist can guide the parent through the assessment options and process, touching the wheel when needed and discussing how assessment information can be used to plan the route and steer towards the parent and child's destination. With time and experience, parents may hold the wheel, requesting more, or less, navigation support as needed. When the decision making terrain becomes complex, parents may prefer their co-driver to hold the wheel. When parents feel the need to protect their child's identity or themselves, they can 'honk the horn'. Co-drivers come and go in children's lives, so within this capacity-building paradigm for assessment, parents and children are better placed to hold the wheel and navigate the next trip with a new co-driver.

Participant member-checking responses

Ten parents provided their impressions on how and whether the themes, sub-themes and descriptors, and Steering Wheel schema, related to their experience of evidence-based assessment. The themes and Steering Wheel schema were received positively by all respondents. All parents reported they could see themselves somewhere in the Steering Wheel, either in all, or in some, themes. Where parents did not relate to a theme personally, parents were able to relate the theme to the experiences of parents they knew. One parent identified she could see where she was on the Steering Wheel and where she had been.

> *I have read the study findings and I can honestly say that it all rings true*
> *- in all areas of the steering wheel. It either captures our own personal*
> *experiences or my feelings toward the process. Nothing in these findings*
> *is awkward or uncomfortable - just very relevant. Parent #11*

Some of the information rings true for us and some doesn't, however the
parts that don't match our scenario, I have definitely heard through
other families telling their stories. Parent #10

Following discussion with participant *Parent #1,* the co-driver metaphor was extended to describe how therapists working collaboratively were able to share the Steering Wheel in reponse to parents' capacity to manage the assessment process at different stages and times in their lives. The original theme of Mentor was also extended to Mentor-Mentee to reflect learning as bi-directional between parents and therapists in relation to the assessment of their child—a concept that was present in the data, but not linked thematically.

5.2.5 Discussion

The findings from this study highlight the practical and emotional complexities posed by evidence-based assessment for some parents and demonstrate that these complexities do not necessarily abate with time. The six themes: *Protection; Positively Framed; Bridging the Gap; Involvement; Finding Worth;* and *Trust* provide insight into how evidence-based assessment tools are experienced by parents. The final interpretive description we developed—the Steering Wheel for Collaborative Assessment—may help guide more family-centred evidence-based assessment. Our findings are consistent with previous reports indicating parental discomfort associated with the use of specific evidence-based assessment tools (Bailes et al., 2018; Rich et al., 2014; Scime et al., 2017). By exploring parents' experiences of evidence-based assessment more broadly, further insights have been gained as to why some parents may find the assessment process for their child persistently challenging. Reasons suggested by this study relate to: the way assessments are

used with parents; how the child is represented through assessment; and, the assessment process itself as a possible trigger of grief symptoms for some parents.

This study highlights an aspect of assessment that has not been widely explored in the paediatric literature (Bjorbaekmo & Engelsrud, 2011; Gibson et al., 2017). The experience of grief for some parents of children with disabilities can be cyclic with grieving symptoms revived by specific triggers that expose a disparity between "what could have been or was imagined" with "what is". The term 'chronic sorrow' (Olshansky, 1962; Phillips, 1991) has been used to describe this recurring and ongoing grieving process for parents where symptoms can be triggered by smaller "loss events" (Hobdell, 2004). Our study suggests that evidence-based assessment may trigger a "loss event" for some parents, with symptoms experienced in the lead up to, during and after an assessment encounter. This may explain in part why some parents may find assessment confronting at any time and feel resigned to, rather than engaged with, evidence-based assessment as a routine part of therapy. If, as suggested, evidence-based assessment has the potential to disturb parent well-being and parent-child interactions, we suggest the use of evidence-based assessment tools is not a benign activity. Using an evidence-based assessment tool should be viewed as an intervention requiring that risks of harm be managed accordingly.

Parents desired and valued specific assessment information in many instances but also acknowledged the emotional challenge of receiving assessment information when progress and prognoses were less than expected or hoped for. Therapists have previously recounted their unease with discussing assessment results (Krohne, 2013; O'Connor et al., 2019) and reported concerns about the potential negative impact on the parent-therapist relationship (Reeder & Morris, 2018). Parents in our study sensed therapists' apprehension and

avoidance with discussing less favourable assessment information. It has been proposed that therapists may relieve themselves of their professional responsibility when discussing potentially challenging information to preserve this parent-professional relationship (Reeder & Morris, 2018). Nonetheless, therapists have a duty of care to provide evidence-based information, so parents can make evidence-informed decisions about their child's care. This raises an important issue for health professionals, parents, service providers, educators and researchers—how to implement evidence-based assessment without inducing parent stress or causing harm?

It was concerning that some parents reported feeling and being excluded from the assessment process for their child. Given the personal and practical cost of assessment, and the pivotal role parents performed as *Intermediaries*, it is crucial parents gain as much as possible from the assessment process. Disempowering parents in the decision making process can lead to parents feeling heightened levels of sole responsibility and increased levels of stress (Dempsey et al., 2009; Knox, 2000). Increasing meaningful participation in the assessment process may reduce parental stress with potential benefits for parent-child interactions and child health literacy. Evidence-based assessment can thus be a therapeutic intervention in itself.

This study revealed a harmful legacy for parent mental health and subsequent engagement with therapy when a child's initial diagnosis and early assessment was negatively framed. Careful thought needs to be given to how the language of assessments, diagnosis and prognosis is framed and its implications for parents and children with lifelong disabilities (Svendby, 2017). This study suggests health practitioners may not always be cognisant of the need to shift language and assessment terminology in ways that fully respect and reflect

the promotion of child development, identity and belonging for all. Skill development in how to implement evidence-based assessment with parents from a strengths-based perspective is needed to ensure parent self-efficacy, parent-child intimacy and optimism are preserved.

Limitations

The design of this study has enabled a thorough exploration of the experiences of a small group of primary carers from rural, regional and metropolitan settings in Australia with children represented across all Gross Motor Function Classification System levels. Recruitment strategies used in this study naturally biased results towards participants willing and able to share their stories. The views expressed are representative of a small number of parents and, as is the case with many qualitative studies, cannot necessarily be generalised beyond this parent group and context. However, the insights provided may be considered more broadly when working with parents of children with childhood onset disabilities and offer initial data on an important area for further enquiry. The clinical expertise within the research team added strength to the interpretive description (Hunt, 2009). Additional data sources may, however, have further enhanced the trustworthiness of the findings.

Implications

The Steering Wheel for Collaborative Assessment provides a potentially useful platform for health professionals, parents, educators, researchers and tool developers to reflect on how formal evidence-based assessment tools are used with families and to support more participatory assessment practices. Therapists and parents might consider: where their experiences of assessment sit in the Steering Wheel; future aspirations and related

assessment choices; the Steering Wheel as a useful starting point for navigating 'difficult' conversations that acknowledges the experience of assessment for parents and *Bridges the Gap*.

The findings also have relevance to student and professional education. Training in the use of evidence-based assessment tools often occurs in de-contextualised learning environments (e.g. university). The primary focus of training is often to achieve competency and reliability with assessment administration and scoring. Limited focus is provided on how to positively frame and involve parents and children in the assessment process. Thus, when implementing new assessments in practice, therapists and students may be unsure how to navigate parent-therapist interactions when implementing and discussing assessment results. Therapists may choose not to implement the assessment or avoid difficult conversations, both of which undermine good practice and can potentially do harm.

Within the research context, evidence-based assessment tools are used to address the research question rather than guide the therapy needs of an individual child and family. As potential study participants, parents weigh up the cost for themselves and their child. Families may volunteer in anticipation of possible benefits for their own child or other children in the future. Research assessment results, however, may not be shared with individual participants and, if provided, may not be scaffolded positively with individualised support. It is not known how evidence-based assessment tools conducted within research impact parents and children and their participation in future research projects.

For tool developers, the findings strongly support involving parents and children in the conceptual stage of development to clarify purpose, ensure acceptability and develop guidelines for collaborative administration. Traditional criteria to assess clinical utility of assessment tools seem insufficient to capture the subjective experience of specific assessment tools for parents and children. A precedent in this direction has been set by the developers of the Challenge assessment tool. Child and caregiver experiences of the Challenge were integrated with family-centred care principles to develop specific guidelines for collaborative assessment when using the tool (Gibson et al., 2017).

Further research to understand the assessment experiences of other parent groups, and importantly, children, is needed. Further exploration of parent-professional assessment interactions and Steering Wheel concepts in practice is warranted to facilitate family-centred evidence-based assessment.

5.2.6 Conclusions

This study has highlighted that parents' experience of evidence-based assessment is not benign. Evidence-based assessment can be experienced positively but, concerningly, can also induce parent feelings of needing to *Protect* their child's identity and own psychological well-being. The parent perspective can be appreciated clinically through the interpretive description of the thematic findings—the Steering Wheel for Collaborative Assessment. Recognition of the central concepts of *Protection* and *Positively Framed* may help *Bridge the Gap* between parent-professional perspectives during assessment. Concepts of *Involvement* and *Finding Worth* highlight ingredients that may support (or undermine) parents' *Trust* and participation and thereby influence collaboration during assessment. While further work is needed, metaphorically, the Steering Wheel allows parents and health

professionals to reflect on why we are assessing, where we are going, who is holding the assessment wheel and if there a willingness to share the driving.

5.2.7 References

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5.3 Chapter Conclusions

This chapter addressed the fourth objective of the thesis: to design and conduct a study to understand parents' experiences of evidence-based assessment for their child with cerebral palsy. Findings from this study suggest evidence-based assessment is a personal process that has 'therapeutic' impacts that are variably experienced by parents of children who have a child with cerebral palsy. Evidence-based assessment can be positive and empowering but also confronting and disempowering at any stage. The interpretive description developed—the Steering Wheel for Collaborative Assessment—proposes therapists involve parents from the start of the evidence-based assessment process in a way that positively represents child identity, emphasises strengths and identifies possibilities. Implications for practitioners, educators and tool developers were discussed.

Chapter 6 Overall discussion and conclusions

6.1 Summary of findings

This thesis examined therapists' assessment practices for children with cerebral palsy from different perspectives to understand what is needed for evidence-based assessment tools to be meaningfully and easily integrated within clinical practice. The published systematic review (Jan 2000 - May 2015) and associated update (June 2015 - May 2019) (Chapter 2) highlighted a dichotomy between therapists' actual practice and recommended best practice when using evidence-based assessment tools for children with cerebral palsy. Analysis of 23 published and available included studies found many validated and non-validated assessments tools were in use, but were used infrequently. The areas of function assessed were commonly limited to gross motor activity. In addition, although a recent study suggests a small increase in the use of the COPM (Anaby et al., 2017), the use of evidence-based assessment tools for children with cerebral palsy remains low. The most frequently used evidence-based assessment tools continue to be focussed on body structure and function and gross motor activity, with assessment tools related to other activity-level concerns—such as, communication, hand use, participation, quality of life and environment, rarely used. It was found that a knowledge-practice gap still existed even when therapists were aware of specific assessment tools and had positive attitudes towards their use and importance.

The second study in this thesis used mixed methods to investigate therapists' evidence-based assessment practices in two community organisations (Chapter 3). Study 2 identified therapists' motivation to use evidence-based assessment tools as a continuum of five

categories*: I don't*, *I can't*, *I try*, *I do*, and *We do*. Motivation to use evidence-based assessment tools was both personal and contextual. The interpretive description generated the Cultural Cone for Evidence-based Assessment, a framework illustrating therapists' use of evidence-based assessment tools as an interaction between influences related to: personal value and satisfaction with assessment; ability to collaborate with families; organisational expectation; personal alignment with research; and time. Organisational expectation, resource and research support, and smaller organisational size were associated positively with evidence-based assessment tool use however; personal belief in the value of evidence-based assessment was necessary if therapists were to make time to use assessment tools. Consistent with the systematic review findings (Chapter 2), levels of assessment tool use overall were low across both organisations except for two gross motor classification tools. However, personal value and satisfaction with using evidence-based assessment tools, uncertainty about how to use the tools with families, and possible impact on the parent-therapist relationship were concerns raised by therapists, suggesting use of evidence-based assessment tools in a clinical context is more complex than simple provision of adequate knowledge, skills and resources. Further exploration of the assessment interactions among parent, therapist and child, from the parent perspective, was identified as an area for further investigation to gain a deeper understanding of the factors influencing therapists' assessment behaviours.

A scoping literature review was conducted to identify existing research on parents' experiences of formal assessment for their children with cerebral palsy (Chapter 4). A small number of studies (n=9) were located, the majority of which explored the subjective experiences of parents in relation to a limited number of specific evidence-based

assessment tools. Parents generally perceived the evidence-based assessment experience as useful in providing more information about their child's abilities and challenges, and helpful with communication, planning and securing therapy resources. Emotionally however, parents found some evidence-based assessment tools more challenging (PEDI, GMFCS) (Haley et al., 1992; Palisano et al., 1997) than others (MACS, COPM) (Eliasson et al., 2006; Law et al., 1990), particularly when their children were more disabled. A lack of explicit processes regarding assessment tool use for both parents and practitioners was also an identified issue (Scime et al., 2017). The varied responses of parents to specific assessment tools suggested exploration of parents' experiences of evidence-based assessment may provide additional insight into factors identified by therapists, such as assessment satisfaction and ability to collaborate with families (Chapter 4). These findings prompted the development of Study 3.

Study 3 (Chapter 5) explored the use of evidence-based assessment tools from the parent perspective. This study identified an emotional burden and practical cost of assessment for many parents that did not diminish with time; in many instances, this was not perceived by parents to be recognised and/or accommodated by therapists. The way in which evidence-based assessment tools were implemented was critical, as this impacted on how parents felt about the assessment process, therapy and health service. When parents were given the opportunity to be practically, cognitively and emotionally involved in a strengths-based assessment process, assessment value, trust and collaboration was able to develop. Limitation-focussed assessment that negatively-framed the child and future possibilities was harmful and disempowering for parents, particularly in the context of diagnosis, prognosis and evaluation. In these instances, parents felt a need to protect their personal

well-being and child's identity. The Steering Wheel for Collaborative Assessment framework that was developed presents, visually and metaphorically, the factors influencing parents' experiences of evidence-based assessment.

The discussion that follows considers the thesis findings in sections that relate to: clinical and historical contexts for practice; family-centred care; the assessment concept; the role and contribution of evidence-based assessment tools; and, findings that can inform knowledge translation. The implications of these findings for practice, educators, and researchers are discussed, and directions for future research considered. In the discussion that follows the term 'Cultural Cone' will be used when referring to the Cultural Cone for Evidence-based Assessment, and the term 'Steering Wheel' used when referring to the Steering Wheel for Collaborative Assessment.

6.2 Discussion of major findings

6.2.1 The clinical context for evidence-based assessment

Within the current paradigm of evidence-based practice there is academic and professional expectation to implement psychometrically robust forms of assessment (Brunton, 2018; Majnemer, 2010; Van Sant, 2015). However, an evidence-based approach to assessment in the field of childhood disability needs to sit comfortably with the practice context of family-centred care. The contrasting intentions of *I don't* and *We do* therapists reported in Study 2 and the low use of assessment tools overall (O'Connor et al., 2016a) suggest a level of discomfort or difficulty for therapists with using evidence-based assessment tools as part of family-centred care. This discomfort poses a dilemma for healthcare professionals, families, service providers, and funders about how and whether evidence-based assessment tools can be used within a framework of family-centred care. While some therapists

overcame this dilemma, further investigation is needed to understand how this balance was managed. Given the unintended, but real, potential for harm from evidence-based assessment tools identified through this research, it is understandable that evidence-based assessment tools may not be adopted easily by therapists, nor endorsed by some provider organisations. The way evidence-based assessment is understood and implemented needs careful consideration at several levels if such tools are to be safely and sustainably adopted within the context of family-centred care. An historical perspective is provided initially to help understand how this dilemma may have arisen in relation to therapists' use of evidence-based assessment tools.

6.2.2 Historical contexts for current practice and evidence-based assessment

Historical differences exist between the philosophical paradigms underlying evidence-based practice and family-centred care. Evidence-based practice was founded on a positivist theoretical tradition where knowledge of childhood disability developed predominantly through quantitative measurement of biomedical impairments of the individual (Shakespeare & Watson, 2015). The early singular focus on the development of impairment level measures reflects this historical perspective of disability. In contrast, family-centred care emerged from the lived experiences of families with disabled children advocating for greater involvement in their child's health-related care (Kuo et al., 2012; MacKean et al., 2005). Family experiences of disempowerment within professionally driven healthcare services for their child with a disability were captured through qualitative emancipatory and interpretivist perspectives (Espe-Sherwindt, 2008; MacKean et al., 2005). This more holistic perspective challenged the prevailing professionally centred medical paradigm to consider the child within the family and society more broadly. The

ICF-CY (WHO, 2007) has been successful in bringing these different perspectives of disability together in a way that acknowledges disability as a biopsychosocial phenomenon: thus, much more than either an impairment or a social construct.

Families feature in both evidence-based practice and family-centred care; however, within evidence-based practice, the role of 'family' is less prominent and at risk of being overlooked as one of four factors informing clinical decisions. This contrasts with family-centred care where 'family' sits centrally, supported by equal partnerships but with parents as ultimate decision-makers (Espe-Sherwindt, 2008). Standardised assessment is complex due to its potential to define and shape individual identity, and its historical legacy and ongoing function in determining access to, and exclusion from, life opportunities (Stobart, 2008). Assessment tools can reflect professional biases, societal norms and assumptions about what is important. Together, these features afford subliminal power to the provider of assessment of which the assessor may or may not be aware (Bjorbaekmo & Engelsrud, 2011; Stobart, 2008). Navigating assessment and decision making across different paradigms with families can be complex in practice (Deville et al., 2015).

6.2.3 Evidence-based assessment in relation to family-centred care

The following sub-sections consider the thesis findings in relation to collaborative principles of family-centred care and the concept of therapist and parent engagement with assessment. Study 3 (Chapter 5) identified that the experience of formalised assessment for parents did not always support desired family-centred care outcomes, such as empowerment, enhanced parent self-efficacy and well-being (Arakelyan, MacIver, Rush, O'Hare, & Forsyth, 2019). Parents' experiences of being overlooked or onlookers of assessment suggest some therapists gather assessment information without involving

parents. Although parents may have attended assessments, they were not actively involved in decisions about how assessment occurred for them and their child. The therapist determined what information was collected and how, and once interpreted, directed interventions that (possibly) aligned with families' priorities.

Therapists in Study 2 indicated their concerns about how to use recommended evidence-based assessment tools with parents, an experience echoed by parents in Study 3. Therapists reported tool complexity and parent understanding as barriers; a finding that reflects prior research. For example, in a Canadian study, 60% (n=52) of speech pathologists stated they did not use the CFCS in collaboration with parents of children who had speech, language and communication delays (Cunningham, Rosenbaum, & Hidecker, 2016). Reasons cited for completing the tool alone were lack of awareness they should involve parents, time, and parents not understanding the tool. Of the assessment tools audited in Study 2, the GMFCS was recorded in over 80% of children's case files; however, only 53% of physiotherapists reported using the GMFCS consistently to inform decision making (O'Connor, Kerr, Shields, & Imms, 2016b). Two studies included in the updated systematic review (Chapter 2; Deville et al., 2015; Anaby et al., 2017) also support the finding that therapists use the GMFCS more often independently than with parents. A recent parent survey (n=303) found 55% of parents were unaware of their child's GMFCS level (Bailes et al., 2018). Although awareness of the GMFCS among therapists is widespread and documented frequently in case files it cannot be assumed the GMFCS and other tools are being used with families (O'Connor et al., 2019; Obembe et al., 2018). Using evidence-based assessment tools without involving parents, or deciding not to use them, does not support the participatory

principle of collaboration that is advocated and unique to family-centred care (An & Palisano, 2014).

The consequences for parents, children and therapists of not being involved with the assessment process are far-reaching. There is a risk that parents experience evidence-based assessment negatively, leaving parents feeling protective, disempowered and disengaged from therapy. Parent mental health, well-being and self-efficacy beliefs are linked to parenting behaviours (Krech & Johnston, 1992) that impact both participation of children with disabilities (Arakelyan et al., 2019) and child health outcomes (Kuhlthau et al., 2011). When evaluating therapists' use of evidence-based assessment tools, it seems necessary to focus not only on the extent of use of evidence-based assessment tools, but more importantly in relation to family-centred care, how they are used with families.

The question of 'how to' – collaborative evidence-based assessment

Although family-centred care is well established conceptually (King & Chiarello, 2014; Trivette, Dunst, & Hamby, 2010), the types of interactions and behaviours that promote collaborative partnerships have not yet been clearly articulated (Espe-Sherwindt, 2008; Kuo et al., 2012; MacKean et al., 2005). It has been reported that relational behaviours (empathy, respect and active listening) are more readily adopted by health professionals than participatory behaviours that foster equitable decision making, parent capabilities and engagement (Dunst & Trivette, 2008; Espe-Sherwindt, 2008). Collaboration has been considered largely in relation to the processes of goal setting and intervention (Brewer et al., 2014; Pritchard-Wiart & Phelan, 2018) but not specifically in relation to assessment. A four-step collaborative intervention process proposed by An and Palisano (2014) involves: discussing and rating mutually agreed goals; planning individualised therapy interventions

within family routines; implementation and reflection to build family capability; and, joint evaluation of individualised outcomes using the COPM. Evidence-based assessment tools, beyond the COPM measure, are not considered as part of this collaborative intervention process, although parent-therapist collaborative behaviours such as therapist's giving and seeking information, encouraging interactions with parents, and direct interactions with the parent rather than the child can be observed.

In contrast to An and Palisano (2014), Bartlett et al. (2018) have considered a range of evidence-based assessment tools as part of a collaborative decision making approach. Function-specific centile curves for subgroups of children with cerebral palsy are used to routinely monitor a child's progress over time. This detailed information potentially provides the individualised information that parents repeatedly call for when setting realistic goals, intervention planning and making healthcare decisions (King, Schwellnus, Servais, & Baldwin, 2019; McNeilly, Macdonald, & Kelly, 2017; Wiart, Ray, Darrah, & Magill-Evans, 2010). As Bartlett et al. (2018, p. 872) state; "engaging families in the assessment and monitoring process is a right, and builds partnerships, meaning and family capacity to support child development." The elements required at the parent-therapist interface that are needed to make the assessment process collaborative are, however, still not evident.

Engagement in the evidence-based assessment process.
Exploring evidence-based assessment from the perspective of engagement may help with understanding the ongoing low-level use of evidence-based assessment tools by therapists that was identified in the systematic review (Chapter 2) and mixed methods study (Chapter 3). In a recent study of barriers to implementing routine hip surveillance, parent

engagement was reported by health professionals as both the most frequent barrier to implementation and the *key* to success (Willoughby, Toovey, Hodgson, Graham, & Reddihough, 2019). Engagement is central to collaboration and the therapeutic process (D'Arrigo, Copley, Poulsen, & Ziviani, 2019) and understood as a process and state (Bright, Kayes, Worrall, & McPherson, 2015). It is characterised by components of affect (the emotion or feeling about what you are doing), cognition (thinking and beliefs about what you are doing), and behaviour (what you are doing) (Bright et al., 2015; D'Arrigo et al., 2019; King, Currie, & Petersen, 2014). In the context of assessment, engagement can be related to: feelings linked with the assessment process (emotion); perceived value and worth (thinking); and, active contribution to assessment drawn from a sense of self-efficacy (doing). The three components of engagement—feeling, doing, and thinking—will now be considered in the context of the Cultural Cone and Steering Wheel.

Affective and behavioural engagement

In this thesis, two themes, *Involvement* and *Understanding*, shared by the Cultural Cone and Steering Wheel frameworks, can be related to the affective (the feeling) and behavioural (the doing) components of engagement. Differences existed, however, in how involvement and understanding were conceived between therapists and parents. For therapists, involvement and understanding related mainly to the practical aspects of using assessments (behavioural engagement), such as tool complexity, space and equipment, and explaining results to parents. In contrast, parents placed greater emphasis on personal and interpersonal aspects of the assessment process (affective engagement); for example, how they were included, how they felt when their child was being assessed, feelings of support

and being understood, the emotional cost, and feelings linked with not understanding what was being assessed.

Cognitive engagement

A third theme common to both frameworks—*Value* and *Worth*—related to the cognitive (the thinking) component of engagement. Both parents and therapists considered the value and worth of evidence-based assessments in terms of relevance and usefulness. Value and worth were weighed up against the practical logistics (for therapists and parents) and emotional cost (for parents) of gathering assessment information objectively. Cognitive engagement required evidence-based assessment to be meaningful. For example, evidence-based assessment needed to change in line with changing parental priorities that emerged as their child developed: assessments focussed only on getting physically "*better at things*" became less meaningful when parents needed to identify ways to "*adapt to things*" so their child could effectively and efficiently participate.

Cognitive engagement with assessment can be considered also in relation to the research paradigms supporting evidence-based practice and family-centred care outlined in section 6.2.2. The epistemological foundations of research paradigms inform how we see and understand the world and may inform therapists' and parents' worldviews in relation to assessment. For therapists, the highly contrasting assessment intentions of *I don't* compared with *I do* and *We do* therapists in the Cultural Cone suggests that differences in personal practice paradigms could play a role in therapists' cognitive engagement with evidence-based approaches to assessment. Like research paradigms, practice paradigms orientate a therapist to relevant knowledge and intervention priorities (Lindquist, Engardt, Garnham, Poland, & Richardson, 2006; Shaw et al., 2010). While Study 2 did not investigate

therapists' epistemological alignment specifically, it could be hypothesised that *I don't* therapists identify more strongly with an interpretivist worldview. Using evidence-based assessment tools may challenge therapists' core practice values that are aligned with a holistic approach. Non-use of evidence-based assessment tools could be justified from a worldview that believes meaningful outcomes of therapy practice cannot be deconstructed sufficiently to make them measurable. In this instance, assessment knowledge derives from one's own experience, and the expertise of parents and colleagues may be valued more highly. In contrast, *I do* and *We do* therapists may identify more strongly with a positivist practice paradigm that embraces quantitatively derived sources of knowledge, making it easier to engage cognitively with and use evidence-based assessment tools.

Parents may also have preferred paradigms that influence cognitive engagement with assessment. Parents' paradigm preferences were evident through the *Will it work?* sub-theme of *Trust* in the Steering Wheel. Parents described their difficulty engaging when they held different views from the therapist on how to approach therapy for their child. Recognition of the potentially varied paradigm affiliations, and the perceived value of evidence-based information, may be an area for consideration in relation to parents' and therapists' engagement with evidence-based assessment.

The existence of *We do* therapists in Study 2 suggests practice paradigms can prevail within organisations. When an evidence-based practice paradigm is shared by the therapist and the organisation, it may be cognitively easier to use evidence-based assessment tools. Within Organisation B in Study 2, there was an expectation that evidence-based assessment tools be used by therapists. The presence of the '*it's just what you do*' attitude among *We do* therapists suggests the organisation shaped the thinking and practice paradigm of therapists

it employed. Conversely, the small size of Organisation B means it is also feasible that the practice-paradigm affiliations of individual therapists may have shaped the organisation.

I can't and *I try* therapists may be trying to manage a mismatch in practice paradigms in relation to their organisation, colleagues or parents, or even the wider health and disability sector. Therapists may value and be willing to include quantifiable forms of assessment, but this willingness may not be shared by colleagues, parents or indeed their employing organisation. When both the therapist and organisation rigidly align themselves within a single paradigm, it may be difficult to effectively respond to a family's preferred approach to assessment. Families in this instance may disengage with the assessment process and service provider. *I do* therapists may reflect the expert practitioner who recognises the complex nature of practice and is able to draw on and integrate knowledge from multiple paradigms. When the therapist is supported by an organisation that shares this multiple paradigm view, the *I do* therapist may be more able to engage with, and respond to, individual family assessment preferences and needs, making it possible to adopt (or move towards) a 'shall we?' approach to assessment. By recognising their own and the individual ways parents engage with assessment—affectively, behaviourally and cognitively— therapists may find interactions with parents easier and more meaningful when implementing evidence-based assessment.

Therapists who can recognise and accommodate parent orientations may be able to narrow *The Gap* identified by parents in the Steering Wheel. Features of the critical skills therapists need for engagement with the evidence-based assessment process may include: acknowledging how parents feel about formalised assessment (the emotion); involving parents in decisions about whether or not to assess, what is meaningful to assess and how

best to assess (the thinking); and, involving parents in assessment (the doing). If evidence-based assessment is planned and conducted in ways that are emotionally and physically safe, assessment can build parent sense of self-efficacy and capacity that can contribute to their child's health and ongoing health literacy (Anaby & Pozniak, 2019; Arakelyan et al., 2019; Phoenix, Jack, Rosenbaum, & Missiuna, 2019). This does not imply that responsibility for assessment is shifted onto parents and children, but rather that parents and children are involved in assessment as a formative process. Assessment can then be part of, rather than separate from, the therapeutic process.

The expectations of the organisation were perceived as both a potential facilitator and barrier for therapists to use evidence-based assessments. Positive expectations were communicated through encouragement, support systems, processes and opportunities to implement robust assessments. Study 3, however, identified assessment use needs to be promoted within a framework of parent empowerment. For empowerment to occur organisations and management need to be familiar with collaborative and participatory assessment processes. Organisational expectations for use can be conveyed through family-centered policies and processes, that enables assessment to be flexible, individualised and parent led. Therapists require training in how to identify and use assessments in ways that are empowering for families with ongoing organisational support to acquire and maintain assessment skills. Recognition by both organisations and therapists of the additional time needed to individualise assessment to achieve quality assessment outcomes is also needed.

6.2.4 The impact of evidence-based assessment tools on practice

Discussion so far has focussed on the assessment interactions between therapists and parents. The following sub-sections consider the assessment tool in relation to two concepts: 1) clinical utility and 2) the role of assessment tools in changing child and family outcomes. Therapists in Study 2 talked about the specific assessment tools as influencing the parent-therapist assessment interaction and their use. The Cultural Cone theme of *Satisfaction* related to practical challenges of space, time, authenticity and the complexity of some assessment tools for therapists and parents. The finding from the updated systematic review and Studies 2 and 3—that therapists might not share assessment findings with parents—may, in part, reflect therapists concerns about the deficit-based tone of some evidence-based assessment tools. Parents in Study 3 found the administration format, content, scoring criteria, presentation of results and terminology of some evidence-based assessment tools to be deficit-focussed and confronting in terms of the portrayal of their child's disability (e.g. scores of able-unable; 0,1,2,3; pass-fail; typical-atypical). The need for assessment tools and the assessment process to be framed positively from a strengths-based perspective was briefly touched on by therapists, but it was clearly articulated by parents.

 Clinical utility and acceptability

The impact of an assessment tool on clinical practice relates to the multi-dimensional concept of clinical utility, which is understood as a judgement about the usefulness, benefits, and drawbacks of an assessment tool in a clinical situation (Law et al., 1999; Smart, 2006). Typically, assessment tools are recommended based on the strength of their psychometric properties (Janssens et al., 2016; Mäenpää, Autti-Rämö, Varho, Forsten, &

Haataja, 2016; Pavão et al., 2017; Schiariti et al., 2018). Clinical utility is reported less often and, when reported, most often relates to practical criteria impacting the therapist, such as time, cost, training requirements, and portability (Law et al., 1999; Smart, 2006; Tam, Teachman, & Wright, 2008). The central Steering Wheel theme of *Protection* (Study 3) suggests the clinical utility dimension of parent acceptability, a dimension that is rarely evaluated, may need consideration (Smart, 2006). While not formally defined, acceptability is described by Smart (2006) as a judgement of the overall benefits of using the assessment tool against its practical, ethical and emotional burden. Acceptability has some overlap with an assessment tool's face validity, as when the tool "appears to test what it purports to test" (p. 182) it has greater perceived relevance and meaning to users (Laver Fawcett, 2013). Aspects of acceptability have been explored qualitatively in only a small number of evidence-based assessment tools for children with cerebral palsy (Bailes et al., 2018; Gibson et al., 2017; Öhrvall & Eliasson, 2010; Rich et al., 2014; Scime et al., 2017). Little guidance is available to therapists to indicate how acceptable an assessment tool is likely to be to parents and children with disabilities. Design features such as self-report and individualised measures are described as more 'acceptable' to parents and therapists (Wright & Majnemer, 2014). While many factors contribute to selecting an appropriate assessment tool, the research in this thesis suggests 'acceptability' from the parent perspective may also be an important characteristic to consider alongside practical utility and psychometric strength, if evidence-based assessment tools are to be adopted by therapists and parents in practice.

Contribution of evidence-based assessment to improving outcomes

Research shows improved outcomes for children with cerebral palsy when evidence-based assessment tools are used for early diagnostic and surveillance purposes (Dunst & Trivette, 2008; Hägglund et al., 2014; Spittle, Orton, Anderson, Boyd, & Doyle, 2012). What is less apparent is how evidence-based assessment tools impact child and family outcomes when used to measure outcomes of therapy intervention. The benefit and contribution of using evidence-based assessments tools to clinical judgements, decision making and subsequent function, participation and quality of life for children with cerebral palsy has not yet been established (Russell et al., 2010).

In fields other than cerebral palsy, patient-reported outcomes measures were found to have a greater impact on discussion and problem identification than on subsequent decision making, management and health outcomes (Greenhalgh, 2009; Porter et al., 2016). In this thesis, neither therapists nor parents specifically reported valuing the contribution of evidence-based assessment tools as measures of the outcome of therapy interventions. Audited assessment data from children's case files in Study 2 did not identify whether assessment tools were being used as therapy outcome measures, but anecdotally, this did not seem to be the case. Therapists showed concern about the impact of using evidence-based assessment tools on the parent-therapist relationship. For parents, measuring no change in their child's function could be distressing (‘*I don't need to know he's not going anywhere'*), a finding consistent with other fields of practice (Gonçalves Bradley et al., 2015).

A pertinent question for the clinical setting is whether parents and therapists have a desire to know if a single dimension of a child's status has objectively changed as result of a

therapy intervention. If an evaluative assessment shows no meaningful change in one assessed domain, yet positive changes are perceived in other areas, does this mean therapy should cease, change direction, or be deemed non-beneficial? Was the goal unrealistic or were expected levels of achievement poorly predicted when setting levels for goal attainment? Have parents not put in enough effort? Will therapy continue to be funded? These are difficult questions to ask when time and emotion have been invested into therapy, and other aspects of the therapeutic relationship are valued. Instead it may be cognitively more 'comfortable' to not evaluate isolated outcomes, as some aspects of the therapy interaction that parents or therapists feel are important may not be measurable.

If therapists don't experience direct benefits to the parent-therapist relationship or observe a meaningful contribution to the child or family from using evidence-based assessment tools, then uptake is unlikely to be sustained (Jaeger Pedersen & Kaae Kristensen, 2016). This poses a significant challenge to implementation of evidence-based assessment tools, as currently available tools are perceived as being of low and/or indirect benefit by many therapists. If evidence-based assessment tools can be used in ways that directly benefit the parent-therapist relationship, then sustained use may be more likely. This thesis proposes an approach to evidence-based assessment tool use that may directly benefit the parent-therapist relationship and reduce the risk of harm.

The discussion so far has considered the findings from this body of work in relation to family-centre care and engagement, and the impact and outcomes of using evidence-based assessment tools. The knowledge generated from the Steering Wheel provided a new lens through which to view the Cultural Cone. Therapists' use of evidence-based assessment tools is understood as a social process, and as an intervention impacting families, and

indirectly, therapists and the therapeutic relationship. Attention has shifted from 'how much' to 'how to' use evidence-based assessment tools with families. Findings from this thesis add to an identified gap in understanding of therapists' use of evidence-based assessment tools (Bailes et al., 2018; Deville et al., 2015; Oeffinger, 2016). Through this deeper understanding, areas for practice change have emerged that can inform knowledge translation interventions aiming to meaningfully embed evidence-based assessment tools within the context of family-centred care.

6.2.5 Informing the future: knowledge translation

This final section of the discussion considers the thesis findings in relation to knowledge translation. Knowledge translation strategies are more likely to be successful when there is detailed understanding of: the behaviour that needs to be changed; its context; and, the change in behaviour that is needed (Atkins et al., 2017; Grimshaw, Eccles, Lavis, Hill, & Squires, 2012; Johnston & Dixon, 2008; Michie, van Stralen, & West, 2011). Exploration of parents' and therapists' experiences and use of evidence-based assessment tools using mixed methods and qualitative methods in this thesis has provided an in-depth understanding of factors influencing therapists' assessment behaviours, particularly related to the parent-therapist interaction. The findings from this thesis as represented in the Cultural Cone and Steering Wheel, suggests therapists' use of evidence-based assessment tools is a consequence of interacting factors related to: therapist's personal and professional beliefs about the value of evidence-based assessment; communication skills and knowledge of how to use evidence-based assessment tools collaboratively in ways that are safe for parents and the parent-therapist relationship; assessment tool characteristics and purpose; and, organisation-specific supports, processes, expectations and setting. These findings

propose a shift in practice that aligns evidence-based assessment more strongly with participatory and relational aspects of family-centred care. The changes proposed involve:

1) Shifting decision making so that parents (and children) are involved at the front-end of the assessment process rather than the tail-end; that is, meaningful and informed decisions are made with parents from the beginning of the first clinical encounter, and subsequently, about the assessment process—if, when, how, and what evidence-based assessment tools are used and why, and their potential risk;

2) Developing therapist skills in creating emotionally safe assessment environments where evidence-based assessment tools and language are used in ways to promote individual child and family strengths, child identity and parent self-efficacy;

3) Selection and use of evidence-based assessment tools that are acceptable, relevant and meaningful to parents', therapists' and children's priorities;

4) Securing organisational endorsement, through supports, resources and processes that foster the use of evidence-based assessment tools in ways consistent with family-centred care; and,

5) Acting in response to the knowledge that evidence-based assessment is a complex intervention that can negatively or positively impact families and the therapeutic relationship.

It is hypothesised that successful knowledge translation of these proposed changes to practice would: 1) improve therapist knowledge of the potential impacts for parents of formal assessment; 2) increase therapist and parent engagement with evidence-based assessment; 3) positively impact parent-therapist relationship; 4) increase parent satisfaction with evidence-based assessment; 5) increase therapist intention or actual use of acceptable evidence-based assessment tools; 6) increase parent assessment self-efficacy; and 7) impact decision making and therapy intervention choices. Of ultimate interest is whether a collaborative evidence-based assessment approach leads to improvements in child and family outcomes. An implementation science approach is recommended to support changes in clinical practice and to understand which strategies are effective in achieve lasting behavioural change (Scott 2012; Morris 2019; Michie 2012).

6.3 Significance of the research findings

6.3.1 Implications for practice

The findings from this thesis provide a way forward for therapists, families and service providers to implement evidence-based assessment tools within a family-centred approach. The research advocates re-orientating practice in three ways: firstly, moving from a therapist-led decision of *Will I* or *Won't I* use evidence-based assessment tools, to a family-led decision predicated upon discussion about *Shall we* and *How can we* meaningfully include objective strengths-based measurement as part of an evidence-based assessment process; secondly, to consider and acknowledge differences in how parents and therapists may engage with assessment (emotional, behavioural, cognitive) and adjust for these differences during the assessment process; and thirdly, to reframe assessment and diagnosis positively from a strengths-based perspective. This family-centred approach to assessment

proposes that therapists ask, listen, discuss, acknowledge and respect a parents' decision about what assessment information is desired, and when, and how they would like to, or are able to, be involved. Together parents and therapists decide whether, how, and for what purpose, an evidence-based assessment tool will be used, and when. Although these recommendations have arisen from exploring assessment practices among therapists and families specifically in relation to children with cerebral palsy, this work may have wider application to assessment practices with families and children with other childhood conditions.

Adopting a family-centred evidence-based approach to assessment requires support from management, organisations and insurance providers. System-wide changes are needed that promote and enable participation, as opposed to a deficits-based model. Organisational endorsement of processes, resources and training to support therapists to deliver collaborative, strengths-based assessment will be required. Specifically, this would include communication skills, critical selection of tools, practical skills in administering evidence-based assessment tools collaboratively, and strengths-based reporting, while simultaneously building family capacity and understanding of collaborative evidence-based assessment.

Nonetheless, it is recognised that using strengths-based assessment tools is not straight forward for therapists or families. Health systems and many funding streams take a deficit-based approach to determining access to and the need for resources, and the need for and effect of therapy interventions, thus creating discordance between the parent perspective and the system requirement. Such system-wide demands ultimately exert pressure on services to adopt a deficit-driven approach and therapists to be trained in ways that can

meet this demand. The expectation for evidence-based assessment tools to meet the varied demands of all stakeholders (funders, organisations, parents and healthcare professionals), is challenging and further emphasises the need for clarity about the need for and purpose of formalised assessment, and its careful implementation.

The frameworks, Cultural Cone for Evidence-based Assessment and the Steering Wheel for Collaborative Assessment provide two distinct, but related frameworks that can help therapists and parents discuss evidence-based assessment within a family-centred framework. Each schema provides a visual representation and accompanying language that describes a collective experience of evidence-based assessment from the perspectives of therapists and parents. The Cultural Cone can be used by therapists, teams and managers to reflect on contextual influences impacting motivation (*I don't, I can't, I try, I do, We do*), and interpersonal influences impacting collaborative practice in relation to the Steering Wheel. The Steering Wheel can be used by parents and with therapists to aid discussion about collaborative evidence-based assessment, feelings, priorities and preferences for involvement.

The Steering Wheel enables therapists to simultaneously reflect on their role and the assessment experience for parents, particularly when parents feel the need to protect or are not able to engage with an evidence-based assessment process. Therapists might self-reflect on the ways they engage with families, by asking questions such as: *What am I doing in my practice that fosters participation in assessment decisions and implementation? Does my interaction or the language I use disempower, or define a parent's role, or their child's evolving identity, during the assessment process?* and, *What characteristics of the assessment tool make it difficult to involve parents and children positively and without*

causing harm, and how can I manage this? This work can be used clinically to raise health professional awareness of the ongoing emotional (and practical) burden assessment can pose for parents and the implications for practice.

The central theme of the Steering Wheel—*Protection of child identity and self*—underscores the abiding impact of assessment and has significance for the implementation of early detection programmes for cerebral palsy. A significant correlation between parent mental health and how diagnosis is delivered is shown in the work of others (Baird, McConachie, & Scrutton, 2000; Ballantyne et al., 2019; Dagenais et al., 2006). A recent survey found 46% of parents (n=463) felt their child with cerebral palsy exceeded the prognostic expectations provided by their physician irrespective of the age of diagnosis (Guttmann, Flibotte, & DeMauro, 2018). The Steering Wheel and these studies raise questions about prediction, how diagnostic and prognostic information is provided, potential influences on early parent-child interactions and expectations, engagement with services, and negative perceptions of disability more broadly. Early detection programmes talk about infants being 'at risk of cerebral palsy'. Risk is universally associated with less positive or bad events and outcomes such as a fall, a car accident or dying early, and not with having a positive healthy life. A 'breaking bad news' protocol (SPIKES - A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer), inherited from the adult oncology field, has been recommended for 'disclosing' diagnostic and prognostic information for families of children with cerebral palsy (Baile et al., 2000; Novak et al., 2017). This 'disclosing bad news' approach suggests the clinician is revealing a morally-compromised secret, rather than engaging in an open, judgement-free collaboration and discussion about a child's development and identity.

The key recommendations for practice arising from this thesis are: (1) to re-orientate assessment practices towards a family-centred, evidence-based approach; (2) to intervene at an organisation and health system level to acknowledge funding and service drivers are not aligned with parental wishes with respect to assessment; (3) identify appropriate training of therapists in *how to* involve families in assessment decision making; (4) implement the Cultural Cone and Steering Wheel to reflect on practice and frame future communication and practice; and (5) consider how the diagnostic experience and parent mental health may be positively impacted by reframing diagnosis using a strengths-based approach rather than a 'disclosing bad news' protocol.

6.3.2 Implications for educators

This work poses specific challenges as to how to teach a collaborative and individualised assessment approach to new practitioners. In paediatric practice, complex thinking is needed to effectively respond to the changing needs of children and their families (King et al., 2007). This thesis proposes therapists *share the driving* with parents while managing the inherent emotional and practical complexities of assessment. Skills and expertise are needed to be able to tailor interactions with families in ways that facilitate and support decision making (King et al., 2008). Typically, novice practitioners prefer to focus on acquiring concrete skills and techniques, which may mean subtle cues in therapist-parent interactions are missed (Hodgetts & Park, 2017). Further work is now warranted to identify the most important ingredients of collaborative evidence-based assessment that can help inform development of curricula. The Steering Wheel schema may provide a useful teaching tool to articulate what collaborative evidence-based assessment is and isn't. Furthermore, it could be used to develop practical strategies to ensure parents and children

are supported during assessment while students and novice practitioners learn how to use new assessment tools. Learning how to implement assessment collaboratively needs to be integrated alongside learning how to administer evidence-based assessment tools, using instructional, experiential and observational learning opportunities across different environments (King et al., 2008).

Instructional courses for evidence-based assessment tools would benefit from dedicated time spent orientating therapists to collaborative assessment principles, discussion of strategies to address tool-specific acceptability risks and strengths, and how to involve parents and children through the assessment process. Collaborative, critical analysis of videoed assessments viewed through the Steering Wheel lens may be beneficial.

6.3.3 Implications for researchers

The significance of this work for researchers is considered in relation to the design and appraisal of new assessment tools and how evidence-based assessment tools are used in research with children and parents. This thesis suggests that evidence-based assessment tools with low acceptability should be used with great care. The importance of consumer stakeholder (parents, children with cerebral palsy and health professionals) involvement in the conceptual design and ongoing development of new assessment tools is highlighted as a consequence of this work. Involvement of stakeholders would promote development of more appropriate and responsive tools for sub-groups of children with cerebral palsy. Stakeholder consideration of issues impacting acceptability, clinical utility and meaningful content during design may improve assessment satisfaction and reduce the risk of harm. Even though this co-production approach may take more researcher coordination, time and expense, it is more likely to result in a tool that is fit for purpose. Encouraging examples of

assessment tools that have been designed collaboratively with stakeholders have emerged recently, such as, Focus on the Outcomes of Communication Under Six (Thomas-Stonell, Oddson, Robertson, Walker, & Rosenbaum, 2015); The Challenge (Wilson et al., 2011); Transition-Q (Klassen et al., 2015); and the Measure of Early Vision Use (Deramore Denver, Froude, Rosenbaum, & Imms, 2019). The expectation is that these are likely to be more inherently acceptable to all users. Recent appraisals of assessment tools in systematic reviews (Clark, Locke, Hill, Wells, & Bialocerkowski, 2017; Pavão et al., 2017), core data sets (Mäenpää et al., 2016) and common data elements (Schiariti et al., 2018), use quality appraisal systems that focus only on psychometric domains of validity, reliability and responsiveness (for example, Consensus-based Standards for the selection of health Measurement Instruments (Mokkink et al., 2010)). Dimensions of clinical utility, particularly acceptability, are rarely evaluated (Gibson et al., 2017; Smart, 2006). Extending the current appraisal systems to include clinical utility and acceptability may help encourage uptake of 'good' tools in practice.

Children with cerebral palsy and other disabilities are formally assessed many times throughout childhood, and more frequently than their typically developing peers (Bjorbaekmo & Engelsrud, 2011), to the point of assessment fatigue (K. Pozniak, personal communication, December 14, 2018). One source of additional assessment arises from participation in research, particularly when there is a relatively small pool of families for recruitment. The finding that evidence-based assessment carries potential risks to parent well-being, and unclear risks to the child's emerging sense of self is pertinent to researchers. While many factors contribute to a parent's (and child's) decision to enrol in a research study, it is not known how parents and children experience assessment in the research

context, and how this influences parents' future participation in research. Active patient and public involvement in research is now an expectation and requirement in developing and conducting research (Boote, Baird, & Beecroft, 2010). Research partnerships provide the opportunity for consumer knowledge and insights to be integrated into the planning and implementation of research. The findings of the Steering Wheel suggest consumer involvement in decisions related to data collection is important and would benefit research implementation. Consumer involvement in the selection of acceptable tools as outcome measures, and in how they are used, would ensure potential negative and positive impacts are considered. Information materials for participants can then be developed that address potential pragmatic and emotional impacts of assessments, thereby ensuring fully informed consent and potential benefits to participant retention.

6.4 Directions for future research

This thesis proposes that the use of evidence-based assessment tools with families is a unique form of intervention. The knowledge generated about therapists' use of evidence-based assessment tools has begun to articulate a collaborative evidence-based assessment approach and proposes changes as to how evidence-based assessment tools could be implemented within family-centred care. Further areas of research to extend the exploratory work of this thesis include: collaborative evidence-based assessment; individual practitioner characteristics; tool acceptability; and, development of a knowledge translation strategy. Each of these will be briefly described below.

6.4.1 Collaborative evidence-based assessment practice

The understanding developed through exploring therapists' and parents' experiences and use of evidence-based assessment tools has generated the concept of collaborative

evidence-based assessment. This concept opens a new line of investigation into how to meaningfully implement standardised measurement in ways that meet the needs of parents, health professionals and funders. Work is needed to further develop the working definition and theoretical basis for collaborative evidence-based assessment that considers the notions of self-efficacy (Bandura, 1977), capacity building (Dunst & Trivette, 2009a) and engagement (King et al., 2017). Further research to validate the concept of 'collaborative evidence-based assessment' is needed with parents, health professionals and academics. Descriptors linked to specific behaviours embodied in the themes identified through this thesis—such as, positively framed, involvement, understanding, value and worth—need to be developed, coded, scaled and pilot-tested with parents and health professionals.

6.4.2 Understanding practitioner characteristics

Further development of the Cultural Cone as a framework for understanding therapists' motivation to use evidence-based assessment tools is needed. While not yet validated, the motivation categories in the Cultural Cone (*I don't, I can't, I try, I do, We do*) may reflect therapists' personal practice traits, identity and worldviews. Individual practitioner characteristics are a poorly understood determinant of knowledge translation (Korner-Bitensky, Menon-Nair, Thomas, Boutin, & Arafah, 2008). Exploration of therapists' practice beliefs, attitudes and identity in relation to evidence-based assessment practices could be conducted using both qualitative and quantitative methods, for example, by using the Practice Style Questionnaire (Green, Gorenflo, & Wyszewianski, 2002). This questionnaire looks at clinicians' response styles to new information, considering the value of experience versus evidence, the importance of workload versus patient satisfaction, and willingness to diverge from group norms. Further investigation of the Cultural Cone

categories would add to our understanding of the contribution of individual therapist factors to the uptake of a collaborative approach to evidence-based assessment during knowledge translation.

6.4.3 Acceptability of the assessment tool

Further research investigating the concept and definition of clinical utility and its application to current and future evidence-based assessment tools would be beneficial. Overall clinical utility is considered in the Outcome Measures Rating Form (Law, 2004), with clinical utility, availability, reliability and validity of an assessment tool considered together and rated as *excellent, average* or *poor*. In this rating form, specific clinical utility items include clarity of instructions, format, physical invasiveness, active participation of the client, and items related to administration, such as time, training and equipment. The current research suggests further criteria may be needed to capture the concept of tool acceptability to all who are involved in the assessment.

In contrast, Smart (2006) proposes four components of clinical utility—appropriate, accessible, practicable, and acceptable; however, these sub-components have not been fully defined making them difficult to quantify and evaluate. 'Acceptability' will likely change as expectations of practice change; however intuitively, the uptake of an assessment is easier and more likely to be sustained in practice if the tool is 'acceptable' to parents, therapists and children. Development of a consensus definition of clinical utility and its sub-components with descriptors would be helpful. Future lines of enquiry would be to investigate both what makes an evidence-based assessment more, or less, acceptable to parents, therapists and children, and the impact of a tool's acceptability on the assessment interaction. Critical discourse analysis of existing assessment tools in relation to family-

centred care principles may contribute to development of the concept of acceptability within paediatric neurodisability.

Consumer, clinician and researcher involvement in the development of appraisal criteria for the clinical utility sub-components would enable evidence-based assessment tools to be rated. For example, 'acceptability' criteria might be related to strengths-based language, scoring, graphics, item choices for the child, accessibility, novelty, and collaborative guidelines. Research in this area may help reinforce the notion that the assessment tool and how it is used is an important component of therapy intervention.

6.4.4 A knowledge translation strategy for the Cultural Cone and Steering Wheel

This thesis contributes foundational knowledge towards understanding therapists' low-level use of evidence-based assessment tools for children with cerebral palsy, which ultimately may be helpful in closing the research-practice gap between tool development and use in clinical practice. Areas for practice change have been identified that may assist therapists to integrate evidence-based assessment tools more easily and meaningfully within family-centred care. Therapists' evidence-based assessment practices can be further understood through the Cultural Cone and Steering Wheel. Areas of change focus on individual practitioner beliefs, parent-therapist interactions, assessment tool management, and organisational culture. These findings provide the necessary research base to support and develop a knowledge translation programme that aims to change how (and indirectly how much) therapists use evidence-based assessment tools for children who have cerebral palsy, and potentially other childhood conditions.

The Knowledge to Action (Graham et al., 2006) framework is proposed for planning and guiding translation of the Steering Wheel and Cultural Cone concepts and their recommendations for practice. The Cultural Cone and Steering Wheel provide the Knowledge product; that is, they provide clinically useful information and language to describe and understand why using evidence-based assessment tools may be difficult in practice and may be used to identify areas for potential change in practice to foster family-centred, evidence-based assessment.

An important next phase in the Action Cycle is the adaptation of this knowledge to local contexts. Work would be undertaken with interested service providers—therapists, families and management—to determine in what ways the Cultural Cone and Steering Wheel are relevant to their setting and circumstances using face-to-face workshops. Areas for change and barriers can be identified using the Cultural Cone and Steering Wheel and strategies developed that are tailored to the context, for example: focussed attention on collaboration skills; access to acceptable tools; practitioner motivation; and, organisational processes. Translation strategies can be developed and delivered, such as: demonstration videos; parent discussion, critical appraisal of assessment tools and vignettes of practice, mentoring; checklists; and video feedback. The Steering Wheel checklist in Appendix F4 (Imms, Jarvis, Khetani, & O'Connor, 2019) provides a practical example of how the Steering Wheel could be applied in different phases of the assessment process. Initial thought is given to why the assessment tool is being used and the anticipated outcome for stakeholders. Consideration of the assessment process through the parent lens is undertaken in the knowledge that assessment is a complex intervention that can potentially have negative impacts. Exemplar collaborative actions in the checklist are grouped according to

each Steering Wheel segment: Deciding together (*Bridging the Gap);* Planning together (*Involvement);* Doing together (*Developing Trust);* and Discussing together (*Finding Worth).* The vignette, Jack-in-the-Box, in Appendix F6 draws on the voices of parents from Study 3 (O'Connor et al., 2019). The story in the vignette can be used with the Steering Wheel to reflect on health professionals' assessment practices in different contexts. Therapists and managers can consider ways to promote positive involvement of parents and children in an evidence-based assessment process that positively impacts parent-therapist relationships and engagement with therapy.

To evaluate the impact of the translation project, measures would be needed to monitor and evaluate targeted areas for change. Data would be gathered at baseline, during implementation and on completion, to determine the extent of therapist and parent involvement in evidence-based assessment and the framing of communication and practice. Areas of evaluation to consider would relate to involvement in assessment decision making, tool use, attitudes to evidence-based assessment, parent satisfaction, self-efficacy and perceptions of safety. Evaluation of the impact of changes would provide important information about the validity of the Cultural Cone and Steering Wheel, the concept of collaborative evidence-based assessment and potential efficacy. Of importance, ultimately, is to determine whether greater use of collaborative evidence-based assessment (and diagnosis) leads to improvements in child and family outcomes and mental health trajectories for parents of children with a disability.

6.5 Strengths and limitations

The key strength of this thesis lies in the integration of a variety of research methods and the range of stakeholder perspectives investigated. For example, findings from the diverse

sample of healthcare professionals in two different organisations in the mixed methods study (Chapter 3), the qualitative study of parents' perspectives (Chapter 5), and the robust systematic review (Chapter 2) have been wholly integrated in this thesis. The combined use of qualitative, quantitative and systematic review research methods made it possible to generate new insights into the personal, social and organisation-specific processes underpinning evidence-based assessment practice.

A robust and novel systematic review was conducted that highlighted the need for further in-depth investigation into the use of assessment tools. The generalisability of the original review findings was limited by the small number of articles and limited geographical settings (O'Connor et al., 2016a). However, the updated review strengthened the original review, and reinforced the findings overall, there by validating the need for the investigations in this thesis.

A systematic approach to the mixed methods study (Chapter 3) ensured quantitative and qualitative methods were adhered to and study validity was maximised. More than one data source was collected to determine the extent of assessment tools use (self-report and case file audit) in order to reduce the known potential for self-report bias. This enabled differences in use between organisations to be interpreted and validated. Documented use of assessment tools in the case file audit was lower than self-reported use in one organisation but not the other. The ability to triangulate data added to the robustness of Study 2. A limitation of this study was in the description of focus group participants. Full descriptions could not be provided to ensure confidentiality of participants from the small organisation. This limits the extent to which the interpreted focus group findings can be transferred beyond those working in community settings in the Australian context.

A comprehensive approach to data collection and analysis and the integration of findings with member checking contributed to the trustworthiness and rigor of the qualitative study (Chapter 5). Authenticity was enhanced through use of face-to-face interviews conducted in familiar settings with open-ended questions, thereby promoting in-depth exploration and a rich data set. Although a heterogeneous group of participants was sought, assessment experiences will likely be influenced by the socio-cultural context. Therefore, findings from this thesis provide a starting point for exploring formalised assessment in other settings.

The complementary use of different research methods in this thesis has enabled knowledge generation with relevance to 'real-world' clinical practice and policy. Assessment practice has been considered in this thesis within social and medical models and the experiences of families. Implications for policy are raised by this thesis about how to identify the need for and effect of therapy as healthcare demands and disability service provision and funding change. Different values are attributed to assessment by organisations, funders, parents and healthcare professionals. Difficult policy decisions arise in knowing what needs to be assessed, how they will be assessed, for whom, and by whom.

Finally, a strength of this thesis lies in its notable contribution to theory via the Cultural Cone for Evidence-based Assessment and the Steering Wheel for Collaborative Assessment, frameworks that have the potential to inform behaviour change. The two frameworks can be used by therapists to reflect on and plan future practice, by organisations to consider processes and policies that support family-centred evidence-based care, and by educators in the training of students and staff.

6.6 Conclusions

This thesis examined allied health practitioners use of evidence-based assessment tools for children with cerebral palsy. Detailed exploration of evidence-based assessment practices was undertaken from the perspective of therapists working in different organisational settings and parents of children with cerebral palsy. The knowledge generated contributes to understanding about what is needed for effective translation of assessment tools into practice.

The main conclusions are:

- Allied health practitioners use evidence-based assessment tools with children with cerebral palsy infrequently;

- Current assessment practices may not be consistent with accepted best practice frameworks of family-centred care or evidence-based practice in childhood disability;

- Parents are not often involved in the process of evidence-based assessment for their child. In some settings parents are overlooked by healthcare professionals and may need to protect their child and self;

- Using evidence-based assessment tools with parents and children who have a disability can impact families and the therapeutic relationship negatively or positively;

- Assessment must be meaningful and 'worth it' for both therapists and parents;

- This thesis proposes that involvement of families in the assessment process is essential if evidence-based assessment tools are to become embedded in therapy practice. This means:

- o Recognising the different ways therapist and parents engage with assessment and adjusting for these differences during the assessment process;

- o Positively framing diagnostic and assessment processes;

- o Shifting decision making so that parents (and children) are involved at the start of the assessment process about *whether*, *how*, *when* and *for what purpose*, an evidence-based assessment tool is used, and its potential risks.

- Involvement of parents and children in the development of future assessment tools and revisions to existing tools is highly recommended;

- Focus on *the way* evidence-based assessment is implemented is recommended for practice, policy and education;

- The Cultural Cone for evidence-based assessment and the Steering Wheel for collaborative assessment may potentially be useful knowledge products to promote collaborative evidence-based assessment;

- Future investigation is needed to establish whether collaborative evidence-based assessment improves child and parent outcomes;

These findings provide evidence for re-considering best practice in assessment for childhood disability. It is proposed that best practice is not related to *how often* evidence-based assessment tools are used, but rather *how to* use evidence-based assessment tools. If evidence-based tools are to become embedded within therapy, they must be securely wrapped in practices consistent with participatory and relational family-centred care principles, with the end-goal of enhanced child identity and parent self-efficacy.

Fundamental to this approach is the deliberate involvement from the start of parents and children with disabilities in decisions about how evidence-based assessment is implemented. As Crais et al. (2006, p. 365) relate: "*family-centred care is not to identify perfect practice but to recognise the family role in helping decide those practices*". If approached in this way there is no dilemma for healthcare professionals, families, service providers, and funders about how and whether evidence-based assessment is, or is not, compatible with family-centred care. Findings from this research programme have contributed to current understanding about why assessment tools are not easily adopted within routine clinical practice by therapists for children with cerebral palsy.

This research specifically:

1. Contributes foundational knowledge towards understanding therapists' low-level use of evidence-based assessment tools for children with cerebral palsy that may help close the knowledge-practice gap for assessment tools developed for children with disabilities and their use in clinical practice;

2. Recommends knowledge translation strategies that align evidence-based assessment with family-centred care;

3. Generates the concept of collaborative evidence-based assessment and proposes areas for practice change that may assist therapists and families to meaningfully integrate evidence-based assessment tools within family-centred care;

4. Contributes theoretical frameworks (Steering Wheel and Cultural Cone) and language to discuss the complexity of formal assessment in clinical practice, organisations and policy, education and research;

5. Instigates a new line of enquiry into how to navigate family-professional relationships and the conditions needed to 'share the wheel' in an environment of enhanced consumer selection of services.

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APPENDICES

Appendix A: Supporting information for Study 1

A1: Appendix S1: example database search history

Cinahl search via EBSCO February 2014

Nº	Query
S1	(MH "Clinical Assessment Tools") OR (MH "Occupational Therapy Assessment") OR (MH "Speech and Language Assessment") OR (MH "Outcome Assessment") OR (MH "Physical Therapy Assessment") OR (MH "Disability Evaluation") OR (MH "Functional Assessment")
S2	TI (assess* OR measure* OR outcome* OR outcome N1 measure* OR health N1 outcome* OR classification* OR assessment N1 tool* OR surve* OR evidence based N1 assessment*) OR AB (assess* OR measure* OR outcome* OR outcome N1 measure* OR health N1 outcome* OR classification* OR assessment N1 tool* OR surve* OR evidence based N1 assessment*)
S3	S1 OR S2
S4	(MH "Allied Health Personnel") OR (MH "Occupational Therapists") OR (MH "Physical Therapists") OR (MH "Speech-Language Pathologists")
S5	TI (physiotherapist* OR physical therapist* OR occupational therapist* OR speech therapist* OR speech pathologist* OR speech-language pathologist* OR allied health practi* OR allied health profession* OR rehabilitation OR practice*) AB (physiotherapist* OR physical therapist* OR occupational therapist* OR speech therapist* OR speech pathologist* OR speech-language pathologist* OR allied health practi* OR allied health profession* OR rehabilitation OR practice*)
S6	S4 OR S5
S7	(MH "Cerebral Palsy")
S8	TI (cerebral palsy OR child* N1 disab* OR diplegia OR spastic N1 quadriplegia OR hemiplegia OR GMFCS) AB (cerebral palsy OR child* N1 disab* OR diplegia OR spastic N1 quadriplegia OR hemiplegia OR GMFCS)
S9	S7 OR S8
S10	(MH "Child") OR (MH "Infant") OR (MH "Infant, Newborn") OR (MH "Child, Preschool") OR (MH "Child, Disabled") OR (MH "Adolescence")
S11	TI (child* OR infant* OR p?ediatric* OR youth OR adolescen*) OR AB (child* OR infant* OR p?ediatric* OR youth OR adolescen*)
S12	S10 OR S11
S13	S3 AND S6
S14	S3 AND S6 AND S9
S15	S12 AND S14
S16	S12 AND S14 Limiters - Published Date: 20000101-20141231

A2: Appendix S2: tool abbreviations for Tables III and IV.

ABILHAND, ABILHAND-Kids Questionnaire (Arnoud et al 2004);
ACE, Assessment of Comprehension and Expression (Adams et al. 2001);
AHA, Assisting Hand Assessment (Krumlinde-Sundholm & Eliasson 2003);
AIMS, Alberta Infant Motor Scale (Piper & Darrah 1994);
APP-R, Analysis of Phonological Processes - revised (APP-R) (Williams-Hodson 1986);
Ashworth, Ashworth Scale (Ashworth 1964);
ASBI, Analysis of Sensory Behaviour Inventory (Morton & Wolford 1994);
Batelle DI, Battelle Developmental Inventory-II (Riverside Publishing Co 2005);
BFMF, Bimanual Fine Motor Function (Beckung 2002);
Boehm-TBC, Boehm Test of Basic Concepts (Kiernan & Reid (1987);
BOTMP, Bruininks-Oseretsky Test of Motor Proficiency (Bruininks 1978);
BPVS, British Picture Vocabulary Scales (Dunn et al 2009);
Bracken-BCS, Bracken Basic Concept Scale (Bracken 2006);
Bus Story, Renfrew Bus Story (Renfrew 2010);
CAPE, Children's Assessment of Participation and Enjoyment (King et al 2004);
CCC, Children's Communication Checklist-2 (Bishop 2003b);
CDI, McArthur communicative development inventories (Fenson et al 2000);
CELF, Evaluation of Language Fundamentals (Seme et al 2004);
Chailey Levels of Activity, (Green et al 1995);
CLEAR, Phonology Screening Assessment (Keeling & Keeling 2006);
COPM, Canadian occupational performance measure (Law et al 1990);
CP QOL-Child, Cerebral Palsy Quality of Life for Children (Waters et al 2007);
DEAP, Evaluation of Articulation and Phonology (Dodd et al 2006);
De Gangi-Burke, De Gangi- Burke Test of Sensory Integration (Berk & DeGangi-Berk, 1983);
DLS, Derbyshire Language Scheme (Knowles & Masidlover 1982);
Draw-a-Man Test, Goodenough-Harris Drawing Test (Harris 1963);
DVPT, Developmental Test of Visual Perception-2 (Hammill 1993);
EOWPVT, Expressive One-word Picture Vocabulary Test (Gardner 1979);
ERRNI, Expression Reception and Recall of Narrative Instrument (Bishop 2004);
Erhardt, Erhardt Developmental Prehension Test (Pollock et al 1991);
ETCH, Evaluation Tool of Children's Handwriting (Koziatek & Powell 2002);
EVT, Expressive Vocabulary Test (Williams 2007);
FACES Pain Scale, (Bieri et al 1990);
Frenchay, Frenchay Dysarthria Assessment (Enderby and Palmer 2007);
GAS, Goal Attainment Scale (King et al 1999);
GMFCS, Gross Motor Function Classification System (Palisano et al 1997);
GMFM-66, Gross Motor Function Measure-66 item (Russell et al 2002);
GMFM-88, Gross Motor Function Measure-88 item (Russell et al 1989);
G-FTA, Goldman-Fristoe Test of Articulation (Goldman and Fristoe 2000);
Goniometry, (Gajdosik and Bohannon1987);
HHD, Hand Held Dynamometry (Mathiowetz 1986);
LAC-G, Lifestyle Assessment Questionnaire-generic (Jessen et al 2003);
m-ABC, Movement Assessment Battery for Children (Henderson and Sugden 1992);
MACS, Manual Abilities Classification System (Eliasson et al 2006);

MAI, Movement Assessment of Infants (Chandler 1980);

MAP, Assessment for Preschoolers (Miller 1988);

mAshworth, modified Ashworth Scale (Bohannon and Smith 1987);

MMT, Manual Muscle Testing (Kendall 1993);

MUUL, Melbourne Assessment of Unilateral Upper Limb Function (Randall et al 1999);

MVPT, Motor Free Visual Perception Test (Colarusso & Hammill 1995);

NRS, Numerical rating scale (McCaffery et al 1989);

Nuffield-DPAT, Nuffield Dyspraxia Programme Assessment Tool (Nuffield Hearing & Speech Centre-Miracle Factory 2004)

Paediatric Pain Profile, (Hunt et al 2004);

PDMS, Peabody Developmental Motor Scales (Folio & Fewell, 2000);

PEDI, Pediatric Evaluation of Disabilities Inventory (Haley et al 1992);

PedsQL, Pediatric QOL Questionnaire CP Module (Varni et al 2006);

PEM-CY, Participation and Environment Measure for Children and Youth (Coster et al 2011);

PLS, Preschool Language Scale (Zimmerman & Castilleja 2005);

PPVT, Peabody Picture Vocabulary Test (Peabody Picture Vocabulary Test 4th ed 2007);

PVCS, Preverbal Communication Scales (Kiernan & Reid 1987);

QUEST, Quality of Upper Extremity Skills Test (eMatteo et al 1993);

RAPT, Action Picture Test (Renfrew & Hancox 1997);

Reynell-DLS, Reynell Developmental Language Scales (Edwards et al. 2011);

ROM, Range of Motion;

Rossetti, Rossetti Infant-toddler Language scale (Rossetti 2006);

Sensory Profile, (Dunn 1999);

SFA, School Function Assessment (Coster et al 1999);

SHUEE, Shriners Hospital Upper Extremity Evaluation (Davids et al 2006);

SPAT, Structured Photographic Articulation Test (Dawson &Tattersall 2001);

SPELT, Structured Photographic Expressive Language Test (Dawson et al 2003);

SSI, Stuttering Severity Instrument (Riley 1972);

STAP, South Tyneside Assessment of Phonology (Armstrong & Ainley 2012a);

STASS, South Tyneside Assessment of Syntactic Structures (Armstrong & Ainley 2012b);

Talbot Battery, (Talbot 1993);

Tardieu, Tardieu Scale (Tardieu et al 1954);

TACL, Test of Auditory Comprehension of Language (Carrow-Woolfolk 1999);

TOLD, Test of Language Development (Newcomer & Hammill 2008);

TROG, Test of Reception of Grammar (Bishop 2003a);

TUDS, Timed Up and Down Stairs (Zaino, Marchese & Westcott 2004);

TVMS, Test of Visual Motor Skills (Gardner 1992);

TVPS, Test of Visual Perceptual Skills (Gardner 1982);

VAPS, Voice assessment protocols (Pindzola 1987);

VAS, Visual Analogue Scale (Huskisson 1974);

VMI, Developmental Test of Visual-Motor Integration (Beery & Buktenika 1997);

Wee FIM, Functional Independence Measure for Children (Msall et al 1994);

30s walk test, (Knutson 1999);

A3: Journal commentary Study 1 (Permission to reproduce obtained)

Use of standardized outcome measures should be common place in the clinical care of children with cerebral palsy: why isn't it?

DONNA OEFFINGER

Shriners Hospitals for Children, Lexington, KY, USA.

This commentary is on the original article by O'Connor et al. To view this paper visit http:/dx.doi.org/10.1111/dmcn.12973.

Monitoring outcomes is important to the healthcare industry because it provides an efficient and objective mecha-nism for improving care for individual patients. Over the past two decades, phrases such as 'evidence-based practice' and 'outcome assessments' have become commonplace in the medical community. Today there continues to be an increasing focus on outcome assessments and documentation of clinical outcomes within clinical practice. Clinical outcomes include measurable changes in a patient's health or quality of life that result from the healthcare provider's care, services, interventions, and education. By collecting data through standardized assessment tools that include patient-reported outcomes and functional outcomes, one can objectively document current state, demonstrate changes over time, and support clinical judgments.

The availability and psychometric properties of outcome assessments used for individuals with cerebral palsy (CP) have been assessed in many studies. Many robust tools exist to objectively assess individuals with CP. The use of standardized assessments to assess function and document changes has become routine and expected within the CP research arena. However, incorporation of these assessments into clinical practice seems to be limited. To date, little research has documented the extent to which outcome assessments are used by medical professionals in routine clinical practices. The systematic review by O'Connor et al.[1] provides a useful summary of current literature on the clinical use of assessment tools by allied health practitioners for individuals with CP. The review highlights that published work on this topic is currently limited, and points out the inconsistency in tool selection and frequency of use within their sample.

Based on the limited body of work available to review, O'Connor et al.'s article left me wondering whether this is truly representative of what is being done in clinical settings. It is not the case at my institution, nor at the many with which we collaborate. The reviewed studies included data from different countries and various types of medical systems: what impact does geographical location or the type of medical system have on the clinical use of outcome assessments?

While it might be argued that this article does not provide definitive information about the use of assessment tools in clinical settings for individuals with CP, and the generalizability of the information may be limited, the conclusions reached by the authors are pertinent for healthcare providers. The authors should be commended on their investigation of this topic, and for drawing attention to the lack of clinical utilization of assessment tools. Readers should recognize that there are limitations to the work, but the message about the importance of integrating assessment tools into clinical practice should be heard.

Healthcare providers acknowledge the importance and benefits of using outcome assessments in clinical treatment, yet they haven't been incorporated into practice. What factors prevent clinicians from integrating outcome assessments into their practice? What will it take to increase the use of outcome assessments, and make them commonplace in the treatment of CP? O'Connor et al. touch on these questions, but further research is needed. Many of the existing tools are only available on paper, and are not easily entered into electronic medical records, which encumbers data collection, data retrieval and the tracking of changes over time. These limitations need to be addressed by developers of tools and electronic medical records.

Processes that help to standardize the selection, administration, and use of outcome instruments would be advantageous to clinicians. Time to conduct these assessments needs to be recognized as valuable and reimbursable. Future research into the use of evidence-based assessments in clinical practice is warranted, and should assess the limitations or barriers. As O'Connor et al. state, 'Optimizing health and quality of life outcomes for children with cerebral palsy is an aspiration shared by families, clinicians and researchers. The use of robust assessment tools in allied health practice is an essential step towards achieving this'.

REFERENCE

1. O'Connor B, Kerr C, Shields N, Imms C. A systematic review of evidence-based assessment practices by allied health practitioners for children with cerebral palsy. *Dev Med Child Neurol* 2015; doi: 10.1111/dmcn.12973.

Oeffinger, D. (2016). Use of standardized outcome measures should be common place in the clinical care of children with cerebral palsy: why isn't it? *Developmental Medicine and Child Neurology, 58*(4), 321. doi:10.1111/dmcn.13031

Appendix B: Supporting information for Study 2

B1: Ethics approval for Study 2 – Australian Catholic University

ACU
AUSTRALIAN CATHOLIC UNIVERSITY

Human Research Ethics Committee
Committee Approval Form

Principal Investigator/Supervisor: Christine Imms   Melbourne Campus

Co-Investigators: Melbourne Campus

Student Researcher: Melbourne Campus

Ethics approval has been granted for the following project:
The best service at the best time: improving allied health professionals research implementation behaviours for children with cerebral palsy

for the period: 5/3/2013-31/12/2013

Human Research Ethics Committee (HREC) Register Number: 2012 309V

Special Condition/s of Approval
Prior to commencement of your research, the following permissions are required to be submitted to the ACU HREC:

The following standard conditions as stipulated in the *National Statement on Ethical Conduct in Research Involving Humans* (2007) apply:

(i)   that Principal Investigators / Supervisors provide, on the form supplied by the Human Research Ethics Committee, annual reports on matters such as:
- security of records
- compliance with approved consent procedures and documentation
- compliance with special conditions, and

(ii)   that researchers report to the HREC immediately any matter that might affect the ethical acceptability of the protocol, such as:
- proposed changes to the protocol
- unforeseen circumstances or events
- adverse effects on participants

The HREC will conduct an audit each year of all projects deemed to be of more than low risk. There will also be random audits of a sample of projects considered to be of negligible risk and low risk on all campuses each year.

Within one month of the conclusion of the project, researchers are required to complete a *Final Report Form* and submit it to the local Research Services Officer.

If the project continues for more than one year, researchers are required to complete an *Annual Progress Report Form* and submit it to the local Research Services Officer within one month of the anniversary date of the ethics approval.

Signed: ……………………………………….   Date: ……….06/03/2013………….
          (Research Services Officer, Melbourne Campus)

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B2: Updated ethics approval for Study 2

system and notify the sender. You must not disclose, copy or rely on any part of this correspondence if you are not the intended recipient.

-----Original Message-----
From: Kylie Pashley [mailto:Kylie.Pashley@acu.edu.au]
Sent: Monday, 30 September 2013 3:08 PM
To: Christine Imms
Cc: Kylie Pashley
Subject: 2012 209V Modification

Dear Christine,

Ethics Register Number : 2012 309V
Project Title : The best service at the best time: Improving allied health professionals research implementation behaviours for children with cerebral palsy.
End Date : 31/12/2013

Thank you for submitting the request to modify form for the above project.

The Chair of the Human Research Ethics Committee has approved the following
modification(s):
1. New researchers - Dr Claire Kerr, Ms Mahek Dudhwala, Mrs Bridget O'Connor.
2. Removal of Dr Michael Coory.
3. Amendment to recruitment process for children at Novita site. Minor modificaiton to the particpatn information sheets, consent form and recruitment information poster.
4. Revision of allied health professional partiicpant information sheet for research partner Cerebral Palsy Alliance.
5. HREC approval required from Cerebral Palsy Allicnace ethics Committee.
Please provide approval to HREC once received.
6. Amendment to information leaflet and consent form for therapy manager focus groups.

We wish you well in this ongoing research project.

Kind regards,
Kylie Pashley

Ethics Officer | Research Services
Office of the Deputy Vice Chancellor (Research) Australian Catholic University PO Box 456, Virginia, QLD, 4014
T: 07 3623 7429 F: 07 3623 7328

B3: Letters of agreement – Organisation A and B

yoralla
you can

To Australian Catholic University

Human Research Ethics Committee

14th November 2012

Re: implementation of the following study at Yooralla

The best service at the best time: Improving allied health professionals' research implementation behaviours for children with cerebral palsy.

Principal investigators:

Professor Christine Imms

Associate Professor Iona Novak

Professor Dinah Reddihough

Professor Kerr Graham

Associate Professor Nora Shields

Associate Professor Michael Coory

Associate investigators:

Dr Angela Crettenden

Dr Elspeth Froude

Mr Ashley Creighton

Ms Sarah Foley

Dr Adrienne Harvey

Ms Hayley Smithers-Sheedy

Ms Petra Karlsson

Yooralla consents to the conduct of this project within the organisation pending ethical clearance from the Australian Catholic University. We have reviewed the project protocol and understand that the study involves recruitment of both employees and clients of the organisation to the study.

Yours sincerely,
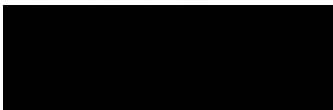
Meredith Fordyce

Group Manager,
Yooralla Children's Services

Kids+
the
KIDS PLUS FOUNDATION

Kids Plus Foundation
163 Myers St
Geelong
VIC 3220

13 November 2012

To Australian Catholic University
Human Research Ethics Committee
250 Victoria Parade
Fitzroy VIC 3065

Re: implementation of the following study at Kids Plus Foundation

The best service at the best time: Improving allied health professionals' research implementation behaviours for children with cerebral palsy.

Principal investigators:
        Professor Christine Imms
        Associate Professor Iona Novak
        Professor Dinah Reddihough
        Professor Kerr Graham
        Associate Professor Nora Shields
        Associate Professor Michael Coory
Associate investigators:
        Dr Angela Crettenden
        Dr Elspeth Froude
        Mr Ashley Creighton
        Ms Sarah Foley
        Dr Adrienne Harvey
        Ms Hayley Smithers-Sheedy
        Ms Petra Karlsson

Kids Plus Foundation consents to the conduct of this project within the organisation pending ethical clearance from the Australian Catholic University.

We have reviewed the project protocol and understand that the study involves recruitment of both employees and clients of the organisation to the study.

Yours sincerely.
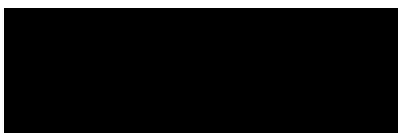
Sarah Olliff
Executive Officer
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B4: Allied health practitioner information letters – Organisation A and B

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W: www.acu.edu.au

PARTICIPANT INFORMATION LETTER (Allied Health Professionals)

PROJECT TITLE:

Cerebral Palsy Check-Up: Providing the best service at the best time

PRINCIPAL INVESTIGATOR: Professor Christine Imms

Dear Allied Health Professional,

You are invited to take part in the research project described below.

What is the project about?

The "CP Check Up" research project will investigate how therapists who work at Yooralla can be supported to find the most effective treatments for children (and young people) with cerebral palsy. The project will also examine whether regular assessments contribute to improved knowledge of the needs of children (and young people) with cerebral palsy and lead to better services.

Who is undertaking the project?

This project is being conducted by the Australian Catholic University, research partners from the Murdoch Childrens Research Institute and La Trobe University and key providers of services to children and young people with cerebral palsy across Australia. These service providers include the Cerebral Palsy Alliance in New South Wales, Kids Plus and Yooralla in Victoria, St Giles in Tasmania and Novita Children's Services in South Australia. The project is being funded by the National Health and Medical Research Council (NHMRC), along with cash and/or in-kind contributions from each of the partner organisations.

What will I be asked to do?

The project is focused on supporting therapists in their work with children with cerebral palsy. The project will start in April 2013 and will finish at the end of 2015. If you agree to take part in the project you will:

1) Complete two questionnaires at four time points (at baseline, 6, 12 and 24 months). These questionnaires will take approximately 40 minutes to complete at each time point.

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2) Review the customised e-evidence library of synthesised and critiqued cerebral palsy research evidence that you can use to support your clinical decision making. The amount of time for this task is at the discretion of the clinician.

3) Take part in 1 to 3 education days per year for the duration of the project.

4) Undertake routine data collection about children with cerebral palsy on your caseload who are aged 3 to 18 years using the Cerebral Palsy Check-up web-based tool. The tool is implemented each 6 months for children under the age of 6 years, and after an initial 6 month follow up, annually for those over 6 years. The time commitment for this will vary depending on your caseload but it is anticipated that it will take up to 1.5 hours per child each 6 months, although it is likely that the tool includes some measures that are already routinely completed.

5) (Optional). Take part in up to four focus groups (baseline, 6, 12, and 24 months). Each focus group will take approximately one hour. The focus groups will be audio-taped and transcribed. A pseudonym will be given to each participant at the time of transcription and participants will have the opportunity to review a summary of the focus group information.

Yooralla is a partner organisation for the CP Check-Up study and endorses the use of your time as required, if you choose to participate.

Parents of the children with cerebral palsy who meet the inclusion criteria for the study and who receive treatment by participating therapists will also be asked to give consent to take part in the study. With their consent, data from the CP Check Up will be shared with the researchers.

Each included organisation will identify one or more knowledge brokers who will work with the allied health professionals in the study to support them in using the study tools and with the researchers to assist in the implementation of the study at each site.

What are the benefits of the research project?

It is expected that the allied health professionals who take part in the study will benefit from the provision of education related to evidence based interventions and skills training in the included outcome measures, as well as from access to a customised e-evidence library specifically for children and young people with cerebral palsy. In addition, children with cerebral palsy and their families will benefit from the improved knowledge and evidence based decision making of their therapy team. Routine assessment is expected to lead to more timely responses to each child's therapy needs. In the long term it is anticipated that the project will embed systems, processes and professional behaviours that will increase the responsiveness of health services to new evidence to inform clinical practice for children with cerebral palsy.

Are there any risks associated with participating in this project?

It's possible that you could find changes to services as a result of the research project as disruptive to your practice, and the extra time to complete assessments of the children and for you to participate in the education days could be stressful to manage. It is also possible that feedback from the CP-Check Up

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about the effectiveness of interventions provided may be confronting. The project activities are however designed to provide organisational and researcher support for changing practice.

Can I withdraw from the study?
Participation in this research is completely voluntary. You are not under any obligation to take part and can withdraw from the project at any time without affecting your work situation at Yooralla.

Will anyone else know the results of the project?
Information collected from you during the project is confidential and can only be accessed by the researchers. Information collected about the children using the CP-Check Up, will be included on each child's client file at Yooralla and will be available to the child's therapists and to members of the research team. Information from the CP Check Up will also be recorded electronically on a database located at the NSW Cerebral Palsy Register. The Cerebral Palsy Alliance, one of the partners in this research project, is the custodian of this database. The database is strictly confidential and will only be seen by staff who have secure access to the database. All staff are bound by privacy and confidentiality policies.

Results for all participants will be combined when reporting results of the project. You will not be identified in any publications or other documents that arise from the project. Results from the "CP Check Up" project will be presented at conferences, published in professional journals and may be written in research student theses. The results will contribute to knowledge about best practice for community based services for children (and young people) with cerebral palsy.

Will I be able to find out the results of the project?
A summary of results will be sent to all participants at the end of the project. As well, results will be published in the Yooralla newsletter, and participants will be invited to information sessions at Yooralla.

Who do I contact if I have questions about the project?
If you have questions about the "CP Check Up" project please contact Meredith Fordyce on 0412 008 417.

What if I have a complaint or any concerns?
The study has been approved by the Human Research Ethics Committee at Australian Catholic University (number 2012 309V). If you have any complaints or concerns about the way that the project is being carried out, you may write to the Chair of the Human Research Ethics Committee care of the Office of the Deputy Vice Chancellor (Research).

Chair, HREC
c/o Office of the Deputy Vice Chancellor (Research)
Australian Catholic University, Melbourne Campus
Locked Bag 4115, FITZROY, VIC, 3065
Ph: 03 9953 3150;
Fax: 03 9953 3315;
Email: res.ethics@acu.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If you have any concerns relating to your involvement, you can contact

Ashley Creighton
Deputy General Manager, Yooralla
Suite 2/587 Canterbury Road
Surrey Hills 3127
Telephone: 0418326324
ashley.crieghton@yooralla.com.au

I want to participate! How do I sign up?
If you are interested in participating please complete the enclosed consent form. You will be offered the opportunity to talk to a member of the research team, about what will be involved if you take part and to answer any questions you may have.

We look forward to hearing from you!

Thank you for helping us to find the best ways to support allied health professionals in achieving positive outcomes for all children (and young people) with cerebral palsy.

Yours sincerely,

RESEARCHER NAME/S AND SIGNATURE/S

Professor Christine Imms	Ms Meredith Fordyce
███████	███████
Australian Catholic University	*Yooralla*

Associate Professor Iona Novak	Dr Angela Crettenden
███████	███████
Cerebral Palsy Alliance	*Novita Children's Services*
Professor Dinah Reddihough	Ms Sarah Foley
███████	███████
Murdoch Childrens Research Institute	*Kids Plus Foundation*

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Professor Kerr Graham

■■■■■■■■■■

Murdoch Childrens Research Institute

Dr Elspeth Froude

■■■■■■■■

St Giles Society

Associate Professor Nora Shields

■■■■■■■

La Trobe University

Ms Petra Karlsson

■■■■■■

Cerebral Palsy Alliance

Associate Professor Michael Coory

■■■■■■

Murdoch Childrens Research Institute

Dr Adrienne Harvey

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Murdoch Childrens Research Institute

Ms Hayley Smithers Sheedy

■■■■■■■■

Cerebral Palsy Alliance

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PARTICIPANT INFORMATION LETTER (Allied Health Professional)

PROJECT TITLE:

Cerebral Palsy Check-Up: Providing the best service at the best time

PRINCIPAL INVESTIGATOR: Professor Christine Imms

Dear Allied Health Professional,

You are invited to take part in the research project described below.

What is the project about?

The "CP Check Up" research project will investigate how therapists who work at Kids Plus can be supported to find the most effective treatments for children (and young people) with cerebral palsy. The project will also examine whether regular assessments contribute to improved knowledge of the needs of children (and young people) with cerebral palsy and lead to better services.

Who is undertaking the project?

This project is being conducted by the Australian Catholic University, research partners from the Murdoch Childrens Research Institute and La Trobe University and key providers of services to children and young people with cerebral palsy across Australia. These service providers include the Cerebral Palsy Alliance in New South Wales, Kids Plus and Yooralla in Victoria, St Giles in Tasmania and Novita Children's Services in South Australia. The project is being funded by the National Health and Medical Research Council (NHMRC), along with cash and/or in-kind contributions from each of the partner organisations.

What will I be asked to do?

The project is focused on supporting therapists in their work with children with cerebral palsy. The project will start in February 2013 and will finish at the end of 2015. If you agree to take part in the project you will:

1) Complete two questionnaires at four time points (at 6, 12 and 24 months). These questionnaires will take approximately 40 minutes to complete at each time point.

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2) Review the customised e-evidence library of synthesised and critiqued cerebral palsy research evidence that you can use to support your clinical decision making. The amount of time for this task is at the discretion of the clinician.
3) Take part in 1 to 3 education days per year for the duration of the project.
4) Undertake routine data collection about children with cerebral palsy on your caseload who are aged 3 to 18 years using the Cerebral Palsy Check-up web-based tool. The tool is implemented each 6 months for children under the age of 6 years, and after an initial 6 month follow up, annually for those over 6 years.
5) (Optional). Take part in up to four focus groups (baseline, 6, 12, and 24 months). Each focus group will take approximately one hour. The focus groups will be audio-taped and transcribed. A pseudonym will be given to each participant at the time of transcription if you choose to take part in the study. With their consent, data from the CP-Check Up will be shared with the researchers.

Each included organisation will identify one or more knowledge brokers who will work with the allied health professionals in the study to support them in using the study tools and with the researchers to assist in the implementation of the study at each site.

What are the benefits of the research project?
It is expected that the allied health professionals who take part in the study will benefit from the provision of education related to evidence based interventions and skills training in the included outcome measures, as well as from access to a customised e-evidence library specifically for children and young people with cerebral palsy. In addition, children with cerebral palsy and their families will benefit from the improved knowledge and evidence based decision making of their therapy team. Routine assessment is expected to lead to more timely responses to each child's therapy needs. In the long term it is anticipated that the project will embed systems, processes and professional behaviours that will increase the responsiveness of health services to new evidence to inform clinical practice for children with cerebral palsy.

Are there any risks associated with participating in this project?
It's possible that you could find changes to services as a result of the research project as disruptive to your practice, and the extra time to complete assessments of the children and for you to participate in the education days could be stressful to manage. It is also possible that feedback from the CP-Check Up about the effectiveness of interventions provided may be confronting. The project activities are however designed to provide organisational and researcher support for changing practice.

Can I withdraw from the study?
Participation in this research is completely voluntary. You are not under any obligation to take part and can withdraw from the project at any time without affecting your work situation at Kids Plus.

Will anyone else know the results of the project?

Information collected from you during the project is confidential and can only be accessed by the researchers. Information collected about the children using the CP-COR, will be included on each child's client file at Kids Plus and will be available to the child's therapists and to members of the research team. Information from the CP Check Up will also be recorded electronically on a database located at the NSW Cerebral Palsy Register. The Cerebral Palsy Alliance, one of the partners in this research project, is the custodian of this database. The database is strictly confidential and will only be seen by staff who have secure access to the database. All staff are bound by privacy and confidentiality policies. Results for all participants will be combined when reporting results of the project. You will not be identified in any publications or other documents that arise from the project. Results from the "CP Check Up" project will be presented at conferences, published in professional journals and may be written in research student theses. The results will contribute to knowledge about best practice for community based services for children (and young people) with cerebral palsy.

Will I be able to find out the results of the project?

A summary of results will be sent to all participants at the end of the project. As well, results will be published in the Kids Plus newsletter, and participants will be invited to information sessions at Kids Plus.

Who do I contact if I have questions about the project?

If you have questions about the "CP Check Up" project please contact Sarah Foley on 03 5223 1475.

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at Australian Catholic University (approval number 2012 309V). If you have any complaints or concerns about the way that the project is being carried out, you may write to the Chair of the Human Research Ethics Committee care of the Office of the Deputy Vice Chancellor (Research).

Chair, HREC
c/o Office of the Deputy Vice Chancellor (Research)
Australian Catholic University, Melbourne Campus
Locked Bag 4115, FITZROY, VIC, 3065
Ph: 03 9953 3150;
Fax: 03 9953 3315;
Email: res.ethics@acu.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If you have any concerns relating to your involvement, you can contact

Kelly Reynolds

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163 Myers St, Geelong 3220
gkone@bigpond.com
03-52231475

I want to participate! How do I sign up?
If you are interested in participating please complete the enclosed consent form. You will be offered the opportunity to talk to a member of the research team, about what will be involved if you take part and to answer any questions you may have.

We look forward to hearing from you!

Thank you for helping us to find the best ways to support allied health professionals in achieving positive outcomes for all children (and young people) with cerebral palsy.

Yours sincerely,

RESEARCHER NAME/S AND SIGNATURE/S

Professor Christine Imms	Ms Sarah Foley
Australian Catholic University	*Kids Plus Foundation*
Associate Professor Iona Novak	Dr Angela Crettenden
Cerebral Palsy Alliance	*Novita Children's Services*
Professor Dinah Reddihough	Dr Elspeth Froude
Murdoch Childrens Research Institute	*St Giles Society*
Professor Kerr Graham	Ms Meredith Fordyce
Murdoch Childrens Research Institute	*Yooralla*
Associate Professor Nora Shields	Ms Petra Karlsson
La Trobe University	*Cerebral Palsy Alliance*

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Associate Professor Michael Coory

Dr Adrienne Harvey

██████████

██████████

Murdoch Childrens Research Institute

Murdoch Childrens Research Institute

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B5: Parent information letters – Organisation A and B

PARTICIPANT INFORMATION LETTER (Parent / Guardian)

School of Allied & Public Health
Locked Bag 4115, Fitzroy VIC 3065
T: +61 3 9953 3404
E: christine.imms@acu.edu.au
W: www.acu.edu.au

PROJECT TITLE:

CP Check Up: Providing the best service at the best time

PRINCIPAL INVESTIGATOR: Professor Christine Imms

Dear Parent or Guardian,

You and your child are invited to take part in the research project described below.

What is the project about?
The "CP Check Up" research project will investigate how therapists who work at Yooralla can be supported to find the most effective treatments for children (and young people) with cerebral palsy. The project will also find out if regular assessments contribute to improved knowledge of the needs of children (and young people) with cerebral palsy and lead to better services.

Who is undertaking the project?
This project is being conducted by the Australian Catholic University, research partners from the Murdoch Childrens Research Institute and La Trobe University and key providers of services to children and young people with cerebral palsy across Australia. These service providers include the Cerebral Palsy Alliance in New South Wales, Kids Plus and Yooralla in Victoria, St Giles in Tasmania and Novita Children's Services in South Australia. The project is being funded by the National Health and Medical Research Council (NHMRC), along with some cash and/or in-kind contributions from each of the partner organisations.

What will I be asked to do?
The project will start in April 2013 and will finish at the end of 2015. If you agree to take part in the study you will be asked to:
1. Give consent for your child to have additional assessments using a new web based tool called Cerebral Palsy Check-up (CP Check-Up). For children <6 years of age, assessments will be completed every 6 months and may take up to 1.5 hours at each time point. For children 6 years

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and over, assessments will be completed every 12 months and may take up to 1.5 hours at each time point.

2. Give consent for your child's information, collected as part of the CP Check Up, to be stored centrally, in electronic form, at the NSW Cerebral Palsy Register. The Cerebral Palsy Alliance is the custodian of this database. This will involve you signing an additional 'Consent to Share and Release Information' form.

3. Provide consent for the project researchers to access your child's Yooralla file and CP Check Up information. This will be done at the beginning of the study, and at 6, 12 and 24 months.

What are the benefits of the research project?
It is expected that children (and young people) with cerebral palsy and their families will benefit from the improved knowledge and evidence based decision making of their therapy team. As well, routine assessment is expected to lead to more timely response to your child's therapy needs.

Are there any risks associated with participating in this project?
It is possible that you could see the changes to services provided by Yooralla as a result of the research project as disruptive to your child and family. You may also find the additional assessments of your child will take extra time. We will try to limit the impact of changes and to make sure that arrangements for any additional assessments are at times that are convenient to you.

Can I withdraw from the study?
Participation in this research is completely voluntary. You are not under any obligation to take part and can withdraw from the project at any time without affecting the services you and your child receive from Yooralla.

Will anyone else know the results of the project?
Information about your child collected during the project, using the CP-Check Up, will be included in your child's client file at Yooralla and will only be available to Yooralla staff and to members of the research team.

Information from the CP Check Up will also be recorded electronically on a database located at the NSW Palsy Register. The Cerebral Palsy Alliance, one of the partners in this research project, is the custodian of this database. The database is strictly confidential and will only be seen by staff who have secure access to the database. All staff are bound by privacy and confidentiality policies. You, your child's therapists and the researchers will receive a copy of your child's assessment results.

Results for all participants will be combined when reporting results of the project. You and your child will not be identified in any publications or other documents that arise from the project. Results from the "CP Check Up" project will be published in professional journals and will contribute to knowledge about best practice for community based services for children (and young people) with cerebral palsy.

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Will I be able to find out the results of the project?

A summary of results will be sent to all participants at the end of the project. As well, results will be published in the Yooralla newsletter, and participants will be invited to information sessions at Yooralla.

Who do I contact if I have questions about the project?

If you have questions about the "CP Check Up" project please contact Meredith Forsyth on 0412 008 417.

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at Australian Catholic University (approval number 2012 309V). If you have any complaints or concerns about the way that the project is being carried out, you may write to the Chair of the Human Research Ethics Committee care of the Office of the Deputy Vice Chancellor (Research).

Chair, HREC
c/o Office of the Deputy Vice Chancellor (Research)
Australian Catholic University, Melbourne Campus
Locked Bag 4115, FITZROY, VIC, 3065
Ph: 03 9953 3150;
Fax: 03 9953 3315;
Email: res.ethics@acu.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If you have any concerns relating to your child or other family members, you can contact
Ashley Creighton
Deputy General Manager, Yooralla
Suite 2/587 Canterbury Road
Surrey Hills 3127
Telephone: 0418326324
ashley.crieghton@yooralla.com.au

I want to participate! How do I sign up?

If you are interested in participating and agree for your child to be part of the project, please complete the enclosed consent form. You will be offered the opportunity to talk to one of your child's therapists, and a member of the research team, about what will be involved if you and your child take part and to answer any questions you may have.

We look forward to hearing from you!

Thank you for helping us to find the best ways to support allied health professionals in achieving positive outcomes for all children (and young people) with cerebral palsy.

Yours sincerely,

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RESEARCHER NAME/S AND SIGNATURE/S

Professor Christine Imms

Australian Catholic University

Ms Meredith Fordyce

Yooralla

Associate Professor Iona Novak

Cerebral Palsy Alliance

Dr Angela Crettenden

Novita Children's Services

Professor Dinah Reddihough

Murdoch Childrens Research Institute

Ms Sarah Foley

Kids Plus Foundation

Professor Kerr Graham

Murdoch Childrens Research Institute

Dr Elspeth Froude

St Giles Society

Associate Professor Nora Shields

La Trobe University

Ms Petra Karlsson

Cerebral Palsy Alliance

Associate Professor Michael Coory

Murdoch Childrens Research Institute

Dr Adrienne Harvey

Murdoch Childrens Research Institute

Ms Hayley Smithers Sheedy

Cerebral Palsy Alliance

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PARTICIPANT INFORMATION LETTER (Parents/Guardians)

PROJECT TITLE:

CP Check Up: Providing the best service at the best time

PRINCIPAL INVESTIGATOR: Professor Christine Imms

Dear Parent or Guardian,

You and your child are invited to take part in the research project described below.

What is the project about?
The "CP Check Up" research project will investigate how therapists who work at Kids Plus can be supported to find the most effective treatments for children (and young people) with cerebral palsy. The project will also find out if regular assessments contribute to improved knowledge of the needs of children (and young people) with cerebral palsy and lead to better services.

Who is undertaking the project?
This project is being conducted by the Australian Catholic University, research partners from the Murdoch Childrens Research Institute and La Trobe University and key providers of services to children and young people with cerebral palsy across Australia. These service providers include the Cerebral Palsy Alliance in New South Wales, Kids Plus and Yooralla in Victoria, St Giles in Tasmania and Novita Children's Services in South Australia. The project is being funded by the National Health and Medical Research Council (NHMRC), along with some cash and/or in-kind contributions from each of the partner organisations.

What will I be asked to do?
The project will start in February April 2013 and will finish at the end of 2015. If you agree to take part in the study you will be asked to:
1. Give consent for your child to have additional assessments using a new web based tool called Cerebral Palsy Check-up (CP Check-Up). For children <6 years of age, assessments will be completed every 6 months and may take up to 1.5 hours at each time point. For children 6 years

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and over, assessments will be completed every 12 months and may take up to 1.5 hours at each time point.

2. Give consent for your child's information, collected as part of the CP Check Up, to be stored centrally, in electronic form, at the NSW Cerebral Palsy Register. The Cerebral Palsy Alliance is the custodian of this database. This will involve you signing an additional 'Consent to Share and Release Information' form.

3. Provide consent for the project researchers to access your child's Kids Plus file and CP Check Up information. This will be done at the beginning of the study, and at 6, 12 and 24 months.

What are the benefits of the research project?

It is expected that children (and young people) with cerebral palsy and their families will benefit from the improved knowledge and evidence based decision making of their therapy team. As well, routine assessment is expected to lead to more timely response to your child's therapy needs.

Are there any risks associated with participating in this project?

It is possible that you could see the changes to services provided by Kids Plus as a result of the research project as disruptive to your child and family. You may also find the additional assessments of your child will take extra time. We will try to limit the impact of changes and to make sure that arrangements for any additional assessments are at times that are convenient to you.

Can I withdraw from the study?

Participation in this research is completely voluntary. You are not under any obligation to take part and can withdraw from the project at any time without affecting the services you and your child receive from Kids Plus.

Will anyone else know the results of the project?

Information about your child collected during the project, using the CP-Check Up, will be included in your child's client file at Kids Plus and will only be available to your child's therapists and to members of the research team.

Information from the CP Check Up will also be recorded electronically on a database located at the NSW Palsy Register. The Cerebral Palsy Alliance, one of the partners in this research project, is the custodian of this database. The database is strictly confidential and will only be seen by staff who have secure access to the database. All staff are bound by privacy and confidentiality policies. You, your child's therapists and the researchers will receive a copy of your child's assessment results.

Results for all participants will be combined when reporting results of the project. You and your child will not be identified in any publications or other documents that arise from the project. Results from the "CP Check Up" project will be published in professional journals and will contribute to knowledge about best practice for community based services for children (and young people) with cerebral palsy.

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Will I be able to find out the results of the project?
A summary of results will be sent to all participants at the end of the project. As well, results will be published in the Kids Plus newsletter, and participants will be invited to information sessions at Kids Plus.

Who do I contact if I have questions about the project?
If you have questions about the "CP Check Up" project please contact Sarah Foley on 03-5223 1475.

What if I have a complaint or any concerns?
The study has been approved by the Human Research Ethics Committee at Australian Catholic University (approval number 2012 309V). If you have any complaints or concerns about the way that the project is being carried out, you may write to the Chair of the Human Research Ethics Committee care of the Office of the Deputy Vice Chancellor (Research).

Chair, HREC
c/o Office of the Deputy Vice Chancellor (Research)
Australian Catholic University, Melbourne Campus
Locked Bag 4115, FITZROY, VIC, 3065
Ph: 03 9953 3150;
Fax: 03 9953 3315;
Email: res.ethics@acu.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If you have any concerns relating to your child or other family members, you can contact
Kelly Reynolds
163 Myers St, Geelong 3220
gkone@bigpond.com
03-52231475

I want to participate! How do I sign up?
If you are interested in participating and agree for your child to be part of the project, please complete the enclosed consent form. You will be offered the opportunity to talk to one of your child's therapists, and a member of the research team, about what will be involved if you and your child take part and to answer any questions you may have.

We look forward to hearing from you!

Thank you for helping us to find the best ways to support allied health professionals in achieving positive outcomes for all children (and young people) with cerebral palsy.

Yours sincerely,

RESEARCHER NAME/S AND SIGNATURE/S

Professor Christine Imms

Australian Catholic University

Ms Sarah Foley

Kids Plus Foundation

Associate Professor Iona Novak

Cerebral Palsy Alliance

Dr Angela Crettenden

Novita Children's Services

Professor Dinah Reddihough

Murdoch Childrens Research Institute

Dr Elspeth Froude

St Giles Society

Professor Kerr Graham

Murdoch Childrens Research Institute

Ms Meredith Fordyce

Yooralla

Associate Professor Nora Shields

La Trobe University

Ms Petra Karlsson

Cerebral Palsy Alliance

Associate Professor Michael Coory

Murdoch Childrens Research Institute

Dr Adrienne Harvey

Murdoch Childrens Research Institute

Ms Hayley Smithers Sheedy

Cerebral Palsy Alliance

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B6: Allied health practitioner consent forms – Organisation A and B

CONSENT FORM: ALLIED HEALTH PROFESSIONAL

TITLE OF PROJECT: Cerebral Palsy Check-Up: Providing the best service at the best time.

PRINCIPAL INVESTIGATOR: Professor Christine Imms

I ....(the participant) have read and understood the information provided in the Letter to Allied Health Participants. Any questions I have asked have been answered to my satisfaction.

I agree to participate in this three year study, to
- Complete two questionnaires at four time-points (baseline, 6, 12 and 24 months). These questionnaires will take approximately 40 minutes to complete at each time-point
- Take part in 1-3 annual education days per year for the duration of the project
- Review the customised e-evidence library of synthesised and critiqued cerebral palsy research evidence that can be used to support clinical decision making. The amount of time for this task is at my discretion.
- Undertake routine data collection about children with cerebral palsy on my caseload who are aged 3 to 18 years using the Cerebral Palsy Check-up tool. The tool is implemented each 6 months for children under the age of 6 years, and after an initial 6 month follow up, annually for those over 6 years. The time commitment for this will vary depending on my caseload but it is anticipated that it will take up to 1.5 hours per child each 6 months, although likely includes some measures that are already routinely completed.
- (Optional) Take part in up to four focus groups at baseline, 6, 12, and 24 months. Each focus group will take approximately 1 hour and will be audio-taped.

I realise that I can withdraw my consent at any time without adverse consequences. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in any way.

NAME OF PARTICIPANT: ....

SIGNATURE .... DATE ....

SIGNATURE OF PRINCIPAL INVESTIGATOR: ....

DATE:.............................

CONSENT FORM: ALLIED HEALTH PROFESSIONAL

TITLE OF PROJECT: Cerebral Palsy Check-Up: Providing the best service at the best time.

 PRINCIPAL INVESTIGATOR: Professor Christine Imms

I ....(the participant) have read and understood the information provided in the Letter to Allied Health Participants. Any questions I have asked have been answered to my satisfaction.

I agree to participate in this three year study, to
- Complete two questionnaires at four time-points (baseline, 6, 12 and 24 months). These questionnaires will take approximately 40 minutes to complete at each time-point
- Take part in 1-3 annual education days per year for the duration of the project
- Review the customised e-evidence library of synthesised and critiqued cerebral palsy research evidence that can be used to support clinical decision making. The amount of time for this task is at my discretion.
- Undertake routine data collection about children with cerebral palsy on my caseload who are aged 3 to 18 years using the Cerebral Palsy Check-up tool. The tool is implemented each 6 months for children under the age of 6 years, and after an initial 6 month follow up, annually for those over 6 years. The time commitment for this will vary depending on my caseload but it is anticipated that it will take up to 1.5 hours per child each 6 months, although likely includes some measures that are already routinely completed.
- (Optional) Take part in up to four focus groups at baseline, 6, 12, and 24 months. Each focus group will take approximately 1 hour and will be audio-taped.

I realise that I can withdraw my consent at any time without adverse consequences. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in any way.

NAME OF PARTICIPANT: ....

SIGNATURE ....   DATE ....

SIGNATURE OF PRINCIPAL INVESTIGATOR: ....

                                                                   DATE:………………………..

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B7: Parent consent forms – Organisation A and B

CONSENT FORM: FOR PARENT / GUARDIAN AND YOUTH

TITLE OF PROJECT: Cerebral Palsy Check-Up: Providing the best service at the best time.

PRINCIPAL INVESTIGATOR: Professor Christine Imms

I ....*(the parent/guardian)* have read and understood the information provided in the Letter to Parent/Guardian Participants. Any questions I have asked have been answered to my satisfaction.

I agree that my child, nominated below, may participate in the assessments using the Cerebral Palsy Check Up in this three year study. I understand that the assessments may take up to 1.5 hours at each time point. For children <6 years of age, assessments will be completed every 6 months. For children 6 years and over, assessments will be completed every 12 months. I also agree that the information collected on the CP Check Up may be securely stored electronically at the NSW Cerebral Palsy Register. I give consent for the researchers to have access to my child's files at Yooralla and the results of the CP Check Up.

I realise that I can withdraw my consent at any time without adverse consequences. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in any way.

NAME OF PARENT/GUARDIAN: ....

SIGNATURE ....…………………… DATE:............................

NAME OF CHILD ....

SIGNATURE OF PRINCIPAL INVESTIGATOR: ....

DATE:.............................

ASSENT OF PARTICIPANTS AGED UNDER 18 YEARS

I .... *(the participant aged under 18 years)* understand what this research project is about. What I will be asked to do has been explained to me. I agree to take part in the assessments involved in this three year study. I realise that I can withdraw at any time without having to give a reason for my decision.

NAME OF PARTICIPANT AGED UNDER 18: ....

SIGNATURE:...DATE:............................

SIGNATURE OF PRINCIPAL INVESTIGATOR (or SUPERVISOR):..

DATE:.............................

Consent V2 Feb 2013

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CONSENT FORM: FOR PARENT / GUARDIAN AND YOUTH

TITLE OF PROJECT: Cerebral Palsy Check-Up: Providing the best service at the best time.

 PRINCIPAL INVESTIGATOR: Professor Christine Imms

I ....(the parent/guardian) have read and understood the information provided in the Letter to Parent/Guardian Participants. Any questions I have asked have been answered to my satisfaction.

I agree that my child, nominated below, may participate in the assessments using the Cerebral Palsy Check Up in this three year study. I understand that the assessments may take up to 1.5 hours at each time point. For children <6 years of age, assessments will be completed every 6 months. For children 6 years and over, assessments will be completed every 12 months. I also agree that the information collected on the CP Check Up may be securely stored electronically at the NSW Cerebral Palsy Register. I give consent for the researchers to have access to my child's files at Yooralla and the results of the CP Check Up.

I realise that I can withdraw my consent at any time without adverse consequences. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in any way.

NAME OF PARENT/GUARDIAN: ....

SIGNATURE ....…………………… DATE:.............................

NAME OF CHILD   ....

SIGNATURE OF PRINCIPAL INVESTIGATOR: ....

DATE:.............................

ASSENT OF PARTICIPANTS AGED UNDER 18 YEARS

I ……………………… (the participant aged under 18 years) understand what this research project is about. What I will be asked to do has been explained to me. I agree to take part in the assessments involved in this three year study. I realise that I can withdraw at any time without having to give a reason for my decision.

NAME OF PARTICIPANT AGED UNDER 18: ....

SIGNATURE:..DATE:.............................

SIGNATURE OF PRINCIPAL INVESTIGATOR (or SUPERVISOR):..

DATE:.............................

Consent V2 Feb 2013

B.8: Organisational Profile

CP CHECK –UP: BEST SERVICE BEST TIME: ORGANISATIONAL PROFILE

Instructions:

This profile is to be completed at Baseline, 6 months, 12 months and 24 month time points. The Baseline date is determined by project implementation at each site and will be provided to you when the survey is distributed.

Some organisations will need to complete a separate profile for different sections or service streams within the organisation (e.g. Special School, Early Childhood Intervention Service or Fee-for service streams) or for different sites of the same organisation (e.g. regional sites).

Please provide organisational data for the specified data collection date.

Date of completion:	
Person/s completing:	
Date specified for data extraction from organisation: *(this will be completed for you)*	
Time point:	☐ Baseline ☐ 6 months ☐ 12 months ☐ 24 months
Name of organisation:	
Name of section or regional site reported in this profile:	_____ **Is this the only profile for this organisation?** ☐ Yes ☐ No
Number of physical sites from where this service is provided: *(please answer this question in relation to the service described in this profile)*	
Brief statement of main organisational purpose / mission:	

Main sources of funding for organisation:	☐ State or Federal Government _____ (%)
	☐ Philanthropic _____ (%)
	☐ Other _____ (%)
Total number of staff:	**Head count:** **EFT:**
	☐ Physiotherapists: _____ (number) _____ (EFT)
	☐ Occupational Therapists: _____ (number) _____ (EFT)
	☐ Speech Pathologists: _____ (number) _____ (EFT)
	☐ Psychologists: _____ (number) _____ (EFT)
	☐ Social Workers: _____ (number) _____ (EFT)
	☐ Other Allied Health: _____ (number) _____ (EFT)
	☐ Other professional staff: _____ (number) _____ (EFT) e.g. educators, engineers, technicians
	☐ Administrative staff: _____ (number) _____ (EFT)
	☐ Senior executives: _____ (number) _____ (EFT)
Number of knowledge brokers identified for the study	
Discipline (s) of knowledge brokers identified for the study	☐ Physiotherapists: _____ (number) _____ (EFT)
	☐ Occupational Therapists: _____ (number) _____ (EFT)
	☐ Speech Pathologists: _____ (number) _____ (EFT)
Client characteristics: **Total number of clients registered in the service:**	
Diagnostic groups:	☐ Cerebral palsy only
	☐ Cerebral Palsy and other
	☐ Other (ie. no children with Cerebral Palsy)

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Age groups (check all that apply)	☐	Early intervention (preschool)
	☐	School aged
	☐	Adults
Total number of children with Cerebral Palsy eligible for this study within this site:	☐	3 – 6 years of age _____ (number)
	☐	Greater than 6 years – 18 years of age _____ (number)
Funding sources under which ELIGIBLE families access services	☐	Government /Philanthropic _____ (%) *(i.e. families don't pay the organisation)*
	☐	Better Start / FaHCSIA _____ (%)
	☐	Both _____ (%)
Is this an NDIS (*DisabilityCare Australia)* Trial site?	☐	No
	☐	Yes: *For which children?*
Please add any clarifying comments as needed:		

THANK YOU FOR COMPLETING THIS SURVEY

TOPIC GUIDE/SCRIPT for AHP focus group

Introduction given by the researcher (5 mins)

Welcome and thank; Introduce facilitator and co-facilitator -

- *the facilitator will ensure that we get through our questions and keep an eye on the time*

- *our co-facilitator will take some notes and keep the facilitator on track*

- *Brief participant introductions (name, profession, organisation)*

Review AHP participant information sheet:

- *We just want to be sure that you all received and read the information around confidentiality of the focus group.*

- *Just to recap – the session will be recorded and transcribed, but your names will be de-identified.*

- *Is everyone happy that we use our given names?*

- *We would ask that everyone respects the privacy of each other within this group, and that our discussions remain confidential.*

- *Have you any questions in relation to this?*

*******************************START RECORDING*************************

Outline of session:

- *In today's focus group we hope to explore your understanding of the knowledge translation strategies used in the 'Cerebral Palsy Check Up: Providing the best service at the best time' project, acknowledging that we are at the start of this process.*

- *We'd then like to discuss the factors within your organization that you feel will impact on your use of these strategies.*

ICEBREAKER (5 mins)

You are here today as part of this research project which aims to translate current research about cerebral palsy into our clinical practice. How did you come to be interested in this project?
Follow up/alternate Q: How do you feel about being involved with the project?

Background to topics 1 and 2

TOPIC 1: Organisational resources relating to the multi-strategy intervention
TOPIC 2: Organisational structure relating to multi-strategy intervention

The project that we are talking about today is trying to use Knowledge Translation strategies to increase the use of evidence-based practice in Allied health practitioners who work with children with CP. The multi-strategy intervention that is being used in this research study has four main parts. These are:

(1) The CP Check Up tool: this is a system for recording assessments and interventions for the children you see on a routine basis. It covers areas of mobility, self-care, communication, swallowing, nutrition, cognition and wellbeing.
(2) An electronic evidence library called CP Decision that you can use to inform your assessment and intervention practices.
(3) Knowledge Brokers within your service, who will provide support around the project.
(4) Education and training days on topics related to evidence-based practice.

Keeping these 4 strategies in mind I'd like you to discuss the resources available within your organization and how these may impact on implementing the multi-strategy intervention.
By resources I mean things like the measurement tools/manuals, admin support to implement the measures, time to complete CP Check Up, staff/co-ordinator/Knowledge broker availability, or re-imbursement for Allied health practitioners to facilitate their extra efforts in implementing the tool.

We will firstly look resources you already have and then look at what you think might be needed.

TOPIC 1: Organisational <u>resources</u> relating to the multi-strategy intervention
(12min)

What resources already exist in your organization that will assist you to implement the multi-strategy intervention?
Follow up/alternate Q: What has assisted you so far with accessing research in your organisation?
Likely responses: equipment, enthusiastic team, some expertise, admin support, assessment tools and manuals, knowledge brokers a good resource, funding - reimbursement of time and purchase of materials, space/adequate physical facilities

What are some of the challenges you foresee within your organisation in relation to implementation of the multi-strategy intervention?
Alternate Q 1: Can your organisation provide all the necessary resources?
Alternate Q 2: Are there difficulties in getting these resources?
Likely responses: Time poor, no funding - reimbursement of time and purchase of materials, access to knowledge brokers, availability of equipment, unenthusiastic team, inadequate expertise, lack of admin support, missing assessment tools and manuals, no space/inadequate physical facilities

Back up question if discussion difficult/limited/narrow in focus: "Do you feel these comments represent the views of all of your colleagues? What other opinions might people have?"

TOPIC 2: Organisational <u>structure</u> relating to multi-strategy intervention
(12min)

I would now like to discuss how the structure of your organization may impact on implementation of the multi-strategy intervention. By 'structure of your organisation' I mean things like the size and scope of the organisation, staff turnover, management support, and procedures and processes around decision making in the organisation.

Firstly, we will look at factors that might positively impact on the multi-strategy intervention and then look at barriers to implementation.

What things about the structure of your organisation do you think will assist with the implementation of the multi-strategy intervention?
Alternate 1: How might these strategies fit in to or work in with the structure of your organisation?
Alternate 2: How feasible is the implementation of these strategies in your work team?
(Facilitator reminder: CP Check Up, CP Decision/e-evidence library, knowledge broker /education and training days)
Likely responses: senior management supportive, organisational vision, service delivery model, clinical versus management roles, location/geography, team structures, decision making processes, size of organisation

What difficulties, related to your organisational structure, do you anticipate with implementation of the multi strategy intervention?
Alternate Q: What would you like more organisational support with?
Likely responses: service delivery model, government mandate, funding constraints, team structures, management structures, location/geography, staff turnover and availability, organisational processes/decision making

Back up question if discussion difficult/limited/narrow in focus: "Do you feel these comments represent the views of all of your colleagues? What other opinions might people have?"

TOPIC 3: AHP experiences of <u>Evidence Based Practice and assessment</u>
(18min)

I would now like you to reflect on your personal use of Evidence Based Practice and then later on your thoughts around using evidence- based assessment measures.
What is your understanding of evidence-based practice? (3 min)

Thank you for these perspectives. We have a range of understandings within the group, so, for the purposes of today we will define evidence-based practice as 'the integration of research evidence… with clinical expertise and patients' values and circumstances, to inform … decisions about clinical practice … '(Sackett 1996). **Considering the definition that I have just given you, what do you think is the relevance of evidence-based practice in your day-to-day work? (3 min)**
Likely responses: professional accountability, effective practice, avoid wasting time and resources, organisational mandate, moral obligation, family demands, assist with goal setting

I now want to go on and talk more specifically about evidence-based assessment. By this I mean assessment tools that can be used to evaluate the impacts of, or change in, a child's attributes over time. For example, the Canadian occupational performance Measure (COPM), Goal Attainment Scaling (GAS), the Pediatric Evaluation of Disability Inventory (PEDI) or Gross Motor Function Measure (GMFM). **What is your experience of using evidence-based assessment measures within your workplace? (6min)**

Can you expand on why you use, or don't use, evidence-based assessment measures with the children and families you see?
Alternate Q: What do you take into consideration when selecting an assessment tool for use with a child and family? **(6 min)**
Likely responses: Not familiar with assessment tools for the children I see, takes up too much therapy time, the organization does or doesn't ask for it, courses available or not, Limited CPD allocation, cost and time to do, we don't have the measures available, children don't change very much, can see most things that need doing, don't see the point in generating numbers, the parents don't understand them/ haven't asked for them, Ease of use, Will the child understand /cooperate, What I'm doing it for, Will it give me some more information, Who is going to read the report .

Back up question if needed/time: *What is your perspective of your colleagues' approach to using evidence-based assessment measures? Are they similar or different from yours and in what way?*

Summing Up Sheet (8 min)

So today we have talked about your understanding of the multi-strategy knowledge translation intervention in this research project

TOPIC 1: We talked about how resources in your organisation might impact on the implementation of these strategies and you told us:

Supports

-

Barriers

-

TOPIC 2: In terms of the impact of organisational structure on implementing the interventions you told us:

Supports

-

Barriers

-

TOPIC 3: Finally, we talked about evidence-based practice

Your experience of using it in your organisation is….

Factors influencing your use of evidence-based assessments in your workplace were

Do you feel that that is an accurate reflection of our discussion, and is there anything that you wish to add at this point?

Thank you for your participation.

.

B10: Best Service Best Time Questionnaire

BEST SERVICE BEST TIME EVALUATION

<div style="border: 2px solid gray; background: #e8e8e8;">

PART 1:   **Participant Information**

PART 2:   **Self-Ratings of Goal-Setting, Evidence Based Practice & Outcome Measurement Competencies**

PART 3:   **Evidence Based Practice & Outcome Measurement Competencies**

Part 4:   **Evidence Based Practice Scale**

</div>

To protect your privacy, we are asking each participating allied health professional to provide their own unique identifying code. You must do this using the following formula:

First letter of your first name + Day of Birth (e.g. 24) + First letter of mother's first name + number of siblings you have.

For, example: Name = Joe Blogs; D.O.B. = 24th June; Mother = Julie Blogs; Siblings = 3 sisters: therefore **Joe Blogs' ID Code = J24J3**.

PART 1: Participant Information

Data Collection Period: Baseline   Six Months   Twelve Months   Twenty-Four Months

Please enter your ID Code *
(see instructions on page 1)

Organisation
I am employed at…..(e.g. Cerebral Palsy Alliance, Novita, Kids Plus, St Giles, Yooralla)

Profession
I am employed at this organisation as a …(eg. Physiotherapist, Occupational Therapist, Speech Pathologist)

Employment
I have been working at this organisation for… _____ year/s

Number of years practising

What year did you graduate with your professional degree line OT/PT/SP?

Clinical experience in the disability field
Including my time at this organisation I have been working with people with disabilities for… _____ year/s

Highest level of education
In addition to my professional practice degree (e.g. Bachelor of Speech Pathology, Master of Occupational Therapy practice…), I have also attained the following post graduate degree…..

☐	☐	☐	☐	☐
Post Graduate certificate	Post Graduate Diploma	Master's including coursework	Research Master's Degree	Doctoral Degree (PhD or Clinical Doctorate)

Previous continuing education
I have attended evidence based practice training before.

☐ Yes   ☐ No

Please list the continuing education you have undertaken in the **past 12 months** that is pertinent to your work with children with cerebral palsy (e.g. conferences, workshops, seminars **external to your organisation**…)

Language	☐	☐
English is my first language.	Yes	No

Self-nomination Scale of Expertise in Paediatric Rehabilitation. :
Select the category that best describes you by placing a tick in the box.

Reference:
King, G., Bartlett, D.J., Curriea, M., Gilpin, M., Baxter, D., Willoughby, C., Tucker, M.A., & Strachan, D. (2008). Measuring the expertise of paediatric rehabilitation therapists. *International Journal of Disability, Development and Education*, 55(1): 5–26.

☐ **Novice**

A novice therapist [or worker] is defined as a therapist [or worker] whose foundational skills are still developing but who has not yet reached consistent competence in all areas of practice.

☐ **Intermediate**

An intermediate therapist [or worker] is defined as a therapist [or worker] who is well grounded in foundational clinical skills but has not yet reached an expert level of practice, even if considered to be a specialist in a specific clinical area.

☐ **Expert**

An expert therapist [or worker] is defined as a therapist [or worker] who fits most or all of the definition of expertise and who would be seen as an expert in their field
"An expert is someone who displays a deep understanding of clinical problems and has the ability to deal with complex problems. An expert is well-respected and has a good reputation within their work environment, is sought out by colleagues as a source of consultation for difficult or complicated cases, and is effective in helping to bring about positive outcomes for clients. An expert displays caring, compassion, and commitment in their work. An expert shows a high degree of creativity and flexibility in their decisions by considering multiple perspectives. An expert is highly motivated to improve his or her practice and makes meaningful contributions to their professional field. An expert is someone that you would refer a family member to and whose recommendations you would trust." (King et al, 2008, p.13)

PART 2: Self-Ratings of Goal-Setting, Evidence Based Practice & Outcome Measurement Competencies

INSTRUCTIONS: *Select the answer that most accurately reflects your practice today*

ID Code [   ]

	0 - 5% of the time	6 - 24% of the time	25 - 49% of the time	50 - 74% of the time	75 -100% of the time
I develop and document measurable goals with families/clients	☐	☐	☐	☐	☐
I conduct and document COPM [a] interviews with families/clients to assist with service planning	☐	☐	☐	☐	☐
I construct and document GAS [b] scales to describe the expected outcome from intervention for families/clients	☐	☐	☐	☐	☐
I score and document my client's COPM and GAS measures and use this information for planning	☐	☐	☐	☐	☐
I determine and document my client's GMFCS [c], MACS [d] or CFCS [e] level to help inform decision-making	☐	☐	☐	☐	☐
I ask parents/clients to consent to joining the CP register and notify them to the register	☐	☐	☐	☐	☐
I communicate news or facts to families/clients, to help them develop realistic expectations from intervention	☐	☐	☐	☐	☐

[a] COPM: Canadian Occupational Performance Measure; [b] GAS: Goal Attainment Scale; [c] GMFCS: Gross Motor Function Classification System; [d] MACS: Manual Ability Classification System; [e] CFCS: Communication Function Classification System

	0 - 5% of the time	6 - 24% of the time	25 - 49% of the time	50 - 74% of the time	75 - 100% of the time
I identify if a goal (in my speciality) is realistic based on assessment information and prognostic evidence	☐	☐	☐	☐	☐
I reword goals with families/clients to be realistic, if they set goals that are unrealistic	☐	☐	☐	☐	☐
I check what interventions (in my speciality) have higher levels of supporting evidence, using e.g. databases, CATs [f]	☐	☐	☐	☐	☐
I select interventions with the highest levels of evidence that match the goals identified by my families/clients using a systematic EBP approach, e.g. CATs [f], PICO [g] searches	☐	☐	☐	☐	☐
I communicate the outcomes of intervention to families/clients using outcome measures, even when goals aren't achieved	☐	☐	☐	☐	☐

[f] CATs: Critically Appraised Topics; [g] PICO: Population, Intervention, Comparison, Outcome

PART 3: Evidence Based Practice & Outcome Measurement Competencies

1. Name up to two valid, reliable, sensitive to change outcome measures that could be used with a client with cerebral palsy.

2. Choose 3 interventions from the list (see page 11) and state the level of research evidence according to the STOP, MEASURE, GO system (see page 12).	
Intervention	**Stop, Measure or Go?**

3. A client is referred who wants to improve his walking, especially at school. He walks independently but falls quite a lot. He also is being bullied at school but is too frightened to tell anyone. He wonders if his poor articulation might have something to do with why he is bullied. He wants the bullying to stop but is not sure how to make it happen. Write one hypothetical goal that you could set for this client.

4. A client is referred who has a GMFCS of 5. He is 5 years old. What key information will you discuss with his parents regarding expectations for his future?

What types of studies/articles are considered to be high evidence?

Name 2 interventions, pertinent to your professional practice with children with cerebral palsy that have high level evidence supporting their effectiveness.

*Pages 11 and 12 include a full list of interventions plus the evidence alert system summary.

PART 4: Evidence-Based Practice Scale Items

INSTRUCTIONS: *Select the answer that most accurately reflects your attitude today*

ID Code [   ]

	Not at All	To a Slight Extent	To a Moderate Extent	To a Great Extent	To a Very Great Extent
I like to use new types of therapy/interventions to help my clients	☐	☐	☐	☐	☐
I am willing to try new types of therapy/interventions even if I have to follow a treatment manual [h]	☐	☐	☐	☐	☐
I know better than academic researchers how to care for my clients	☐	☐	☐	☐	☐
I am willing to use new and different types of therapy/interventions developed by researchers	☐	☐	☐	☐	☐
Research based treatments/interventions are not clinically useful	☐	☐	☐	☐	☐
Clinical experience is more important than using manualised [h] therapy/interventions	☐	☐	☐	☐	☐
I would not use manualised therapy/interventions	☐	☐	☐	☐	☐
I would try a new therapy/intervention even if it were very different from what I am used to doing	☐	☐	☐	☐	☐

[h] Manualised: Manualised therapy, treatment or intervention refers to any intervention that has specific guidelines and/or components that are outlined in a manual and/or that are to be followed in a structured or predetermined way.

Intervention list for Part 3, Question 2:

Acupuncture	Home Programs
Alcohol	Hydrotherapy
Alternative and Augmentative Communication	Hyperbaric Oxygen
Animal Assisted Therapy	Intrathecal Baclofen
Anti-epileptics	Massage
Assistive Technology [equipment or devices to improve independence]	Neuro-Developmental Therapy
Baclofen [oral]	Occupational Therapy post Botulinum Toxin
Behaviour Therapy [Positive behaviour support, behavioural intervention, parenting]	Oral Motor Treatment
Bimanual Training	Orthopaedic Surgery
Biofeedback	Orthotics [Splints]
Bisphosphonates	Parent Training
Botulinum Toxin	Phenol
Casting	Play Therapy
Coaching Parents	Pressure Care
Cognitive Behaviour Therapy	Respite
Communication Training [Interaction Training; Hanen; It Takes Two to Talk]	Seating & Positioning
Conductive Education	Selective Dorsal Rhizotomy
Constraint Induced Movement Therapy	Sensory Integration
Context Focused Therapy	Sensory Processing [non-Sensory Integration approaches]
Counselling [Parents]	Single Event Multi-Level Surgery with therapy
Dantrolene	Social Stories
Diazepam	Solution Focussed Brief Therapy
Dysphagia Management [oral sensori-motor; food consistency; positioning; oral appliances; equipment]	Strength Training [Resistance]
Early Intervention	Stretching
Electrical Stimulation	Therasuits
Fitness Training	Tizanidine
Fundoplication [Including: Nissen & Laparoscopic; Gastric Plication]	Treadmill training
Gastrostomy [Including: Percutaneous Endoscopic Gastrostomy; PEG; Non oral feeding; Jejunostomy]	Vitamin D [+/- calcium or growth hormones]
Goal-Directed Training/Functional Training	Vojta
Hand Surgery	Whole Body Vibration
Hippotherapy [Therapy on a Horse]	

Evidence Alert System
Novak & McIntyre (2010)
The evidence alert system includes three levels: Stop, Measure, Go according to the level of supporting evidence.

	STOP	***Description:*** good quality published research evidence demonstrates this intervention is ineffective. ***Action:*** Stop – do not use this approach. Choose another approach with positive supporting evidence.
	MEASURE	***Description:*** Only low level published research evidence supports the effectiveness of this intervention OR good quality evidence is inconclusive. ***Action:*** Caution – use this intervention and measure its effectiveness using an outcome measure. *If effective* notify the research team.
	GO	***Description:*** Good quality published research evidence supports the effectiveness of this intervention. ***Action:*** Go – use this intervention.

B11: Supports and Barriers Questionnaire

Supports and Barriers Questionnaire

Rivard, L., Russell, D. J., Roxborough, L. Ketelaar, M. Bartlett, D. J. Rosenbaum P. (Adapted with permission)

To protect your privacy, we are asking each participating allied health professional to provide their own unique identifying code. You must do this using the following formula:

First letter of your first name + Day of Birth (e.g. 24) + First letter of mother's first name + number of siblings you have.
For, example: Name = Joe Blogs; D.O.B. = 24th June; Mother = Julie Blogs; Siblings = 3 sisters: therefore **Joe Blogs' ID Code = J24J3**.

ID Code	
Organisation	

Questionnaire About Possible Supports and Barriers to Use of Routine Data Collection at Your Organization

The purpose of this questionnaire is to find out from you what you perceive to be the possible supports and barriers to implementing routine assessment of children with cerebral palsy using the Cerebral Palsy Check Up range of measures in the *Best Service at the Best time* study at your organisation.

This suite of outcome measures includes up to seven forms that can be used depending on the availability of discipline expertise. These forms include three forms that collect diagnostic details (Form A1: Initial meeting data; Form A2 Clinical details and Form B type and topography) and five additional forms: Form C Mobility and Lower limb assessments; Form D Upper limb and self care assessments; Form E Swallowing, nutrition and communication; Form F Cognition and Learning; and Form G wellbeing.

The information you provide in this questionnaire will help us to tailor education sessions to your needs and to facilitate discussion with others in the study.

The questionnaire is divided into sections that inquire about possible supports and barriers related to:

- your organisational structure,
- your organisational resources,
- the therapists at your organisation,
- the measures themselves,
- the children and families at your organisation.

In addition, there is a rating scale for each section that we would ask you to complete.

Data Collection Period: *Baseline*   *Six Months*   *Twelve Months*   *Twenty-Four Months*

1. Possible supports or barriers related to your <u>organisational structure</u>.

Please list below any aspects of your **organisational structure** that you believe may affect the use of routine data collection strategies included in the *Cerebral Palsy Check Up* study at your organisation.

Examples of such factors include: decision-making processes and procedures in your organisation; extent to which decision-making processes are formalised through procedures; formal reinforcement by management to integrate the measures into organisational policies; organisational size (number of therapists); staff turnover; and logistical procedures related to the use of the measures.

Supports:

Barriers:

Possible strategies to overcome identified barriers:

Overall, to what extent do you feel your **<u>organisational structure</u>** is a support or a barrier to implementing the Cerebral Palsy Check Up measures?

-5	-4	-3	-2	-1	0	1	2	3	4	5
Barrier										Support

Adapted from: Fleuren M, Wiefferink K, Paulussen T. Determinants of innovation within health care organizations. *Int J Qual Health Care.* 2004;16:107–123.

2. Possible supports or barriers related to your _organisational resources_.

Please list below any factors related to your **_organisational resources_** that you believe may affect the use of the Cerebral Palsy Check Up.

Examples of such factors include: financial resources made available for the use of the motor growth measures; reimbursement for health care professionals to facilitate extra efforts in using or applying the measures; other resources made available related to the measures (ie, equipment, manuals); administrative support available to therapists for implementation of the measures; time available to implement the measures; availability of staff responsible for coordination, implementation in the organisation/department; degree to which therapists were involved in the development or testing of the measures; available expertise in relation to the measures.

Supports:

Barriers:

Possible strategies:

Overall, to what extent do you feel your **_organisational resources_** are a support or a barrier to the use of the Cerebral Palsy Check Up measures?

-5	-4	-3	-2	-1	0	1	2	3	4	5
Barrier										Support

3. Possible supports and barriers related to <u>the *therapists* at your organisation.</u>

Please list below any factors related to the ***therapists at your organisation*** that you believe may affect the implementation of the Cerebral Palsy Check Up measures.

Examples of such factors include: support from colleagues, supervisors, and the organisation with respect to using the measures; extent to which colleagues use the measures (modeling); extent to which the therapists have the knowledge, skills, and confidence needed to use the measures; extent to which ownership by the therapists is perceived; extent to which the health care professional expects that the children and families will cooperate and be satisfied with the use of the measures; extent to which the measures add to work-related stress or are contrary to the goals of therapists; extent to which the therapists have ethical problems with the measures.

Supports:

Barriers:

Possible strategies to overcome identified barriers:

Overall, to what extent do you feel that the ***<u>therapists at your organisation</u>*** are a support or a barrier to implementing the Cerebral Palsy Check Up measures?

-5	-4	-3	-2	-1	0	1	2	3	4	5
Barrier										Support

4. Possible supports or barriers related to the _measures included in the Cerebral Palsy Check Up_.

Please list below any factors related to the **_measures included in the Cerebral Palsy Check Up_** that you believe may affect the use of these measures at your organisation.

Examples of such factors include: the extent to which the procedures/guidelines for use of the measures are clear, easy to use, and add value to what you already do; the extent to which the measures are consistent with existing work procedures and needs; the extent to which the measures are perceived as advantageous; the frequency with which the measures are required/used.

Supports:

Barriers:

Possible strategies to overcome identified barriers:

Overall, to what extent do you believe that aspects of **_the measures included in the Cerebral Palsy Check Up_** are a support/barrier to the use of the measures at your organization?

-5	-4	-3	-2	-1	0	1	2	3	4	5
Barrier										Support

5. Possible supports or barriers related to the _children and families_ at your organisation.

Please list below any factors related to the **children and families** at your organisation that you believe may affect the implementation of the Cerebral Palsy Check Up measures.

Examples of such factors include: the willingness of the children and families to cooperate with the use of the measures; the extent to which the children and families are aware of the benefits of the measures; the extent to which families are confident regarding the therapist's expertise and competence with respect to the use of the measures; the extent to which parents and children are comfortable (physically or emotionally) with the use of the measures.

Supports:

Barriers:

Possible strategies to overcome identified barriers:

Overall, to what extent do you feel **_the children and families_** at your organisation are a support or a barrier to implementing the Cerebral Palsy Check Up measures?

-5	-4	-3	-2	-1	0	1	2	3	4	5
Barrier										Support

Thank you
For taking the time to complete this questionnaire

B12: CP Check Up form

Cerebral Palsy ALLIANCE

CP Check-Up
FORM A – INITIAL MEETING

Client name

Date of birth

Age [Years : Months]

Date of assessment

Assessor

Medicare no

CPA client no

Already on the CP Register? ☐ Yes ☐ No
If yes, please go to the next page and fill up the highlighted items

BIRTH DETAILS

Birth place
(e.g. Hornsby Hospital, home birth, birth centre)

State

If home birth ☐ Planned ☐ Unplanned

Birth weight

Weeks gestation

Hospital of neonatal transfer (if applicable)

State of hospital

Received more than routine care? ☐ Yes – NICU ☐ No – routine care only ☐ Yes – special care
If yes, total length of stay [ ] days

Was this a multiple birth? ☐ Yes ☐ No

If yes, number of children: ☐ Twins ☐ Triplets ☐ 4 ☐ 5 ☐ 6 ☐ >6

Birth order of child with CP (e.g. 2nd)

Was there any assistance with conception?
(please tick)
☐ No
☐ Yes, type unknown
☐ Yes, if known please circle type of assistance:
 fertility drugs only
 ovulation stimulation only
 artificial insemination
 ICSI
 IVF
 IGIFT
☐ Other

Number of previous live births to mother

Number of previous stillbirths (> 20 weeks) to mother

Number of previous miscarriages (> 20 weeks) to mother

Birth length (cm)

Head circumference (cm)

Respiratory care required in neonatal period? ☐ Yes ☐ No ☐ Unknown

Apgar scores, if known   If unknown, baby at birth

1 minute [ ]   ☐ Well

5 minute [ ]   ☐ Unwell

10 minute [ ]   ☐ Unknown

Were any birth defects present? ☐ Yes ☐ No
(e.g. congenital heart defect)
If yes, please give details

TIMING AND CAUSE OF CEREBRAL PALSY

Timing of cerebral palsy
☐ Unknown
☐ During pregnancy and up to first 28 days of life (pre & perinatal)
☐ Up to first 28 days of life in a previously well infant
☐ After first 28 days of life (postnatal)

Was there a confirmed cause of cerebral palsy?
☐ Unknown
☐ In utero cytomegalovirus
☐ Other infection (toxoplasmosis, rubella, herpes simplex virus)
☐ Other infection (please list in comments)
☐ Other (please list in comments)

Head injury
☐ Motor vehicle accident
☐ Non accidental
☐ Fall
☐ Other (please describe in comments)

Infection
☐ Unspecified cause
☐ Viral
☐ Bacterial
☐ Dehydration due to gastroenteritis

Stroke or CVA
☐ During or following surgical procedure
☐ Spontaneous
☐ Associated with other cardiac complications

Other
☐ Post seizure
☐ Near sudden infant death syndrome (SIDS)
☐ Post immunisation
☐ Near drowning
☐ Peri-operative hypoxia
☐ Apparent life-threatening event
☐ Other (please describe in comments)

COMMENTS

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BIRTH PARENT DETAILS

Mother

First name		Maiden Name	
Surname		DOB	/ /

Country of birth

Educational level at time of child's birth

Aboriginal or Torres Strait Islander origin?
- ☐ Aboriginal but not Torres Strait Islander origin
- ☐ Torres Strait Islander but not Aboriginal origin
- ☐ Both Aboriginal and Torres Strait Islander origin
- ☐ Neither Aboriginal nor Torres Strait Islander origin

Father

First name			
Surname		DOB	/ /

Country of birth

Educational level at time of child's birth

Aboriginal or Torres Strait Islander origin?
- ☐ Aboriginal but not Torres Strait Islander origin
- ☐ Torres Strait Islander but not Aboriginal origin
- ☐ Both Aboriginal and Torres Strait Islander origin
- ☐ Neither Aboriginal nor Torres Strait Islander origin

BRAIN AND BRAIN IMAGING

Ultrasound completed? ☐ Yes ☐ No ☐ Unknown

Hospital

Approximate date / /

CT completed? ☐ Yes ☐ No ☐ Unknown

Hospital

Approximate date / /

MRI completed? ☐ Yes ☐ No ☐ Unknown

Hospital

Approximate date / /

Dominant morphology:
- ☐ Normal findings
- ☐ White matter injury of prematurity
- ☐ Basal ganglia pattern
- ☐ No information
- ☐ Focal cortical injury
- ☐ Diffuse cortical injury
- ☐ Malformation

Injury damage found
- ☐ Nil
- ☐ Unilateral right
- ☐ Unilateral left
- ☐ Blateral injury

Cerebellum
- ☐ Normal ☐ Pathological ☐ Unknown

Corpus callosum
- ☐ Normal ☐ Pathological ☐ Unknown

Sign of infection
- ☐ Normal ☐ Pathological ☐ Unknown

Hydrocephalus neurosurgically treated
- ☐ Yes ☐ No ☐ Unknown

ASSOCIATED IMPAIRMENTS OR CONDITIONS
(please tick one for each section)

Epilepsy
- ☐ Yes ☐ No
- ☐ Resolved by age 5 ☐ Unknown

Intellectual
- ☐ No impairment ☐ Mild
- ☐ Probably no impairment ☐ Moderate
- ☐ Probably some impairment ☐ Severe
- ☐ Unknown

Visual
- ☐ No impairment ☐ Functionally blind
- ☐ Some impairment ☐ Unknown

Strabismus ☐ Yes ☐ No ☐ Unknown

Hearing
- ☐ No impairment ☐ Bilateral deafness
- ☐ Some impairment (includes conductive hearing loss) ☐ Unknown

Speech
- ☐ No impairment ☐ Nonverbal
- ☐ Some impairment ☐ Unknown

RESPIRATORY

☐ No impairment ☐ Pathological ☐ Unknown

GENERAL MOVEMENTS

Writhing period

- ☐ Normal ☐ Poor Repetoire ☐ Cramped–Synchronised
- ☐ Chaotic ☐ Unknown ☐ Not assessed

Fidgety period

- ☐ Normal ☐ Absent ☐ Abnormal
- ☐ Unknown ☐ Not assessed

COMMENTS

Please use this space to record any general comments regarding this assessment period:

Cerebral Palsy ALLIANCE

CP Check-Up

FORM A – CLINICAL DETAILS

Client name	
Date of birth		Age	Years : Months
Date of assessment		Assessor	
Medicare no		CPA client no	

PAIN

Does person or proxy report any pain? ☐ Yes ☐ No
If yes, indicate location, frequency and description of pain

Location	Frequency	Intensity	Description
	All the time Daily Twice or more weekly Weekly Monthly Unknown	0–10 0 = none 10 = agonising Unknown	e.g. Aching, dull, tingling or numb, sharp, burning or stabbing, cramped, combination, unknown
☐ Head or neck			
☐ Teeth			
☐ Back			
☐ Stomach			
☐ Right arm / hand			
☐ Left arm / hand			
☐ Right hip			
☐ Left hip			
☐ Right leg			
☐ Left leg			
☐ Right foot			
☐ Left foot			

If yes, please indicate if the experience of pain impact on any of the following areas

☐ Movement and activity ☐ Sleep and rest
☐ Emotions and concentration ☐ School or work attendance
☐ Other: ☐ Unknown

If yes, please indicate if the experience of pain is intensified by

☐ Movement and activity ☐ Immobility
☐ Fatigue ☐ Combination
☐ Other: ☐ Unknown

FRACTURES

Has the person had any fractures since the last assessment?
☐ Yes ☐ No

If yes, how many fractures? _____

Please describe

Skin Integrity / Health

Has the person had any indicators of pressure? ☐ Yes ☐ No
If yes, please indicate location and type of pressure (redness, pressure sores, ulcers)

Location	Description (redness, pressure sores, ulcers)
☐ Head or neck	
☐ Back	
☐ Stomach	
☐ Right arm / hand	
☐ Left arm / hand	
☐ Right hip	
☐ Left hip	
☐ Right leg	
☐ Left leg	
☐ Right foot	
☐ Left foot	

Surgical Interventions
(not including Upper or Lower Limb Orthopaedic Surgery)

Has the person had any surgery since the last assessment?
☐ Yes ☐ No
If yes, what surgery?

If yes, what date? ___ / ___ / ___

SLEEP

Sleep Scale (Children 0-2 yrs)
(Sleep scale for children 3-18 years on next page)
How many hours of sleep does your child get on most nights?
(Excl. feeding breaks)
☐ 9–11 hrs ☐ 8–9 hrs ☐ 7–8 hrs
☐ 5–7 hrs ☐ less than 5 hrs

How many times a night does your child wake? _____

How many hours of sleep does your child have during the day?
☐ 9–11 hrs ☐ 8–9 hrs ☐ 7–8 hrs
☐ 5–7 hrs ☐ 3–5 hrs ☐ less than 3 hrs

How satisfied are you with your child's sleep patterns? (please tick)
Very unsatisfied ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10 Very satisfied

Is the family concerned about the child's sleep pattern? ☐ Yes ☐ No

* Dark green highlighted areas = To be completed twice a year for children aged 6 and younger

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Sleep Disturbance Scale (Children 3-18 yrs)

1. How many hours of sleep does your child get on most nights?
   ☐ 9–11 hrs (1)   ☐ 8–9 hrs (2)   ☐ 7–8 hrs (3)
   ☐ 5–7 hrs (4)   ☐ less than 5 hrs (5)

2. How long after going to bed does your child usually fall asleep?
   ☐ < 15 mins (1)   ☐ 15–30 mins (2)   ☐ 30–45 mins (3)
   ☐ 45–60 mins (4)   ☐ >60 mins (5)

	Never	Occasionally Once/twice per month or less	Sometimes Once/twice per week	Often 3 to 5 times per week	Always Daily
	(1)	(2)	(3)	(4)	(5)
3. The child goes to bed reluctantly	☐	☐	☐	☐	☐
4. The child has difficulty getting to sleep at night	☐	☐	☐	☐	☐
5. The child feels anxious/afraid when falling asleep at night	☐	☐	☐	☐	☐
6. The child startles or jerks part of the body while falling asleep	☐	☐	☐	☐	☐
7. The child shows repetitive actions such as rocking or head banging while falling asleep	☐	☐	☐	☐	☐
8. The child experiences vivid/dream like scenes when falling asleep	☐	☐	☐	☐	☐
9. The child sweats excessively while falling asleep	☐	☐	☐	☐	☐
10. The child wakes up more than twice per night	☐	☐	☐	☐	☐
11. After waking in the night, the child has difficulty falling asleep again	☐	☐	☐	☐	☐
12. The child has frequent twitching or jerking of legs while asleep or often changes position during the night or kicks the covers off the bed	☐	☐	☐	☐	☐
13. The child has difficulty in breathing during the night	☐	☐	☐	☐	☐
14. The child gasps for breath or is unable to breathe during sleep	☐	☐	☐	☐	☐
15. The child snores	☐	☐	☐	☐	☐
16. The child sweats excessively during the night	☐	☐	☐	☐	☐
17. You have observed the child sleepwalking	☐	☐	☐	☐	☐
18. You have observed the child talking in his/her sleep	☐	☐	☐	☐	☐
19. The child grinds teeth during sleep	☐	☐	☐	☐	☐
20. The child wakes from sleep screaming or confused so you cannot seem to get through to him/her, but has no memory of these events the next morning	☐	☐	☐	☐	☐
21. The child has nightmares which he/she cannot remember the next day	☐	☐	☐	☐	☐
22. The child is unusually difficult to wake in the morning	☐	☐	☐	☐	☐
23. The child wakes in the morning feeling tired	☐	☐	☐	☐	☐
24. The child feels unable to move when waking up in the morning	☐	☐	☐	☐	☐
25. The child experiences daytime somnolence (drowsiness)	☐	☐	☐	☐	☐
26. The child falls asleep suddenly in inappropriate situations	☐	☐	☐	☐	☐

* Office use only

Disorders of initiating and maintaining sleep (sum the score of the items 1,2,3,4,5,10,11) ☐
Sleep breathing disorders (sum the score of the items 13,14,15) ☐
Disorders of arousal (sum the score of the items 17,20,21) ☐
Sleep-wake transition disorders (sum the score of the items 6,7,8,12,18,19) ☐
Disorders of excessive somnolence (sum the score of the items 22,23,24,25,26) ☐
Sleep hyperhydrosis (sum the score of the items 9,16) ☐
Total score (sum 6 factors' scores) ☐

Areas of intervention	**Intervention Approach 1** Record any interventions the client has received. If known, include interventions provided from other service providers.	**Intervention Approach 2** Record any interventions the client has received. If known, include interventions provided from other service providers.	**Intervention Approach 3** Record any interventions the client has received. If known, include interventions provided from other service providers.
Pain	Please only tick one intervention per invention approach		
	☐ Active range of motion	☐ Active range of motion	☐ Active range of motion
	☐ Baclofen	☐ Baclofen	☐ Baclofen
	☐ BoNT–A	☐ BoNT–A	☐ BoNT–A
	☐ CBT	☐ CBT	☐ CBT
	☐ Casting/Splint	☐ Casting/Splint	☐ Casting/Splint
	☐ Drug prescription	☐ Drug prescription	☐ Drug prescription
	☐ Hydrotherapy	☐ Hydrotherapy	☐ Hydrotherapy
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Pain heat/cold	☐ Pain heat/cold	☐ Pain heat/cold
	☐ Pain massage	☐ Pain massage	☐ Pain massage
	☐ Passive range of motion	☐ Passive range of motion	☐ Passive range of motion
	☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
	☐ Strength training	☐ Strength training	☐ Strength training
	☐ Referral	☐ Referral	☐ Referral
	☐ Other:	☐ Other:	☐ Other:
Sleep	Please only tick one intervention per invention approach		
	☐ Behaviour support program	☐ Behaviour support program	☐ Behaviour support program
	☐ Equipment prescription	☐ Equipment prescription	☐ Equipment prescription
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Parenting program	☐ Parenting program	☐ Parenting program
	☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
	☐ Referral to sleep clinic	☐ Referral to sleep clinic	☐ Referral to sleep clinic
	☐ Other:	☐ Other:	☐ Other:

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Cerebral Palsy ALLIANCE

CP Check-Up
FORM B — TYPE AND TOPOGRAPHY

Client name:

Date of birth: Age:

Date of assessment: Assessor:

Medicare no: CPA client no:

TYPE AND TOPOGRAPHY
Australian Spasticity Assessment Scale

1. Is there spastic tone in one or more limbs?

Please tick Yes/No boxes as applicable

☐ Yes   ☐ No

Go to 2

In stick figure circles write highest ASAS score for each upper and lower limb

Is the person? ☐ Male   ☐ Female

Head and Neck
Head
Neck
Face
Trunk

Axial, neck & face tone
↓ Hypotonic
↑ Hypertonic
↕ Fluctuating
Normal

Upper Limb	**Right**	**Upper Limb**	**Left**
Bicep		Bicep	
Forearm pronators		Forearm pronators	
Wrist flexors		Wrist flexors	
Lower Limb		**Lower Limb**	
Adductors		Adductors	
Knee flexors		Knee flexors	
Plantar flexors		Plantar flexors	

R   L

Go to 2

Stick Figure 1

---

2. Is muscle tone varying

☐ Yes   ☐ No

3. Are there any signs of ataxia?

☐ Yes   ☐ No

Dystonic   Athetoid

Is there generalised hypotonia with increased reflexes?

☐ Yes   ☐ No

R   L   R   L

Stick Figure 2a   **Stick Figure 2b** → Go to 3

Please number tone/movement abnormalities present in this person in order of predominance. (1 = most predominant)

Spasticity
Dystonia
Athetosis
Ataxia
Generalised hypotonia

TOPOGRAPHY FROM ASAS:

☐ Hemiplegia (spasticity present in 1 arm, 1 leg, trunk, +/- face and pseudobulbar palsy)
☐ Diplegia (spasticity all four limbs with LL > ULs and trunk, +/- face and pseudobulbar palsy)
☐ Quadriplegia (spasticity all limbs and trunk UL LLs. +/- face and pseudobulbar palsy)

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* Dark green highlighted areas = To be completed twice a year for children aged 6 and younger

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Hypertonicity Assessment Tool (Children 4-19 yrs)

(Please tick if present)

	Left Upper Limb	Right Upper Limb	Left Lower Limb	Right Lower Limb	
1. Increased involuntary movements or postures of the designated limb with tactile stimulus of a distant body part	☐	☐	☐	☐	Dystonia
2. Increased voluntary movements or postures with purposeful movement of a distant body part	☐	☐	☐	☐	Dystonia
3. Velocity-dependent resistance to stretch	☐	☐	☐	☐	Spasticity
4. Presence of a spastic catch	☐	☐	☐	☐	Spasticity
5. Equal resistance to passive stretch during bidirectional movement of a joint	☐	☐	☐	☐	Rigidity
6. Increased tone with movement of a distant body part	☐	☐	☐	☐	Dystonia
7. Maintenance of limb position after passive movement	☐	☐	☐	☐	Rigidity

SUMMARY SCORE

Dystonia	Positive score (1) on at least one of Items #1, 2, or 6	☐ Yes*	☐ No
Spasticity	Positive score (1) on either one or both of Items #3 or 4	☐ Yes	☐ No
Rigidity	Positive score (1) on either one or both of Items #5 or 7	☐ Yes	☐ No
Mixed Tone	Presence of items from more than one subgroup (e.g. dystonia, spasticity, rigidity)	☐ Yes	☐ No

* Have you completed ASAS Figure 2A

* Dark green highlighted areas = To be completed twice a year for children aged 6 and younger

The Australian Spasticity Assessment Scale

0   No catch on rapid passive movement (RPM) (no spasticity).

1   Catch occurs on RPM followed by release. There is no resistance to RPM throughout range.

2   Catch occurs in second half of available range (after halfway point) during RPM and is followed by resistance throughout remaining range.

3   Catch occurs in the first half of range (up to and including halfway point) during RPM and is followed by resistance throughout remaining range.

4   When attempting RPM, the body part appears fixed but moves on slow passive movement.

CP Check-Up

FORM C – MOBILITY & LOWER LIMB

Client name

Date of birth

Age | Years : Months

Date of assessment

Assessor

Medicare no

CPA client no

LOWER LIMB – MUSCULOSKELETAL ASSESSMENT

ANKLES–SUPINE

	Left			Right		
	R1°	R2°	Deviates from starting position?	R1°	R2°	Deviates from starting position?
Dorsiflexion (knee flexion) (≥20° GMFCS I-III) (≥ 10° GMFCS IV-V)						
Dorsiflexion (knee extension) (≥10° GMFCS I-III) (≥0° GMFCS IV-V)						

Showing signs of pain during examination? ☐ Yes ☐ No

KNEES–SUPINE

	Left			Right		
	R1°	R2°	Deviates from starting position?	R1°	R2°	Deviates from starting position?
Hamstring angle 90° hip flexion (full extended knee = 180°) (≥140° GMFCS I-III) (≥130° GMFCS IV-V)						
Extension hip extension (full extension = 0°) (≥0° GMFCS I-III) (≥-10° GMFCS IV-V)						

Showing signs of pain during examination? ☐ Yes ☐ No

HIPS–PRONE

	Left		Right	
	EOR°	Deviates from starting position?	EOR°	Deviates from starting position?
Internal rotation (hip extension, knee flexion) (≥40°)				
External rotation (hip extension, knee flexion) (≥40°)				
Elys Test (length of rectus, fix the pelvis, flex the knee) (≥120° GMFCS I-III) (≥110° GMFCS IV-V)				
Extension (Staheli test) (legs off edge of bed, extend one of the legs, your other hand on the pelvis) (≥0°)				
Extension (Thomas test) (NB. If the child is unable to lie in prone you may use the Thomas test as a last resort)				

Showing signs of pain during examinaion? ☐ Yes ☐ No

HIPS–SUPINE

	Left			Right		
	R1°	R2°	Deviates from starting position?	R1°	R2°	Deviates from starting position?
Hip abduction (with lower legs off the edge of bed, extended hips with flexed knees) (≥40° GMFCS I-III) (≥30° GMFCS IV-V)						
Hip abduction (hips and knees extended)						
Hip flexion (≥120°)						

Showing signs of pain during examination? ☐ Yes ☐ No

FEET

Able to put weight on both feet ☐ Yes ☐ No

Able to put weight on both heel Right ☐ Yes ☐ No

Left ☐ Yes ☐ No

If yes, weight bearing on heel is

	Normal	Varus	Valgus
Right	☐	☐	☐
Left	☐	☐	☐

Other comments:

Showing signs of pain during examination? ☐ Yes ☐ No

SPINE

Scoliosis surgery? ☐ Yes ☐ No

If no, assessed in ☐ Standing ☐ Sitting on plinth

Scoliosis present? ☐ Yes ☐ No

If yes, please indicate location

	Convex to L	Convex to R
Cervical	☐	☐
Thoracic	☐	☐
Thoracolumbar	☐	☐
Lumbar	☐	☐

Scoliosis is ☐ Correctable ☐ No

If no, assessed in ☐ Standing ☐ Sitting on plinth

Scoliosis present? ☐ Yes ☐ No

Showing signs of pain during examination? ☐ Yes ☐ No

Kyphosis present? ☐ Yes ☐ No

If yes, please describe

Lordosis present? ☐ Yes ☐ No

If yes, please describe

Spine rotated? ☐ Yes ☐ No

If yes, please describe

* Dark green highlighted areas = To be completed twice a year for children aged 6 and younger

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PELVIS

In sitting, is pelvis positioned in neutral? ☐ Yes ☐ No

If no, please indicate position

Tilt	☐ Neutral	☐ Posterior	☐ Anterior	FL/ L/ F
Obliquity	☐ Neutral	☐ Left ↑	☐ Right ↑	FL/ L/ F
Rotation	☐ Neutral	☐ Forward L	☐ Forward R	FL/ L/ F

Please circle FL = flexible, L = limited or F = fixed

HIP XRAY

Has the person had a hip xray since the last assessment? ☐ Yes ☐ No

If yes, please provide details:

Date ☐ / / Left MP ☐ Right MP ☐

☐ Details not currently available

MOBILITY

GMFCS E&R (Children 0-18 yrs)
☐ Level I
☐ Level II
☐ Level III
☐ Level IV
☐ Level V

FMS (Children 4 – 18 yrs)

5m	50m	500m
☐ N	☐ N	☐ N
☐ C	☐ C	☐ C
☐ 1	☐ 1	☐ 1
☐ 2	☐ 2	☐ 2
☐ 3	☐ 3	☐ 3
☐ 4	☐ 4	☐ 4
☐ 5	☐ 5	☐ 5
☐ 6	☐ 6	☐ 6

LOWER LIMB ASSESSMENT

Gross Motor Function Measure (GMFM) (Children 0-18 yrs)

Date GMFM performed within this assessment period: / /

Was the person tested wearing orthoses? ☐ Yes ☐ No
Was the person tested using mobility device? ☐ Yes ☐ No

☐ GMFM–66
☐ GMFM–88

Total (%)	
Dimension score (%) A	
Dimension score (%) B	
Dimension score (%) C	
Dimension score (%) D	
Dimension score (%) E	

	Score	95% CI
GMAE		

MOST COMMON TRANSITIONAL MOVEMENTS

	Without assistance	With assistance*	Unable
Floor sitting to standing	☐	☐	☐
Standing to floor sitting	☐	☐	☐
Sit to stand from chair	☐	☐	☐
Sitting in chair from standing	☐	☐	☐
Lying to sitting	☐	☐	☐

* with assistance may include mobility device include use of walls, furniture, person

SITTING (TICK ALL THAT APPLY)
Chair
☐ Not sitting ☐ High chair ☐ Specialised ☐ Regular chair

STANDING
Uses standing frame ☐ Yes ☐ No
If yes, please indicate

Days/week	☐ 1–2 days	☐ 3–4 days	☐ 5–6 days	☐ 7 days
Times/day	☐ 1	☐ 2	☐ 3	☐ >3

Type of standing frame	☐ Tilt table	☐ Supine	☐ Prone	☐ Upright

STAIRS

	Ascend stairs	Descend stairs
Independent without support	☐	☐
Independent with handrail	☐	☐
Person assisting	☐	☐
Person assisting and handrail	☐	☐
Unable	☐	☐

USE OF WHEELCHAIR
(please tick all that apply)

	Not used	Self-propelled	Propelled by assistant	Seating System˜
Inside				
Manual wheelchair	☐	☐	☐	
Power wheelchair	☐	☐	☐	
Outside				
Manual wheelchair	☐	☐	☐	
Power wheelchair	☐	☐	☐	

˜ Seating system C = custom made, CA = commercially available, N= No

Mobility equipment
Other mobility equipment used
☐ Walker
☐ Crutches
☐ Sticks

Mobility device prescribed since the last assessment? ☐ Yes ☐ No

If yes, please describe

* Dark green highlighted areas = To be completed twice a year for children aged 6 and younger

LOWER LIMB ORTHOSES

	LEFT					RIGHT				
	Purpose					Purpose				
	Function	Maintain ROM	Pain	Time worn (hr/day)	Duration (months)	Function	Maintain ROM	Pain	Time worn (hr/day)	Duration (months)
'FO Orthoses' shoe insert	☐	☐	☐			☐	☐	☐		
Rigid AFO (day)	☐	☐	☐			☐	☐	☐		
Rigid AFO (night)	☐	☐	☐			☐	☐	☐		
Hinged AFO (day)	☐	☐	☐			☐	☐	☐		
Hinged AFO (night)	☐	☐	☐			☐	☐	☐		
GRAFO	☐	☐	☐			☐	☐	☐		
KO (night)	☐	☐	☐			☐	☐	☐		
Hip abduction brace	☐	☐	☐			☐	☐	☐		
KAFO	☐	☐	☐			☐	☐	☐		

Have skin irritation/ulcers occurred in connection with the use of orthoses?　☐ Yes　No

If yes, comments

SPASTICITY MANAGEMENT

Selective Dorsal Rhizotomy

☐ Yes　　☐ No
If yes, what date?　　　/　　/

Botulinum toxin

Has the person received botulinum toxin in the lower limbs since the last assessment?　☐ Yes　☐ No
If yes, what date?　　　/　　/

Has the person been referred for botulinum toxin injections?　☐ Yes　☐ No
If yes, what date?　　　/　　/

If yes, which muscles?	L	R
Psoas	☐	☐
Adductors	☐	☐
Hamstrings	☐	☐
Gastrocs	☐	☐
Soleus	☐	☐
Tib post	☐	☐

Spasticity reducing medication e.g. Baclofen

Is the person treated with spasticity reducing medication such as Baclofen?　☐ Yes　☐ No
If yes,　☐ Oral
　　　　☐ ITB pump – date inserted:
　　　　　　/　　/

LOWER LIMB SURGERY

SEMLS

Has the person received SEMLS since the last assessment?　☐ Yes　☐ No

If yes, what date?　　　/　　/

Which procedures?

Bony	L	R
Femoral osteotomy	☐	☐
Pelvic osteotomy	☐	☐
Tibial osteotomy	☐	☐
Supracondylar extension osteotomy	☐	☐
Supramalleolar osteotomy	☐	☐
8 plates/ Epiphysiodesis	☐	☐

Soft tissue	L	R
Hip flexors	☐	☐
Adductors	☐	☐
Knee flexors	☐	☐
Knee extensors	☐	☐
Calf	☐	☐
Foot	☐	☐
Other:	☐	☐

---

* Dark green highlighted areas = To be completed twice a year for children aged 6 and younger

SEPARATE SURGICAL INTERVENTIONS (SEPARATE TO SEMLS)

Bony

Has the person received separate surgical interventions since the last assessment? ☐ Yes ☐ No

If yes, which procedures?

	L	R		
Femoral osteotomy	☐	☐	/	/
Pelvic osteotomy	☐	☐	/	/
Tibial osteotomy	☐	☐	/	/
Supracondylar extension osteotomy	☐	☐	/	/
Supramalleolar osteotomy	☐	☐	/	/
8 plates/Epiphysiodesis	☐	☐	/	/
Other:	☐	☐	/	/

Soft tissue surgery

Has the person received separate surgical interventions since the last assessment? ☐ Yes ☐ No

If yes, which muscles?

	L	R		
Hip flexors	☐	☐	/	/
Adductors	☐	☐	/	/
Knee flexors	☐	☐	/	/
Knee extensors	☐	☐	/	/
Calf	☐	☐	/	/
Foot	☐	☐	/	/
Other:	☐	☐	/	/

Any other comments for form C

* Dark green highlighted areas = To be completed twice a year for children aged 6 and younger

Areas of intervention	Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.
Mobility	Please only tick one intervention per invention approach		
	☐ Active Range of Motion	☐ Active Range of Motion	☐ Active Range of Motion
	☐ Biofeedback	☐ Biofeedback	☐ Biofeedback
	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy
	☐ Botulinum Toxin	☐ Botulinum Toxin	☐ Botulinum Toxin
	☐ Functional strength training	☐ Functional strength training	☐ Functional strength training
	☐ Goal directed training of gross motor tasks	☐ Goal directed training of gross motor tasks	☐ Goal directed training of gross motor tasks
	☐ Hippotherapy	☐ Hippotherapy	☐ Hippotherapy
	☐ Hydrotherapy	☐ Hydrotherapy	☐ Hydrotherapy
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Mobility equipment prescription	☐ Mobility equipment prescription	☐ Mobility equipment prescription
	☐ Mobility equipment use training	☐ Mobility equipment use training	☐ Mobility equipment use training
	☐ Passive Range of Motion	☐ Passive Range of Motion	☐ Passive Range of Motion
	☐ Progressive strength training	☐ Progressive strength training	☐ Progressive strength training
	☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
	☐ Referral for spasticity management	☐ Referral for spasticity management	☐ Referral for spasticity management
	☐ Seating and positioning equipment prescription	☐ Seating and positioning equipment prescription	☐ Seating and positioning equipment prescription
	☐ Sports	☐ Sports	☐ Sports
	☐ Treadmill training	☐ Treadmill training	☐ Treadmill training
	☐ Other:	☐ Other:	☐ Other:

Areas of intervention	Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.

Hips

Please only tick one intervention per invention approach

Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
☐ Active Range of Motion	☐ Active Range of Motion	☐ Active Range of Motion
☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy
☐ Botulinum Toxin	☐ Botulinum Toxin	☐ Botulinum Toxin
☐ Casting	☐ Casting	☐ Casting
☐ Conductive education	☐ Conductive education	☐ Conductive education
☐ Drug/ointment prescription	☐ Drug/ointment prescription	☐ Drug/ointment prescription
☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)
☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
☐ Passive Range of Motion	☐ Passive Range of Motion	☐ Passive Range of Motion
☐ Pressure care	☐ Pressure care	☐ Pressure care
☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
☐ Referral for hip xray	☐ Referral for hip xray	☐ Referral for hip xray
☐ Referral for spasticity management	☐ Referral for spasticity management	☐ Referral for spasticity management
☐ Referral for surgery	☐ Referral for surgery	☐ Referral for surgery
☐ Stretching	☐ Stretching	☐ Stretching
☐ Therapy after surgery	☐ Therapy after surgery	☐ Therapy after surgery
☐ TheraSuits	☐ TheraSuits	☐ TheraSuits
☐ Other:	☐ Other:	☐ Other:

Knees

Please only tick one intervention per invention approach

Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
☐ Active Range of Motion	☐ Active Range of Motion	☐ Active Range of Motion
☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy
☐ Botulinum Toxin	☐ Botulinum Toxin	☐ Botulinum Toxin
☐ Casting	☐ Casting	☐ Casting
☐ Conductive education	☐ Conductive education	☐ Conductive education
☐ Drug/ointment prescription	☐ Drug/ointment prescription	☐ Drug/ointment prescription
☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)
☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
☐ Passive Range of Motion	☐ Passive Range of Motion	☐ Passive Range of Motion
☐ Pressure care	☐ Pressure care	☐ Pressure care
☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
☐ Referral for spasticity management	☐ Referral for spasticity management	☐ Referral for spasticity management
☐ Referral for surgery	☐ Referral for surgery	☐ Referral for surgery
☐ Stretching	☐ Stretching	☐ Stretching
☐ Therapy after surgery	☐ Therapy after surgery	☐ Therapy after surgery
☐ TheraSuits	☐ TheraSuits	☐ TheraSuits
☐ Other:	☐ Other:	☐ Other:

Ankles

Please only tick one intervention per invention approach

Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
☐ Active Range of Motion	☐ Active Range of Motion	☐ Active Range of Motion
☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy
☐ Botulinum Toxin	☐ Botulinum Toxin	☐ Botulinum Toxin
☐ Casting	☐ Casting	☐ Casting
☐ Conductive education	☐ Conductive education	☐ Conductive education
☐ Drug/ointment prescription	☐ Drug/ointment prescription	☐ Drug/ointment prescription
☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)
☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
☐ Passive Range of Motion	☐ Passive Range of Motion	☐ Passive Range of Motion
☐ Pressure care	☐ Pressure care	☐ Pressure care
☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
☐ Referral for spasticity management	☐ Referral for spasticity management	☐ Referral for spasticity management
☐ Stretching	☐ Stretching	☐ Stretching
☐ Therapy after surgery	☐ Therapy after surgery	☐ Therapy after surgery
☐ TheraSuits	☐ TheraSuits	☐ TheraSuits
☐ Other:	☐ Other:	☐ Other:

Areas of intervention	Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.

Feet

Please only tick one intervention per invention approach

Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
☐ Active Range of Motion	☐ Active Range of Motion	☐ Active Range of Motion
☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy
☐ Botulinum Toxin	☐ Botulinum Toxin	☐ Botulinum Toxin
☐ Casting	☐ Casting	☐ Casting
☐ Conductive education	☐ Conductive education	☐ Conductive education
☐ Drug/ointment prescription	☐ Drug/ointment prescription	☐ Drug/ointment prescription
☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)
☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
☐ Passive Range of Motion	☐ Passive Range of Motion	☐ Passive Range of Motion
☐ Pressure care	☐ Pressure care	☐ Pressure care
☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
☐ Referral for hip xray	☐ Referral for hip xray	☐ Referral for hip xray
☐ Referral for spasticity management	☐ Referral for spasticity management	☐ Referral for spasticity management
☐ Referral for surgery	☐ Referral for surgery	☐ Referral for surgery
☐ Stretching	☐ Stretching	☐ Stretching
☐ Therapy after surgery	☐ Therapy after surgery	☐ Therapy after surgery
☐ TheraSuits	☐ TheraSuits	☐ TheraSuits
☐ Other:	☐ Other:	☐ Other:

Spine

Please only tick one intervention per invention approach

Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
☐ Active Range of Motion	☐ Active Range of Motion	☐ Active Range of Motion
☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy
☐ Botulinum Toxin	☐ Botulinum Toxin	☐ Botulinum Toxin
☐ Casting	☐ Casting	☐ Casting
☐ Conductive education	☐ Conductive education	☐ Conductive education
☐ Drug/ointment prescription	☐ Drug/ointment prescription	☐ Drug/ointment prescription
☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)
☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
☐ Passive Range of Motion	☐ Passive Range of Motion	☐ Passive Range of Motion
☐ Pressure care	☐ Pressure care	☐ Pressure care
☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
☐ Referral for spasticity management	☐ Referral for spasticity management	☐ Referral for spasticity management
☐ Referral for surgery	☐ Referral for surgery	☐ Referral for surgery
☐ Stretching	☐ Stretching	☐ Stretching
☐ Therapy after surgery	☐ Therapy after surgery	☐ Therapy after surgery
☐ TheraSuits	☐ TheraSuits	☐ TheraSuits
☐ Other:	☐ Other:	☐ Other:

Pelvis

Please only tick one intervention per invention approach

Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
☐ Active Range of Motion	☐ Active Range of Motion	☐ Active Range of Motion
☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy
☐ Botulinum Toxin	☐ Botulinum Toxin	☐ Botulinum Toxin
☐ Casting	☐ Casting	☐ Casting
☐ Conductive education	☐ Conductive education	☐ Conductive education
☐ Drug/ointment prescription	☐ Drug/ointment prescription	☐ Drug/ointment prescription
☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)
☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
☐ Passive Range of Motion	☐ Passive Range of Motion	☐ Passive Range of Motion
☐ Pressure care	☐ Pressure care	☐ Pressure care
☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
☐ Referral for spasticity management	☐ Referral for spasticity management	☐ Referral for spasticity management
☐ Stretching	☐ Stretching	☐ Stretching
☐ Therapy after surgery	☐ Therapy after surgery	☐ Therapy after surgery
☐ TheraSuits	☐ TheraSuits	☐ TheraSuits
☐ Other:	☐ Other:	☐ Other:

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Cerebral Palsy ALLIANCE

CP Check-Up

FORM D – UPPER LIMB & SELF CARE

Client name:

Date of birth: Age: Years : Months

Date of assessment: Assessor:

Medicare no: CPA client no:

UPPER LIMB MUSCULOSKELETAL ASSESSMENT

Passive joint mobility upper limb

Please take the following measurements in sitting (where possible) or lying/supine if unable to measure in sitting.

SHOULDERS

	Left		Right	
	R1°	R2°	R1°	R2°
Abduction 180°				
Flexion 180°				
External rotation 90° *				

*External rotation performed in supine (if possible)

Showing signs of pain during examination? ☐ Yes ☐ No

ELBOWS

	Left		Right	
	R1°	R2°	R1°	R2°
Extension 0°				
Flexion 150°				

Showing signs of pain during examination? ☐ Yes ☐ No

FOREARMS

	Left		Right	
	R1°	R2°	R1°	R2°
Supination 90°				
Pronation 90°				
Active supination				

Showing signs of pain during examination? ☐ Yes ☐ No

WRISTS

	Left		Right	
	R1°	R2°	R1°	R2°
Extension 70°				
Extension with extended fingers				
Ulnar deviation 30°				
Radial deviation 20°				

Showing signs of pain during examination? ☐ Yes ☐ No

* Dark green highlighted areas = To be completed twice a year for children aged 6 and younger

---

Thumb & thumb position (Children 0–18 yrs)

	Left	Right
	R2°	R2°
Volar abduction		
Thumb-in-palm (Please circle)	Y/N	Y/N
If yes, classification of thumb-in-palm by House Type I - IV		

Fingers: simultaneous wrist and finger active extension (Children 6 mths – 18 yrs)

	Left	Right
Active Zancolli 1x, 1, 2A, 2B, 3 or unable to assess		

UPPER LIMB ASSESSMENT

Preferred hand ☐ Left ☐ Right ☐ Mixed
Bimanual ability ☐ Yes ☐ No ☐ Limited

Manual Ability Classification System (MACS) (Children 2 - 18 yrs)
☐ Level I ☐ Level II ☐ Level III ☐ Level IV
☐ Level V ☐ Unable to assess due to age

Hand Function Classification (Modified House) (Children 6 mths – 18 yrs)
Right (0-8):
Left (0-8):

Assisting Hand Assessment (AHA)
(18 mths - 12 yrs for children with hemiplegia)
Please transfer test scores if the AHA was administered in the last 12 months.

Sum Score:
% of Total Score:

☐ Unable to asses ☐ Not applicable ☐ Test not available

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Melbourne Assessment 2 (MA2)
(Children 2.5–15 yrs, classified MACS I–IV)
If you have administered QUEST please tick 'Not applicable'
Please transfer test scores if the MA2 was administered in the last 12 mths.

Sub-Scale	Raw Score	(%)
Range of movement	/27	
Accuracy of reach and placement	/25	
Dexterity of grasp, release and manipulation	/14-19	
Fluency of movement	/21	

☐ Unable to assess ☐ Not applicable ☐ Test not available

Quality of Upper Extremity Skills Test (QUEST)
(Children 18 mths – 16 yrs, classified MACS I – IV, presenting spastic CP +/- Dystonia)
If you have administered MA2 please tick 'Not applicable'

	Left	Right
A. Dissociative movement		
B. Grasps (Do not score postures)		

☐ Unable to assess ☐ Not applicable

Pediatric Evaluation of Disability Inventory (PEDI)
(Children 6 mths – 7.5 yrs)

Age at time of PEDI [Years : Months] ☐ Not applicable

Part 1
Functional skills

	Raw Score	Standard Score	Standard Error	Scales Score	Standard Error
Self Care					
Mobility					
Social Function					

*Mobility and Social Function scores are optional, fill in if available

Any other comments for form D

UPPER LIMB BOTULINUM TOXIN

Has the person received botulinum toxin injections in the upper limbs since the last time of assessment?
☐ Yes ☐ No ☐ Unknown
If yes, what date? [/ /]

Has the person been referred for botulinum toxin injections?
☐ Yes ☐ No ☐ Unknown
If yes, what date? [/ /]

If yes, which muscles?

	Left	Right
Brachialis	☐	☐
Biceps brachii	☐	☐
Pronator quadratus	☐	☐
Pronator teres	☐	☐
Flexor carpi radialis	☐	☐
Flexor carpi ulnaris	☐	☐
Flexor digitorum profundus	☐	☐
Flexor digitorum superficialis	☐	☐
Flexor pollicis longus	☐	☐
Flexor pollicis brevis	☐	☐
Adductor pollicis	☐	☐
Opponens pollicis	☐	☐

UPPER LIMB SURGERY

Has the person received hand or arm surgery since the last time of assessment?
☐ Yes ☐ No ☐ Unknown

If yes, what date? [/ /]

If yes, what surgery?

---

* Dark green highlighted areas = To be completed twice a year for children aged 6 and younger

UPPER LIMB ORTHOSES

The person currently uses one or more orthoses or splints:

☐ Yes (please describe by ticking below) ☐ No ☐ Unknown

Type	Left					Right				
	Purpose					**Purpose**				
e.g. thumb, wrist, elbow	Function	Maintain ROM	Pain	Time worn (hr/day)	Duration months	Function	Maintain ROM	Pain	Time worn (hr/day)	Duration months
	☐	☐	☐			☐	☐	☐		
	☐	☐	☐			☐	☐	☐		
	☐	☐	☐			☐	☐	☐		
	☐	☐	☐			☐	☐	☐		
	☐	☐	☐			☐	☐	☐		
	☐	☐	☐			☐	☐	☐		

Have skin irritation/pressure sores occurred in connection with the use of orthoses? ☐ Yes ☐ No

If yes, comments:

* Dark green highlighted areas = To be completed twice a year

Areas of intervention	Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.
Hand function	Please only tick one intervention per invention approach		
	☐ Activities incorporated into play (no specific bimanual aim)	☐ Activities incorporated into play (no specific bimanual aim)	☐ Activities incorporated into play (no specific bimanual aim)
	☐ Assistive technology prescription (e.g. alternate access. ECU)	☐ Assistive technology prescription (e.g. alternate access. ECU)	☐ Assistive technology prescription (e.g. alternate access. ECU)
	☐ Bimanual therapy	☐ Bimanual therapy	☐ Bimanual therapy
	☐ Constraint induced therapy	☐ Constraint induced therapy	☐ Constraint induced therapy
	☐ Equipment prescription (daily living aids)	☐ Equipment prescription (daily living aids)	☐ Equipment prescription (daily living aids)
	☐ Goal directed training of fine motor tasks	☐ Goal directed training of fine motor tasks	☐ Goal directed training of fine motor tasks
	☐ Hand function equipment use training	☐ Hand function equipment use training	☐ Hand function equipment use training
	☐ Handwriting training	☐ Handwriting training	☐ Handwriting training
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
	☐ Referral for spasticity management	☐ Referral for spasticity management	☐ Referral for spasticity management
	☐ Sensory Processing (non sensory integration approaches)	☐ Sensory Processing (non sensory integration approaches)	☐ Sensory Processing (non sensory integration approaches)
	☐ Other:	☐ Other:	☐ Other:

FORM D – UPPER LIMB & SELF CARE

Areas of intervention	Intervention Approach 1 Record any interventions the client has received. If known, include interventions provided from other service providers.	Intervention Approach 2 Record any interventions the client has received. If known, include interventions provided from other service providers.	Intervention Approach 3 Record any interventions the client has received. If known, include interventions provided from other service providers.
Shoulders	Please only tick one intervention per invention approach		
	☐ Active Range of Motion	☐ Active Range of Motion	☐ Active Range of Motion
	☐ Biofeedback	☐ Biofeedback	☐ Biofeedback
	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy
	☐ Botulinum Toxin	☐ Botulinum Toxin	☐ Botulinum Toxin
	☐ Casting/Splint	☐ Casting/Splint	☐ Casting/Splint
	☐ Conductive education	☐ Conductive education	☐ Conductive education
	☐ Drug/ointment prescription	☐ Drug/ointment prescription	☐ Drug/ointment prescription
	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)
	☐ Equipment prescription	☐ Equipment prescription	☐ Equipment prescription
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Muscle strength	☐ Muscle strength	☐ Muscle strength
	☐ Passive Range of Motion	☐ Passive Range of Motion	☐ Passive Range of Motion
	☐ Pressure care	☐ Pressure care	☐ Pressure care
	☐ Referral for spasticity management	☐ Referral for spasticity management	☐ Referral for spasticity management
	☐ Referral for surgery	☐ Referral for surgery	☐ Referral for surgery
	☐ Therapy after surgery	☐ Therapy after surgery	☐ Therapy after surgery
	☐ Other:	☐ Other:	☐ Other:
Elbows	Please only tick one intervention per invention approach		
	☐ Active Range of Motion	☐ Active Range of Motion	☐ Active Range of Motion
	☐ Biofeedback	☐ Biofeedback	☐ Biofeedback
	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy
	☐ Botulinum Toxin	☐ Botulinum Toxin	☐ Botulinum Toxin
	☐ Casting/Splint	☐ Casting/Splint	☐ Casting/Splint
	☐ Conductive education	☐ Conductive education	☐ Conductive education
	☐ Drug/ointment prescription	☐ Drug/ointment prescription	☐ Drug/ointment prescription
	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)
	☐ Equipment prescription	☐ Equipment prescription	☐ Equipment prescription
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Muscle strength	☐ Muscle strength	☐ Muscle strength
	☐ Passive Range of Motion	☐ Passive Range of Motion	☐ Passive Range of Motion
	☐ Pressure care	☐ Pressure care	☐ Pressure care
	☐ Referral for spasticity management	☐ Referral for spasticity management	☐ Referral for spasticity management
	☐ Referral for surgery	☐ Referral for surgery	☐ Referral for surgery
	☐ Therapy after surgery	☐ Therapy after surgery	☐ Therapy after surgery
	☐ Other:	☐ Other:	☐ Other:

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FORM D – UPPER LIMB & SELF CARE

Areas of intervention	Intervention Approach 1 Record any interventions the client has received. If known, include interventions provided from other service providers.	Intervention Approach 2 Record any interventions the client has received. If known, include interventions provided from other service providers.	Intervention Approach 3 Record any interventions the client has received. If known, include interventions provided from other service providers.
Forearms	Please only tick one intervention per invention approach		
	☐ Active Range of Motion	☐ Active Range of Motion	☐ Active Range of Motion
	☐ Biofeedback	☐ Biofeedback	☐ Biofeedback
	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy
	☐ Botulinum Toxin	☐ Botulinum Toxin	☐ Botulinum Toxin
	☐ Casting/Splint	☐ Casting/Splint	☐ Casting/Splint
	☐ Conductive education	☐ Conductive education	☐ Conductive education
	☐ Drug/ointment prescription	☐ Drug/ointment prescription	☐ Drug/ointment prescription
	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)
	☐ Equipment prescription	☐ Equipment prescription	☐ Equipment prescription
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Muscle strength	☐ Muscle strength	☐ Muscle strength
	☐ Passive Range of Motion	☐ Passive Range of Motion	☐ Passive Range of Motion
	☐ Pressure care	☐ Pressure care	☐ Pressure care
	☐ Referral for spasticity management	☐ Referral for spasticity management	☐ Referral for spasticity management
	☐ Referral for surgery	☐ Referral for surgery	☐ Referral for surgery
	☐ Therapy after surgery	☐ Therapy after surgery	☐ Therapy after surgery
	☐ Other:	☐ Other:	☐ Other:
Wrist	Please only tick one intervention per invention approach		
	☐ Active Range of Motion	☐ Active Range of Motion	☐ Active Range of Motion
	☐ Biofeedback	☐ Biofeedback	☐ Biofeedback
	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy
	☐ Botulinum Toxin	☐ Botulinum Toxin	☐ Botulinum Toxin
	☐ Casting/Splint	☐ Casting/Splint	☐ Casting/Splint
	☐ Conductive education	☐ Conductive education	☐ Conductive education
	☐ Drug/ointment prescription	☐ Drug/ointment prescription	☐ Drug/ointment prescription
	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)
	☐ Equipment prescription	☐ Equipment prescription	☐ Equipment prescription
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Muscle strength	☐ Muscle strength	☐ Muscle strength
	☐ Passive Range of Motion	☐ Passive Range of Motion	☐ Passive Range of Motion
	☐ Pressure care	☐ Pressure care	☐ Pressure care
	☐ Referral for spasticity management	☐ Referral for spasticity management	☐ Referral for spasticity management
	☐ Referral for surgery	☐ Referral for surgery	☐ Referral for surgery
	☐ Therapy after surgery	☐ Therapy after surgery	☐ Therapy after surgery
	☐ Other:	☐ Other:	☐ Other:

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Areas of intervention	Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.
Thumbs & Fingers	Please only tick one intervention per invention approach		
	☐ Active Range of Motion	☐ Active Range of Motion	☐ Active Range of Motion
	☐ Biofeedback	☐ Biofeedback	☐ Biofeedback
	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy	☐ BoNT+ OT, Physio therapy
	☐ Botulinum Toxin	☐ Botulinum Toxin	☐ Botulinum Toxin
	☐ Casting/Splint	☐ Casting/Splint	☐ Casting/Splint
	☐ Conductive education	☐ Conductive education	☐ Conductive education
	☐ Drug/ointment prescription	☐ Drug/ointment prescription	☐ Drug/ointment prescription
	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)	☐ Electrical stimulation (FES, NMES, ES)
	☐ Equipment prescription	☐ Equipment prescription	☐ Equipment prescription
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Muscle strength	☐ Muscle strength	☐ Muscle strength
	☐ Passive Range of Motion	☐ Passive Range of Motion	☐ Passive Range of Motion
	☐ Pressure care	☐ Pressure care	☐ Pressure care
	☐ Referral for spasticity management	☐ Referral for spasticity management	☐ Referral for spasticity management
	☐ Referral for surgery	☐ Referral for surgery	☐ Referral for surgery
	☐ Therapy after surgery	☐ Therapy after surgery	☐ Therapy after surgery
	☐ Other:	☐ Other:	☐ Other:

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Cerebral Palsy ALLIANCE

CP Check-Up

FORM E — SWALLOWING, NUTRITION & COMMUNICATION

Client name: _____

Date of birth: _____ Age: _____

Date of assessment: _____ Assessor: _____

Medicare no: _____ CPA client no: _____

SWALLOWING

Does the person have difficulty with feeding? ☐ Yes ☐ No
If yes, is the problem
☐ Structural ☐ Behavioural ☐ Environmental
☐ Psychological ☐ Functional

Does the person have dysphagia? ☐ Yes ☐ No
If yes, to what severity?
☐ Mild ☐ Moderate ☐ Severe

What stage of swallowing is affected?
☐ Oral ☐ Pharyngeal ☐ Oesophageal
☐ Unknown

Does the person have symptoms indicating likelihood of aspiration?
☐ Yes ☐ No ☐ Unknown

If yes, please indicate which apply
☐ Coughing before or after swallowing
☐ Repeated choking episodes
☐ Wet vocal quality during or after eating or drinking
☐ Much throat clearing after a meal
☐ Frequent colds or pneumonias
☐ Unexplained weight loss
☐ Unexplained fevers that come and go

Assessment measure used:
_____

NUTRITION
Enteral Feeding
Does the person receive enteral nutrition?
☐ Yes ☐ No
If yes, how is this received?
☐ Nasogastric tube ☐ Gastrostomy ☐ Jejunostomy
What portion of nutritional intake is received enterally?
☐ Full ☐ Partial
☐ Hydration only ☐ Medication only

Anthropometric Measures (CDC Growth Curves)
Date of measures ____/____/____

Weight _____ kg

Weight for Age Percentile _____

Length _____ cm

Length for Age Percentile _____

REFLUX

Does the person have gastroesophageal reflux? ☐ Yes ☐ No
If yes, to what severity? See manual for descriptors.
☐ Mild ☐ Moderate ☐ Severe ☐ Unknown

If yes, does this impact daily functioning in any of the following areas?
☐ Movement and activity ☐ School or work attendance
☐ Sleep and rest ☐ Yes, other _____
☐ Emotions and concentration

If yes, are medications prescribed? ☐ Yes ☐ No ☐ Unknown

SALIVA/SECRETION AND MANAGEMENT
Does the person have difficulties managing their saliva?
☐ No ☐ Yes, occasionally
☐ Yes, frequently ☐ Yes, constantly

If yes, describe the severity:
1=no difficulty 10=profuse drooling _____

Drooling impact scale: _____

DENTAL HEALTH/ORAL HYGIENE
Does the person have a malocclusion? ☐ Yes ☐ No
Does the person grind their teeth? ☐ Yes ☐ No ☐ Unknown
How regularly does the person visit a dentist?
☐ Every three months
☐ Every six months
☐ Every twelve months
☐ Rarely
☐ Never

SURGICAL INTERVENTIONS
☐ Gastrostomy, if yes date ____/____/____

☐ Nissen Fundoplication, if yes date ____/____/____

☐ Other gastrointestinal surgery, if yes date ____/____/____

☐ Dental surgery, if yes date ____/____/____

☐ Ear Nose Throat, if yes date ____/____/____

Comments
_____

* Dark green highlighted areas = To be completed twice a year for children aged 6 and younger

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COMMUNICATION

Hearing (Children 4 yrs)
Does the person have a hearing impairment?
☐ Yes   ☐ No   ☐ Unknown

If yes, how severe?
☐ Mild   ☐ Moderate   ☐ Severe
☐ Profound   ☐ Unknown

If known, what type?

	Left	Right	Bilateral
Conductive hearing loss	☐	☐	☐
Sensorineural hearing loss	☐	☐	☐
Unknown	☐	☐	☐

Vision (Children 4 yrs)
Does the person have a vision impairment?
☐ Yes   ☐ No   ☐ Unknown
If yes, how severe?
☐ Some Impairment   ☐ Functionally blind   ☐ Unknown

If known, what type?
☐ Strabismus   ☐ Squint
☐ Nystagmus   ☐ Emmetropia
☐ Myopia   ☐ Hypermyopia
☐ Astigmatism   ☐ Cortical Vision Impairment
☐ Other _____

Communication Function Classification System (Children 0-18 yrs)
☐ Level I
☐ Level II
☐ Level III
☐ Level IV
☐ Level V

Primary mode of communication
How does the person communicate?
☐ Verbal   ☐ Non-verbal   ☐ Combination of
                                            verbal & augmented
Language
Does the person have a language impairment/delay?
☐ Yes   ☐ No   ☐ Unknown
               (includes developing
               within normal limits)

If yes, what area/s of language are affected?
☐ Expression (syntax, semantics, pragmatics/social)
☐ Comprehension (syntax, semantics, pragmatics/social)
☐ Literacy

Assessment measure used _____

Speech
Does the person have a speech impairment/delay?
☐ Yes   ☐ No   ☐ Unknown
If no, go to intervention

If yes, what type of speech impairment do they have?
☐ Dysarthria   ☐ Apraxia/Dyspraxia
☐ Articulation   ☐ Phonological disorder
☐ Unknown   ☐ Other _____

Augmentative and Alternative Communication (AAC)

Does the person communicate using AAC? ☐ Yes   ☐ No
If no, go to intervention

If yes, what type of AAC does the person use?
☐ Gestures/Manual sign
☐ Low technology – Objects/Remnants
☐ Low technology – Picture symbols
☐ Low technology – Text
☐ SGD – Static Display Picture Symbols
☐ SGD – Dynamic Display Picture Symbols
☐ SGD – Text Based
☐ SGD – Coded Vocabulary (Minspeak)
☐ Sound
☐ Others

How often does the person use their AAC system?
☐ All the time   ☐ Often   ☐ Sometimes
☐ Rarely   ☐ Never

How often is the person successful using their AAC system?
☐ All the time   ☐ Often   ☐ Sometimes
☐ Rarely   ☐ Never

Does the person/family feel they are   ☐ Yes ☐ No
successful when they use their AAC system?

Fluency/Stuttering
Does the person stutter?
☐ Yes   ☐ No   ☐ Unknown

Voice
Does the person have a voice disorder?
☐ Yes   ☐ No   ☐ Unknown

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* Dark green highlighted areas = To be completed twice a year for children aged 6 and younger

FORM E — SWALLOWING, NUTRITION & COMMUNICATION

Areas of intervention	Intervention Approach 1 Record any interventions the client has received. If known, include interventions provided from other service providers.	Intervention Approach 2 Record any interventions the client has received. If known, include interventions provided from other service providers.	Intervention Approach 3 Record any interventions the client has received. If known, include interventions provided from other service providers.
Feeding/ Swallowing	*Please only tick one intervention per invention approach*		
	☐ Behavioural education ☐ Dietary modification ☐ Equipment modification ☐ Equipment prescription ☐ Initial discussion ☐ Provision of information/education ☐ Referral for surgery ☐ Referral to dysphagia/feeding clinic ☐ Seating and Positioning ☐ Other: _____	☐ Behavioural education ☐ Dietary modification ☐ Equipment modification ☐ Equipment prescription ☐ Initial discussion ☐ Provision of information/education ☐ Referral for surgery ☐ Referral to dysphagia/feeding clinic ☐ Seating and Positioning ☐ Other: _____	☐ Behavioural education ☐ Dietary modification ☐ Equipment modification ☐ Equipment prescription ☐ Initial discussion ☐ Provision of information/education ☐ Referral for surgery ☐ Referral to dysphagia/feeding clinic ☐ Seating and Positioning ☐ Other: _____
Reflux	*Please only tick one intervention per invention approach*		
	☐ Behavioural education ☐ Dietary modification ☐ Drug prescription ☐ Equipment modification ☐ Equipment prescription ☐ Initial discussion ☐ Provision of information/education ☐ Referral to dysphagia/feeding clinic ☐ Seating and Positioning ☐ Other: _____	☐ Behavioural education ☐ Dietary modification ☐ Drug prescription ☐ Equipment modification ☐ Equipment prescription ☐ Initial discussion ☐ Provision of information/education ☐ Referral to dysphagia/feeding clinic ☐ Seating and Positioning ☐ Other: _____	☐ Behavioural education ☐ Dietary modification ☐ Drug prescription ☐ Equipment modification ☐ Equipment prescription ☐ Initial discussion ☐ Provision of information/education ☐ Referral to dysphagia/feeding clinic ☐ Seating and Positioning ☐ Other: _____
Saliva/ Secretion	*Please only tick one intervention per invention approach*		

	☐ Behavioural strategies
	☐ Botulinum Toxin
	☐ Drug prescription
	☐ Equipment modification
	☐ Equipment prescription
	   e.g. intraoral appliances
	☐ Initial discussion
	☐ Provision of information/education
	☐ Sensory/motor education
	☐ Surgery
	☐ Other: _____
		☐ Behavioural strategies
		☐ Botulinum Toxin
		☐ Drug prescription
		☐ Equipment modification
		☐ Equipment prescription
		   e.g. intraoral appliances
		☐ Initial discussion
		☐ Provision of information/education
		☐ Sensory/motor education
		☐ Surgery
		☐ Other: _____
			☐ Behavioural strategies
			☐ Botulinum Toxin
			☐ Drug prescription
			☐ Equipment modification
			☐ Equipment prescription
			   e.g. intraoral appliances
			☐ Initial discussion
			☐ Provision of information/education
			☐ Sensory/motor education
			☐ Surgery
			☐ Other: _____

Nutrition	*Please only tick one intervention per invention approach*		

	☐ Dietary modification
	☐ Dietary supplementation
	☐ Exercise/Fitness
	☐ Initial discussion
	☐ Physiotherapy with focus on
	   weight bearing and strengthening
	☐ Provision of information/education
	☐ Referral for gastroenterologist
	☐ Referral to dietician
	☐ Referral to dysphagia/feeding clinic
	☐ Other: _____
		☐ Dietary modification
		☐ Dietary supplementation
		☐ Exercise/Fitness
		☐ Initial discussion
		☐ Physiotherapy with focus on
		   weight bearing and strengthening
		☐ Provision of information/education
		☐ Referral for gastroenterologist
		☐ Referral to dietician
		☐ Referral to dysphagia/feeding clinic
		☐ Other: _____
			☐ Dietary modification
			☐ Dietary supplementation
			☐ Exercise/Fitness
			☐ Initial discussion
			☐ Physiotherapy with focus on
			   weight bearing and strengthening
			☐ Provision of information/education
			☐ Referral for gastroenterologist
			☐ Referral to dietician
			☐ Referral to dysphagia/feeding clinic
			☐ Other: _____

Dental Health	*Please only tick one intervention per invention approach*		
	☐ Dietary modification ☐ Initial discussion ☐ Intra-oral equipment prescription ☐ Provision of information/education ☐ Referral for surgery ☐ Referral to dental practitioner ☐ Other: _____	☐ Dietary modification ☐ Initial discussion ☐ Intra-oral equipment prescription ☐ Provision of information/education ☐ Referral for surgery ☐ Referral to dental practitioner ☐ Other: _____	☐ Dietary modification ☐ Initial discussion ☐ Intra-oral equipment prescription ☐ Provision of information/education ☐ Referral for surgery ☐ Referral to dental practitioner ☐ Other: _____

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Areas of intervention	Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.
Dysarthria	Please only tick one intervention per invention approach		
	☐ Articulation intervention	☐ Articulation intervention	☐ Articulation intervention
	☐ Augmentative and Alternative Communication high-tech prescription	☐ Augmentative and Alternative Communication high-tech prescription	☐ Augmentative and Alternative Communication high-tech prescription
	☐ Augmentative and Alternative Communication low-tech prescription	☐ Augmentative and Alternative Communication low-tech prescription	☐ Augmentative and Alternative Communication low-tech prescription
	☐ Behavioural compensation and strategies	☐ Behavioural compensation and strategies	☐ Behavioural compensation and strategies
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Prosthetic prescription	☐ Prosthetic prescription	☐ Prosthetic prescription
	☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
	☐ Other:	☐ Other:	☐ Other:
Apraxia/Dyspraxia	Please only tick one intervention per invention approach		
	☐ Augmentative and Alternative Communication high-tech prescription	☐ Augmentative and Alternative Communication high-tech prescription	☐ Augmentative and Alternative Communication high-tech prescription
	☐ Augmentative and Alternative Communication low-tech prescription	☐ Augmentative and Alternative Communication low-tech prescription	☐ Augmentative and Alternative Communication low-tech prescription
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Motor approach	☐ Motor approach	☐ Motor approach
	☐ Prosodic approach	☐ Prosodic approach	☐ Prosodic approach
	☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
	☐ Other:	☐ Other:	☐ Other:
Phonological/ Articulation	Please only tick one intervention per invention approach		
	☐ Articulation intervention	☐ Articulation intervention	☐ Articulation intervention
	☐ Augmentative and Alternative Communication high-tech prescription	☐ Augmentative and Alternative Communication high-tech prescription	☐ Augmentative and Alternative Communication high-tech prescription
	☐ Augmentative and Alternative Communication low-tech prescription	☐ Augmentative and Alternative Communication low-tech prescription	☐ Augmentative and Alternative Communication low-tech prescription
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Motor based intervention	☐ Motor based intervention	☐ Motor based intervention
	☐ Phonological intervention	☐ Phonological intervention	☐ Phonological intervention
	☐ Other:	☐ Other:	☐ Other:
Language	Please only tick one intervention per invention approach		
	☐ Augmentative and Alternative Communication strategies to support comprehension	☐ Augmentative and Alternative Communication strategies to support comprehension	☐ Augmentative and Alternative Communication strategies to support comprehension
	☐ Augmentative and Alternative Communication strategies to support expression	☐ Augmentative and Alternative Communication strategies to support expression	☐ Augmentative and Alternative Communication strategies to support expression
	☐ Comprehension training	☐ Comprehension training	☐ Comprehension training
	☐ Expression training	☐ Expression training	☐ Expression training
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Literacy training	☐ Literacy training	☐ Literacy training
	☐ Pragmatics	☐ Pragmatics	☐ Pragmatics
	☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
	☐ Other:	☐ Other:	☐ Other:
Fluency	Please only tick one intervention per invention approach		
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Lidcombe program	☐ Lidcombe program	☐ Lidcombe program
	☐ Referral to external agency/stuttering unit	☐ Referral to external agency/stuttering unit	☐ Referral to external agency/stuttering unit
	☐ Other:	☐ Other:	☐ Other:
Voice	Please only tick one intervention per invention approach		
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
	☐ Behavioural education	☐ Behavioural education	☐ Behavioural education
	☐ Referral to external agency	☐ Referral to external agency	☐ Referral to external agency
	☐ Other:	☐ Other:	☐ Other:

CP Check-Up
FORM F — COGNITION & LEARNING

Client name	
Date of birth	Age — Years : Months
Date of assessment	Assessor
Medicare no	CPA client no

COGNITION & LEARNING

DEVELOPMENTAL ASSESSMENT (CHILDREN 0-8 YRS)

Screening questions

Gross motor	☐ Same as peers	☐ Difficulties
Fine motor	☐ Same as peers	☐ Difficulties
Talking	☐ Same as peers	☐ Difficulties
Understanding	☐ Same as peers	☐ Difficulties
Self help skills	☐ Same as peers	☐ Difficulties
Social/emotional	☐ Same as peers	☐ Difficulties

If difficulties reported, has your child had a developmental assessment?
☐ No   ☐ Yes, date ___/___/___

Bayley Scale of Infant Development III (BSID) (Children 3-42 mths)

Descriptive Categories
(Very superior, Superior, High average, Average, Low average, Borderline, Extremely low)

Cognitive _____
Motor _____
Language _____
Social/Emotional _____
Adaptive Behaviour _____

☐ No   ☐ Yes, date ___/___/___

Griffiths Mental Developmental Scale (GMDS) (Children 0–2 yrs)

Descriptive Categories
(Very high, High, High average, Average, Low average, Low, Mild DD, Moderate DD, Severe DD, Profound DD)

Locomotor _____
Personal-social _____
Hearing and language _____
Eye and hand coordination _____
Performance _____

☐ No   ☐ Yes, date ___/___/___

Griffiths Mental Developmental Scale (GMDS) (Children 2–8 yrs)

Descriptive Categories
(Very high, High, High average, Average, Low average, Low, Mild DD, Moderate DD, Severe DD, Profound DD)

Locomotor _____
Personal-social _____
Language _____
Eye and hand coordination _____
Performance _____
Practical reasoning _____

☐ No   ☐ Yes, date ___/___/___

COGNITIVE ASSESSMENT (CHILDREN 2.5-17 YRS)

Screening questions

Concentration	☐ Same as peers	☐ Difficulties
Memory	☐ Same as peers	☐ Difficulties
Planning and organisation	☐ Same as peers	☐ Difficulties
Ability to follow instructions	☐ Same as peers	☐ Difficulties
Self help skills	☐ Same as peers	☐ Difficulties
Problem solving	☐ Same as peers	☐ Difficulties
Activity levels	☐ Same as peers	☐ Underactive
	☐ Highly active	

If difficulties reported, has your child had a cognitive assessment?
☐ No   ☐ Yes, date ___/___/___

If yes, assessment measure used _____

Weschler Preschool Primary Scale of Intelligence (WPPSI–III) (Children 2.5–7 yrs)

Descriptive Categories
(Very superior, Superior, High average, Average, Low average, Borderline, Mild ID, Moderate ID, Severe ID, Profound ID)

VIQ _____
PIQ _____
PSQ _____
FSIQ _____

Weschler Intelligence Scale for Children (WISC–IV) (Children 6–16 yrs)

Descriptive Categories
(Very superior, Superior, High average, Average, Low average, Borderline, Mild ID, Moderate ID, Severe ID, Profound ID)

VCI _____
PRI _____
WMI _____
PSI _____
FSIQ _____

School Year Screening Test for the Evaluation of Mental Status (SYSTEMS) (Children 5-11 yrs)

Total Score _____

ACADEMIC ACHIEVEMENT (CHILDREN 7-17 YRS)

Screening questions

Overall school achievement	☐ Same as peers	☐ Difficulties	☐ Not sure
Reading	☐ Same as peers	☐ Difficulties	☐ Not sure
Spelling	☐ Same as peers	☐ Difficulties	☐ Not sure
Writing	☐ Same as peers	☐ Difficulties	☐ Not sure
Maths	☐ Same as peers	☐ Difficulties	☐ Not sure
Social	☐ Same as peers	☐ Difficulties	☐ Not sure

If difficulties reported, has your child had a cognitive assessment?
☐ No   ☐ Yes, date ___/___/___

If yes, assessment measure used _____

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Weschler Individual Achievement Test (WIAT – II, III) (Children 4 yrs–adulthood)

Descriptive Categories
(Very superior, Superior, High average, Average, Low average, Borderline, Mild ID, Moderate ID, Severe ID, Profound ID)

Reading

Mathematics

Written Language

Oral Language

Areas of intervention	Intervention Approach 1 Record any interventions the client has received. If known, include interventions provided from other service providers.	Intervention Approach 2 Record any interventions the client has received. If known, include interventions provided from other service providers.	Intervention Approach 3 Record any interventions the client has received. If known, include interventions provided from other service providers.
Cognition and Learning	Please only tick one intervention per invention approach		
	☐ Adaptation of Environment	☐ Adaptation of Environment	☐ Adaptation of Environment
	☐ Assistive Technology	☐ Assistive Technology	☐ Assistive Technology
	☐ Counselling	☐ Counselling	☐ Counselling
	☐ Focused play and early intervention	☐ Focused play and early intervention	☐ Focused play and early intervention
	☐ IEP or Tailored educational/ program to support individuals with learning difficulties/disabilities	☐ IEP or Tailored educational/ program to support individuals with learning difficulties/disabilities	☐ IEP or Tailored educational/ program to support individuals with learning difficulties/disabilities
	☐ Individual Support Plans	☐ Individual Support Plans	☐ Individual Support Plans
	☐ Play group	☐ Play group	☐ Play group
	☐ Provision of specific information	☐ Provision of specific information	☐ Provision of specific information
	☐ Provision of general information	☐ Provision of general information	☐ Provision of general information
	☐ Referral	☐ Referral	☐ Referral
	☐ Transition to school support	☐ Transition to school support	☐ Transition to school support
	☐ Transition to work support	☐ Transition to work support	☐ Transition to work support
	☐ Other:	☐ Other:	☐ Other:

Cerebral Palsy ALLIANCE

CP Check-Up
FORM G — WELL–BEING

Client name	
Date of birth	Age	Years : Months
Date of assessment	Assessor
Medicare no	CPA client no

PARENT/CAREGIVER

Name of parent/caregiver completing the form

Depression Anxiety & Stress Scale (DASS 21)

Please read each statement and tick the rating box which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

Completed by
☐ Mother   ☐ Father   ☐ Carer Female   ☐ Carer Male

		Did not apply to me at all	Applied to me to some degree or some of the time	Applied to me a considerable degree or a good part of time	Applied to me very much or most of the time
		0	1	2	3
1	I found it hard to wind down	☐	☐	☐	☐
2	I was aware of dryness of my mouth	☐	☐	☐	☐
3	I couldn't seem to experience any positive feeling at all	☐	☐	☐	☐
4	I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion)	☐	☐	☐	☐
5	I found it difficult to work up the initiative to do things	☐	☐	☐	☐
6	I tended to overreact to situations	☐	☐	☐	☐
7	I experienced trembling (e.g., in the hands)	☐	☐	☐	☐
8	I felt that I was using a lot of nervous energy	☐	☐	☐	☐
9	I was worried about situations in which I might panic and make a fool of myself	☐	☐	☐	☐
10	I felt that I had nothing to look forward to	☐	☐	☐	☐
11	I found myself getting agitated	☐	☐	☐	☐
12	I found it difficult to relax	☐	☐	☐	☐
13	I felt down-hearted and blue	☐	☐	☐	☐
14	I was intolerant of anything that kept me from getting on with what I was doing	☐	☐	☐	☐
15	I felt I was close to panic	☐	☐	☐	☐
16	I was unable to become enthusiastic about anything	☐	☐	☐	☐
17	I felt I wasn't worth much as a person	☐	☐	☐	☐
18	I felt that I was rather touchy	☐	☐	☐	☐
19	I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat)	☐	☐	☐	☐
20	I felt scared without any good reason	☐	☐	☐	☐
21	I felt that life was meaningless	☐	☐	☐	☐

	SCORE	RANGE
D		
A		
S		

Source: Lovibond, S.H. & Lovibond, P.F. (1995) Manual for the Depression Anxiety Stress Scales. 2nd edition. Sydney: Psychology Foundation

RELATIONSHIP QUALITY INDEX
Parents of children with cerebral palsy often report they their relationship experiences increased stress. Please identify whether you agree or disagree with the following statements.
Please tick the relevant box to indicate how much you agree with each one of the following statements.

Completed by   ☐ Mother   ☐ Father   ☐ Carer Female   ☐ Carer Male

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree
	1	2	3	4	5	6	7
1 We have a good relationship							
2 My relationship with my partner is very stable							
3 My relationship with my partner is strong							
4 My relationship with my partner makes me happy.							
5 I really feel like part of a team with my partner.							

6   All things considered, what degree of happiness best describes your relationship?
1= Unhappy – 10= Perfectly Happy

TOTAL

With permission: Triple P Positive Parenting Program, Adapted from 'Measuring marital quality: A look at the dependent variable' by R. Norton, 1983, Journal of Marriage and the Family, 45,p. 147. Copyright 1983 by the National Council on Family Reslations, US. Adapted with permission.

CHILD/YOUTH
Completed by
☐ Mother   ☐ Father   ☐ Carer Female   ☐ Carer Male

The strengths and difficulties questionnaires
Parent Rated (Children 4-10 yrs)

Emotional Symptoms Scale

Conduct Problems Scale

Hyperactivity Scale

Peer Problems Scale

Prosocial Scale

Total Difficulties Score

Parent Rated (Children and Youth 11-17 yrs)
Emotional Symptoms Scale

Conduct Problems Scale

Hyperactivity Scale

Peer Problems Scale

Prosocial Scale

Total Difficulties Score

Self Report (Children and Youth 11-17 yrs)
Emotional Symptoms Scale

Conduct Problems Scale

Hyperactivity Scale

Peer Problems Scale

Prosocial Scale

Total Difficulties Score

Areas of intervention	Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.

Emotional support–child/youth

Please only tick one intervention per invention approach

Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
☐ Behavioural support (Toilet training, anger management)	☐ Behavioural support (Toilet training, anger management)	☐ Behavioural support (Toilet training, anger management)
☐ CBT	☐ CBT	☐ CBT
☐ Individual counselling	☐ Individual counselling	☐ Individual counselling
☐ Initial discussion/Detailed assessment	☐ Initial discussion/Detailed assessment	☐ Initial discussion/Detailed assessment
☐ Play therapy	☐ Play therapy	☐ Play therapy
☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
☐ Referral	☐ Referral	☐ Referral
☐ Other:	☐ Other:	☐ Other:

Behaviour support–child/youth

Please only tick one intervention per invention approach

Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
☐ Behavioural support (Toilet training, anger management)	☐ Behavioural support (Toilet training, anger management)	☐ Behavioural support (Toilet training, anger management)
☐ CBT	☐ CBT	☐ CBT
☐ Individual counselling	☐ Individual counselling	☐ Individual counselling
☐ Initial discussion/Detailed assessment	☐ Initial discussion/Detailed assessment	☐ Initial discussion/Detailed assessment
☐ Play therapy	☐ Play therapy	☐ Play therapy
☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
☐ Referral	☐ Referral	☐ Referral
☐ Other:	☐ Other:	☐ Other:

Social support–child/youth

Please only tick one intervention per invention approach

Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
☐ Behavioural support (Toilet training, anger management)	☐ Behavioural support (Toilet training, anger management)	☐ Behavioural support (Toilet training, anger management)
☐ CBT	☐ CBT	☐ CBT
☐ Individual counselling	☐ Individual counselling	☐ Individual counselling
☐ Initial discussion/Detailed assessment	☐ Initial discussion/Detailed assessment	☐ Initial discussion/Detailed assessment
☐ Play group	☐ Play group	☐ Play group
☐ Play therapy	☐ Play therapy	☐ Play therapy
☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
☐ Referral	☐ Referral	☐ Referral
☐ Other:	☐ Other:	☐ Other:

Behaviour support–child/youth

Please only tick one intervention per invention approach

Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
☐ CBT	☐ CBT	☐ CBT
☐ Individual counselling	☐ Individual counselling	☐ Individual counselling
☐ Initial discussion/Detailed assessment	☐ Initial discussion/Detailed assessment	☐ Initial discussion/Detailed assessment
☐ Play therapy	☐ Play therapy	☐ Play therapy
☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
☐ Social stories	☐ Social stories	☐ Social stories
☐ Other:	☐ Other:	☐ Other:

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Areas of intervention	Intervention Approach 1	Intervention Approach 2	Intervention Approach 3
	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.	Record any interventions the client has received. If known, include interventions provided from other service providers.
Practical support- parent	Please only tick one intervention per invention approach		
	☐ Case management	☐ Case management	☐ Case management
	☐ Coaching	☐ Coaching	☐ Coaching
	☐ Early intervention	☐ Early intervention	☐ Early intervention
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Parent groups	☐ Parent groups	☐ Parent groups
	☐ Parent to parent	☐ Parent to parent	☐ Parent to parent
	☐ Play group	☐ Play group	☐ Play group
	☐ Providing general information (Housing, Funding, Financial, Recreation, Support services)	☐ Providing general information (Housing, Funding, Financial, Recreation, Support services)	☐ Providing general information (Housing, Funding, Financial, Recreation, Support services)
	☐ Providing specific information (person and disability related)	☐ Providing specific information (person and disability related)	☐ Providing specific information (person and disability related)
	☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
	☐ Respite	☐ Respite	☐ Respite
	☐ Self advocacy	☐ Self advocacy	☐ Self advocacy
	☐ Sibling groups	☐ Sibling groups	☐ Sibling groups
	☐ Other:	☐ Other:	☐ Other:
Emotional support- parent	Please only tick one intervention per invention approach		
	☐ Individual counselling	☐ Individual counselling	☐ Individual counselling
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Parenting program (Triple P)	☐ Parenting program (Triple P)	☐ Parenting program (Triple P)
	☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
	☐ Relationship counselling	☐ Relationship counselling	☐ Relationship counselling
	☐ Self advocacy	☐ Self advocacy	☐ Self advocacy
	☐ Other:	☐ Other:	☐ Other:
Behavioural support- parent	Please only tick one intervention per invention approach		
	☐ Case management	☐ Case management	☐ Case management
	☐ Individual counselling	☐ Individual counselling	☐ Individual counselling
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Parenting program (Triple P)	☐ Parenting program (Triple P)	☐ Parenting program (Triple P)
	☐ Play therapy	☐ Play therapy	☐ Play therapy
	☐ Provision of information/education	☐ Provision of information/education	☐ Provision of information/education
	☐ Other:	☐ Other:	☐ Other:
Transition activities e.g. into childcare, into school, into work	Please only tick one intervention per invention approach		
	☐ Behaviour management support	☐ Behaviour management support	☐ Behaviour management support
	☐ Child specific information for school/work placement	☐ Child specific information for school/work placement	☐ Child specific information for school/work placement
	☐ Initial discussion	☐ Initial discussion	☐ Initial discussion
	☐ Parent support/counselling	☐ Parent support/counselling	☐ Parent support/counselling
	☐ Self advocacy	☐ Self advocacy	☐ Self advocacy
	☐ Transition to school group – children	☐ Transition to school group – children	☐ Transition to school group – children
	☐ Transition to school group – parents	☐ Transition to school group – parents	☐ Transition to school group – parents
	☐ Other:	☐ Other:	☐ Other:

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Appendix C: Supporting information for scoping review

Query #	Cinahl Complete search strategy November 10, 2017 1:24:28 AM
S11	S3 AND S6 AND S10
S10	S8 OR S9
S9	(MH "Speech and Language Assessment+") OR (MH "Clinical Assessment Tools+") OR (MH "Physical Therapy Assessment") OR (MH "Occupational Therapy Assessment") OR (MH "Outcome Assessment") OR (MH "Patient Assessment+") OR (MH "Functional Assessment+") OR (MH "Physical Examination+") OR (MH "Prognosis+") OR (MH Disability Evaluation+")
S8	TI (assess* OR measure* OR outcome* OR "standardi?ed test*" OR test* OR classification* OR evaluat* OR surve* OR "outcome measure*" OR "health outcome*" OR "assessment tool*" OR "evidence based assessment*") OR AB (assess* OR measure* OR outcome* OR "standardi?ed test*" OR test* OR classification* OR evaluat* OR surve* OR "outcome measure*" OR "health outcome*" OR "assessment tool*" OR "evidence based assessment*")
S7	S3 AND S6
S6	S4 OR S5
S5	(MH "Rehabilitation, Pediatric") OR (MH "Pediatric Physical Therapy") OR (MH "Pediatric Occupational Therapy") OR (MH "Rehabilitation") OR (MH "Allied Health Professions") OR (MH "Physical Therapy") OR (MH "Practice Patterns") OR (MH "Child Health Services") OR (MH "Family Centered Care") OR (MH "Professional-Family Relations")
S4	TI (therapy OR rehabilitation OR service* OR practice* OR healthcare* OR care OR family?centered OR "service delivery" OR "service provision" OR "service provider*") OR AB (therapy OR rehabilitation OR service* OR practice* OR healthcare* OR care OR family?centered OR "service delivery" OR "service provision" OR "service provider*")
S3	S1 OR S2
S2	(MH "Parents+") OR (MH "Parents of Disabled Children") OR (MH "Fathers") OR (MH "Mothers")
S1	TI (parents OR parent OR family OR families OR carer OR caregiver* OR mother* OR father*) OR AU (parents OR parent OR family OR families OR carer OR caregiver* OR mother* OR father*)

Appendix D: Supporting information for Study 3

D1: Ethics approval for Study 3 - Australian Catholic University

2017-257E Ethics application approved!

RE: 2017-257E Ethics application approved!

Res Ethics <Res.Ethics@acu.edu.au>
Thu 23/11/2017 11:18 AM
To: Res Ethics (Res.Ethics@acu.edu.au); Christine Imms (Christine.Imms@acu.edu.au);
Bridget O'Connor (bridget.oconnor2@myacu.edu.au); Brooke Adair (Brooke.Adair@acu.edu.au)

Reply | ∨

Dear Applicant,

Principal Investigator: Prof Christine Imms
Co-Investigator: Dr Brooke Adair, Dr Claire Kerr, Prof Nora Shields
Student Researcher: Bridget O'Connor (HDR Student)
Ethics Register Number: 2017-257E Project Title: Parents' experience of assessment for their child with cerebral palsy.
Date Approved: 21/11/2017
Ethics Clearance End Date: 31/12/2018

This is to certify that the above application has been reviewed by the Australian Catholic University Human Research Ethics Committee (ACU HREC). The application has been approved for the period given above subject to submitting approvals from external organisations once obtained.

Researchers are responsible for ensuring that all conditions of approval are adhered to, that they seek prior approval for any modifications and that they notify the HREC of any incidents or unexpected issues impacting on participants that arise in the course of their research. Researchers are also responsible for ensuring that they adhere to the requirements of the National Statement on Ethical Conduct in Human Research, the Australian Code for the Responsible Conduct of Research and the University¿s Code of Conduct.

Any queries relating to this application should be directed to the Ethics Secretariat (res.ethics@acu.edu.au). It is helpful if you quote your ethics approval number in all communications with us.

If you require a formal approval certificate in addition to this email, please respond via reply email and one will be issued.

We wish you every success with your research.

Kind regards,

Kylie Pashley
on behalf of ACU HREC Chair, Dr Nadia Crittenden

Senior Research Ethics Officer | Research Services Office of the Deputy Vice Chancellor (Research)
Australian Catholic University

THIS IS AN AUTOMATICALLY GENERATED RESEARCHMASTER EMAIL

D2: Ethics modification approval

-----Original Message-----
From: Ms Pratigya Pozniak [mailto:pratigya.pozniak@acu.edu.au]
Sent: Tuesday, 13 February 2018 10:00 AM
To: Christine Imms <Christine.Imms@acu.edu.au>
Cc: O'Connor, Bridget <bridget.oconnor2@myacu.edu.au>; Pratigya Pozniak
<Pratigya.Pozniak@acu.edu.au>
Subject: 2017-257E Modification approved

Dear Christine

Ethics Register Number : 2017-257E
Project Title : Parents' experience of assessment for their child with cerebral palsy.
End Date : 31/12/2018

Thank you for submitting the request to modify form for the above project.

The Chair of the Human Research Ethics Committee has approved the following
modification(s):

- To include eligibility criterion: all caregivers interested in discussing their
experiences of assessment - either informal assessment experiences or formal
assessment experiences - for their child with cerebral palsy by allied health
practitioners.

We wish you well in this ongoing research project.

Kind regards,
Ms Pratigya Pozniak

Research Ethics Officer | Office of the Deputy Vice-Chancellor (Research)
Australian Catholic University
T: 02 9739 2646 E: res.ethics@acu.edu.au

D3: Parent information letter

PARTICIPANT INFORMATION LETTER

PROJECT TITLE: Parents' experience of assessment for their child with cerebral palsy.
PRINCIPAL INVESTIGATOR: Professor Christine Imms
STUDENT RESEARCHER: Bridget O'Connor
STUDENT'S DEGREE: Physiotherapist and Doctor of Philosophy student

Dear Participant,
You are invited to participate in the research project described below.

What is the project about? This research project will explore parents' experiences and views about therapy assessments for their son or daughter with cerebral palsy. Allied health professionals often use formal assessments to assist with decisions about therapy interventions and to document a child's progress. We want to understand what parents think about this experience, so assessments can be used in ways that better support parents' participation in making therapy choices for and with their child.

Who is undertaking the project? This project is being conducted by Bridget O'Connor, a physiotherapist and PhD student at Australian Catholic University under the supervision of Professor Christine Imms (Australian Catholic University, Australia). This research is also supported by Professor Nora Shields (La Trobe University, Australia), Dr Claire Kerr (Queen's University, Northern Ireland) and Dr Brooke Adair (Australian Catholic University, Australia) all of whom have strong research experience in the area of childhood disability.

What will I be asked to do? If you agree to take part in this project you will be asked to participate in the following two tasks:

1) Completion of a questionnaire (paper or electronic as preferred). The questionnaire will take approximately 20 minutes to complete. Questions will ask for: a) information about you, as the parent participating in the project; b) some additional information about your child and his/her abilities; and c) therapy services you have accessed. If completing the paper-based questionnaire, it and the study consent form will be sent to you to complete and return. If completing the questionnaire electronically you will be sent a unique link. The consent form is completed as the first question in the electronic survey. The questionnaire cannot be completed unless study consent is provided.
2) Participation in an interview with the project researcher. The interview will take approximately 60 minutes and take place at a mutually convenient time and place. The interview will be audiotaped and transcribed into written text. A written summary of your interview will be sent to you for review prior to analysis. The interview can be conducted via Skype or Zoom videoconference if a face-to-face interview cannot be arranged.

What are the benefits of the research project? There are no immediate benefits to participants, however we anticipate there may be indirect benefits through increased awareness of the role of assessment. Understanding parent perspectives about current assessment practices will help therapists learn how to involve families more in assessment. Families will benefit through improved communication and participation in well informed decision-making for their child. In the long term greater parent involvement in their child's assessment will assist parents to advocate for and empower their children to manage their own health needs in the future.

Are there any risks associated with participating in this project?
It is possible that the interview may raise concerns in regard to previous assessments for your child. If during the interview you feel distressed, the interview will be suspended. Support and assistance will be provided with referral to appropriate local follow-up services, if requested by you.

1

Can I withdraw from the study? Participation in this study is entirely voluntary. You are not under any obligation to participate. Not participating in this study will have no effect on the services that you and your child currently receive. Having consented to the study you can withdraw your data up to two weeks after the interview. In this situation, your hard copy data will be shredded and audio-files deleted.

Will anyone else know the results of the project? Your name will be replaced by an identification number and pseudonym following your interview. The information will be stored on a password protected computer and available only to the researcher and project supervisors. Results from the project will be published in a professional journal and may be presented at conference to contribute to knowledge about best practice for therapy services for children (and young people) with cerebral palsy. You and your child will <u>not</u> be identified in any individual quotes used, publications or presentations that arise from the project.

Will I be able to find out the results of the project? A summary of the results and their implications for practice will be prepared on completion of the project and shared with participants who provide their contact details for this purpose.

Who do I contact if I have questions about the project? If you have any questions about this project you can contact Bridget O'Connor by email on bridget.oconnor2@myacu.edu.au

What if I have a complaint or any concerns? The study has been reviewed by the Human Research Ethics Committee at Australian Catholic University (review number 2017-257E). If you have any complaints or concerns about the conduct of the project, you may write to the Manager of the Human Research Ethics Committee care of the Office of the Deputy Vice Chancellor (Research).

> Manager, Ethics
> c/o Office of the Deputy Vice Chancellor (Research)
> Australian Catholic University, North Sydney Campus
> PO Box 968, NORTH SYDNEY, NSW 2059
> Ph: 02 9739 2519 Fax: 02 9739 2870
> Email: resethics.manager@acu.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

I want to participate! How do I sign up? Thank you very much for your interest in taking part in this project to support parents and therapists to work together and achieve positive outcomes for children and young people with cerebral palsy.

If you are interested in being involved the next step is to either:
   a) Email Bridget O'Connor directly: bridget.oconnor2@myacu.edu.au ; or
   b) Let one of your child's treating therapists know that you are happy to be contacted by the primary researcher, Bridget O'Connor, and provide your therapist with your preferred contact details.
Bridget will then contact you to talk about the project and answer any questions you may have. We look forward to hearing from you!

Yours sincerely,

Bridget O'Connor, PhD candidate

HREC ACU Ethics review number 2017-257E_approved 21st Nov 2017.   Australian Catholic University Limited ABN 15 050 192 660 CRICOS registered provider: 00004G

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D4: Parent consent form

CONSENT FORM: FOR PARENT

TITLE OF PROJECT: Parents' experience of assessment for their child with cerebral palsy.

PRINCIPAL SUPERVISOR: Christine Imms

STUDENT RESEARCHER: Bridget O'Connor

I .... *(the parent)* have read and understood the information provided to me in the Participant Information letter. Any questions I have asked have been answered to my satisfaction.

I agree to participate in this study which involves me;
a) Completing a questionnaire about me and my child that will take approximately 30 minutes, and
b) Participating in one face-to-face interview that will take approximately one hour which will be digitally recorded.

I realise that participation in this study is entirely voluntary and that participating in this study will have no effect on the services that I, or my child, currently receive.
I realise that I can withdraw my data up to two weeks after the interview.
I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in any way.

NAME OF PARENT/GUARDIAN: ....

SIGNATURE ....   DATE ....

SIGNATURE OF PRINCIPAL SUPERVISOR): ....

                                                                    DATE:............................

SIGNATURE OF STUDENT RESEARCHER: ....

                                                                    DATE:................................

A summary of the study results and their implications will be prepared at the end of the project. If you would like to receive this summary via email please provide your email details. Your contact details will not be shared outside this project.

Email address: _____

D5: Recruitment flyer

Are you a parent or carer of a child who has cerebral palsy?

Would you like to help us with research about your experiences of assessment?
Do you know others who might be interested?

What is this study about? We are doing research about parents' and carers' experiences of participating in assessment.

Who are we looking for? We are interested in primary carers—mothers, fathers, grandparents or guardians—from both regional and metro areas, with a child, aged between 3 and 18 years old, who has cerebral palsy. We are keen to speak with carers who would like to talk about their experiences of formal and informal assessments that their child has undertaken with physiotherapists, occupational therapists or speech pathologists.

What's involved? If you agree to take part, you will be asked to complete one survey that will take about 15 minutes of your time and one face-to-face interview with a researcher. The interview may take up to one hour and will be audio-taped, with your consent.

What are the benefits? There are no immediate benefits. However, being involved may increase your awareness of your role in assessment and help us know how we can be better at involving parents in assessments and decisions about your child's health care and therapy needs.

Who is involved in this research?

Bridget O'Connor - Physiotherapist, ACU
Prof Christine Imms - Centre for Disability & Development Research, ACU
Dr Claire Kerr - Queen's University, Belfast UK
Prof Nora Shields - LaTrobe University, Melbourne
Dr Brooke Adair - ACU Melbourne

TO TAKE PART OR FIND OUT MORE, PLEASE CONTACT

Bridget O'Connor
E: bridget.oconnor2@myacu.edu.au
T: **0439 609 403**

D6: Study questionnaire

PARTICIPANT DEMOGRAPHIC QUESTIONNAIRE

PROJECT TITLE: Parents' experience of assessment for their child with cerebral palsy.
PRINCIPAL INVESTIGATOR: Christine Imms
STUDENT RESEARCHER: Bridget O'Connor

_____

*Thank you for completing this questionnaire that contributes to our study that aims to understand your experiences of assessment for your child with cerebral palsy. The questionnaire is in two parts Part A and Part B. **Part A** asks general questions about you and your family. **Part B** asks about your child, the services you have received, and your child's motor, hand and communication abilities. Please select the relevant boxes [ ] that most closely describe your answer to each question.*

Part A: *This section refers to you - the parent or carer.*

What is your name? _____

Date of birth (dd/mm/yyyy) _____

What is your address? _____

Date of form completion (dd/mm/yyyy) _____

What is your country of birth? _____

Is English your first language?
[ ] Yes   [ ] No

What is your relationship to your child?
[ ] Mother   [ ] Father   [ ] Grandmother   [ ] Grandfather   [ ] Other, please specify_____

How many children do you have in your care? _____

What are your child's care arrangements?
[ ] Sole carer
[ ] Shared care
[ ] Other, (please specify)_____

Do you have more than one child with a disability in your care?
[ ] No   [ ] Yes, if so, how many? _____

What is your combined annual household income before tax?
[ ] Less than $25,000
[ ] $25,000 to $59,999
[ ] $60,000 to $99,999
[ ] $100,000 to $149,999

[ ] $150,000 to $179,999
[ ] $180,000 or more
[ ] prefer not to answer

What is the highest level of education that you completed?
[ ] Did not complete secondary school
[ ] Secondary school/Year 12
[ ] TAFE college certification or apprenticeship
[ ] University degree
[ ] Postgraduate degree

Part B: *This section of the questionnaire refers to your child; the services they have receive and functional abilities.*

What is your child's name? _____

Date of your child's birth (dd/mm/yyyy) _____

Your child's gender   [ ] male   [ ] female

What is your child's year level at school?
[ ] Pre-school/not attending school   [ ] Prep (Vic)/Kindergarten (NSW)
[ ] Grade 1-3   [ ] Grade 4-6
[ ] Year7-10   [ ] Year 11/12
[ ] Other, (please describe) _____

If school age, what type of school does your child go to?
[ ] Home school
[ ] Public school
[ ] Private school
[ ] Special development school
[ ] Not applicable
[ ] Other (please describe) _____

The following table asks about the therapy services your child has or may currently access.
Please tick **all** the relevant boxes.

What type of service provider?	How was the service delivered?	Type of therapy	Is this service current?
[ ] Early intervention	[ ] Individual therapist(s) from one or more services [ ] Multi-disciplinary therapy team from single service [ ] Keyworker, with individual therapist consultations [ ]Early education team	[ ] Occupational Therapy [ ] Physiotherapy [ ] Speech Pathology [ ] Other, please specify _____	[ ] Yes [ ] No

	[ ] Other, _____-_____		
[ ] School Based Service	[ ] Individual therapist(s) from one (or more) services [ ] Multi-disciplinary therapy team from single service [ ] Keyworker, with individual therapist consultations [ ]Education team [ ] Other, _____-_____	[ ] Occupational Therapy [ ] Physiotherapy [ ] Speech Pathology [ ] Other, _____	[ ] Yes [ ] No
[ ] Community rehabilitation centre	[ ] Individual therapist(s) from one (or more) services [ ] Multi-disciplinary therapy team from single service [ ] Keyworker, with individual therapist consultations [ ]Early education team [ ] Other, _____-_____	[ ] Occupational Therapy [ ] Physiotherapy [ ] Speech Pathology [ ] Other, _____	[ ] Yes [ ] No
[ ] Hospital Service	[ ] Individual therapist(s) from one (or more) services [ ] Multi-disciplinary therapy team from single service [ ] Keyworker, with individual therapist consultations [ ]Early education team [ ] Other, _____-_____	[ ] Occupational Therapy [ ] Physiotherapy [ ] Speech Pathology [ ] Other, _____	[ ] Yes [ ] No
[ ] Community Health Centre	[ ] Individual therapist(s) from one (or more) services [ ] Multi-disciplinary therapy team from single service [ ] Keyworker, with individual therapist consultations	[ ] Occupational Therapy [ ] Physiotherapy [ ] Speech Pathology [ ] Other, _____	[ ] Yes [ ] No

	[ ]Early education team [ ] Other, _____		
[ ] Private Practice	[ ] Individual therapist(s) from one (or more) services [ ] Multi-disciplinary therapy team from single service [ ] Keyworker, with individual therapist consultations [ ]Early education team [ ] Other, _____-_____	[ ] Occupational Therapy [ ] Physiotherapy [ ] Speech Pathology [ ] Other, _____	[ ] Yes [ ] No
[ ] Other, please specify _____	[ ] Individual therapist(s) from one (or more) services [ ] Multi-disciplinary therapy team from single service [ ] Keyworker, with individual therapist consultations [ ]Early education team [ ] Other, _____-_____	[ ] Occupational Therapy [ ] Physiotherapy [ ] Speech Pathology [ ] Other, _____	[ ] Yes [ ] No

You will now be asked to indicate your child's functional abilities by reading and selecting a descriptor **that best** represents your child's abilities in each of the following areas;

> 1) how your child mobilises, (GMFCS)
> 2) how your child uses their hands, (MACS)
> 3) how your child communicates, (CFCS)

Instructions

1) **For mobility** you will first need to choose the **GMFCS** page that is applicable to your child's age (birthday between 2-4 years, 4-6 years, 6-12 years, or 12-18 years). Once selected read the descriptors for each level of mobility (V, IV, III, II, or I) and **circle one level** that **best describes** your child.

2) **For hand function.** If your child is **under 4 years old**, select the **mini-MACS** sheet. If your child is **4 years or older** select the **MACS** sheet. Read the descriptor for each level of hand use (I, II, III, IV, or V) and then **circle one level** that **best describes** your child.

3) **For communication** no age selection is needed. Read the definitions provided and then the descriptor for each communication level (I, II, III, IV, or V) and then **circle one level** that **best describes** your child.

When finished, please tick each box to indicate you have circled one response for each of the following.

☐ GMFCS

☐ MACS

☐ CFCS

Thank you for completing this questionnaire!

Please return this questionnaire to the address below using the stamped self-addressed envelope provided.

Prof Christine Imms
Australian Catholic University
c/o Locked Bag 4115
Fitzroy VIC 3065.

Mobility

<u>GMFCS Family Report Questionnaire:</u>

Between 2nd and 4th birthday

My child...

V

Has difficulty controlling head and trunk posture in most positions
and uses specially adapted seating to sit comfortably
and has to be lifted by another person to move about

IV

Can sit on own when placed on the floor and can move within a room
and uses hands for support to maintain sitting balance
and usually uses adaptive equipment for sitting and standing
and moves by rolling, creeping on stomach or crawling

III

Can sit on own and walk short distances with a walking aid (such as a walker, rollator, crutches, canes, etc.)
and may need help from an adult for steering and turning when walking with an aid
and usually sits on floor in a "W-sitting" position and may need help from an adult to get into sitting
and may pull to stand and cruise short distances
and prefers to move by creeping and crawling

II

Can sit on own and usually moves by walking with a walking aid
and may have difficulty with sitting balance when using both hands to play
and can get in and out of sitting positions on own
and can pull to stand and cruise holding onto furniture
and can crawl, but prefers to move by walking

I

Can sit on own and moves by walking without a walking aid
and is able to balance in sitting when using both hands to play
and can move in and out of sitting and standing positions without help from an adult
and prefers to move by walking

Mobility

Between 4th and 6th birthday

My child…

V

Has difficulty sitting on their own and controlling their head and body posture in most positions

and has difficulty achieving any voluntary control of movement

and needs a specially-adapted supportive chair to sit comfortably

and has to be lifted or hoisted by another person to move

IV

Can sit on their own but does not stand or walk without significant support and adult supervision

and may need extra body / trunk support to improve arm and hand function

and usually needs adult assistance to get in and out of a chair

and may achieve self-mobility using a powered wheelchair or is transported in the community

---

III

Can walk on their own using a walking aid (such as a walker, rollator, crutches, canes, etc.)

and can usually get in and out of a chair without adult assistance

and may use a wheelchair when travelling long distances or outside

and finds it difficult to climb stairs or walk on an uneven surface without considerable help

---

II

Can walk on their own without using a walking aid, but has difficulty walking long distances or on uneven surfaces

and can sit in a normal adult chair and use both hands freely

and can move from the floor to standing without adult assistance

and needs to hold the handrail when going up or down stairs

and is not yet able to run and jump

I

Can walk on their own without using a walking aid, including fairly long distances, outdoors and on uneven surfaces

and can move from the floor or a chair to standing without using their hands for support

and can go up and down stairs without needing to hold the handrail

and is beginning to run and jump

Mobility

Between 6th and 12th birthday

My child...

V **Has difficulty sitting on their own and controlling their head and body posture in most positions**

and has difficulty achieving any voluntary control of movement
and needs a specially supportive chair to sit comfortably
and has to be lifted or hoisted by another person to move

IV **Can sit on their own but does not stand or walk without significant support**

and therefore relies mostly on wheelchair at home, school and in the community
and often needs extra body / trunk support to improve arm and hand function
and may achieve self-mobility using a powered wheelchair

III **Can stand on their own and only walks using a walking aid** (such as a walker, rollator, crutches, canes, etc.)

and finds it difficult to climb stairs, or walk on uneven surfaces
and may use a wheelchair when travelling for long distances or in crowds
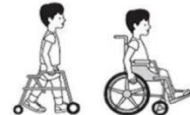
II **Can walk on their own without using walking aids, but needs to hold the handrail when going up or down stairs**

and often finds it difficult to walk on uneven surfaces, slopes or in crowds
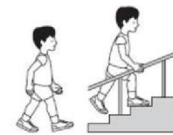
I **Can walk on their own without using walking aids, and can go up or down stairs without needing to hold the handrail**

and walks wherever they want to go (including uneven surfaces, slopes or in crowds)
and can run and jump although their speed, balance, and coordination may be slightly limited
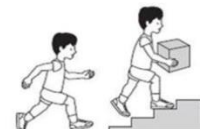
Mobility

Between 12th and 18th birthday

My child...

V **Has difficulty sitting on their own and controlling their head and body posture in most positions**
and has difficulty achieving any voluntary control of movement
and needs a specially adapted chair to sit comfortably and be transported anywhere
and has to be lifted or hoisted by another person or special equipment to move

IV **Can sit with some pelvic and trunk support but does not stand or walk without significant support**
and therefore always relies on wheelchair when outdoors
and can achieve self-mobility using a powered wheelchair
and can crawl or roll to a limited extent to move around indoors

III **Can stand on their own and only walks using a walking aid** (such as a walker, rollator, crutches, canes, etc.)
and finds it difficult to climb stairs, or walk on uneven surfaces without support
and uses a variety of means to move around depending on the circumstances
and prefers to use a wheelchair to travel quickly or over longer distances

II **Can walk on their own without using walking aids, but needs to hold the handrail when going up or down stairs**
and therefore walks in most settings
and often finds it difficult to walk on uneven surfaces, slopes or in crowds
and may occasionally prefer to use a walking aid (such as a cane or crutch) or a wheelchair to travel quickly or over longer distances

I **Can walk on their own without using walking aids, and can go up or down stairs without needing to hold the handrail**
and walks wherever they want to go (including uneven surfaces, slopes or in crowds)
and can run and jump although their speed, balance, and coordination may be limited

Hand function - under 4 years

Mini-**MACS**

I   **Handles objects easily and successfully.** The child may have a slight limitation in performing actions that require precision and coordination between the hands but they can still perform them. The child may need somewhat more adult assistance when handling objects compared to other children of the same age.

II   **Handles most objects, but with somewhat reduced quality and/or speed of achievement.** Some actions can only be performed and accomplished with some difficulty and after practice. The child may try an alternative approach, such as using only one hand. The child need adult assistance to handle objects more frequently compared to children at the same age.

III   **Handles objects with difficulty.** Performance is slow, with limited variation and quality. Easily managed objects are handled independently for short periods. The child often needs adult help and support to handle objects.

IV   **Handles a limited selection of easily managed objects in simple actions.** The actions are performed slowly, with exertion and/or random precision. The child needs constant adult help and support to handle objects.

V   **Does not handle objects and has severely limited ability to perform even simple actions.** At best, the child can push, touch, press, or hold on to a few items, in constant interaction with an adult.

Distinctions between Levels I and II

Children in Level I may have slightly more difficulty handling items that require good fine motor skills compared to children without disabilities of the same age.

Children in Level II handle essentially the same objects as children in Level I, but they may encounter problems performing tasks and/or take longer to perform them, so they often ask for help. Functional differences between hands may cause performance to be less effective. They may need more guidance and practice to learn how to handle objects compared with children in Level I.

Distinctions between Levels II and III

Children in Level II can handle most objects, though they may take longer and do so with somewhat less quality, and they may need a lot of guidance and practice to learn how to handle objects.

Level III children manage to use easily handled objects but often need help placing objects in an easy position in front of them. They perform actions with few subcomponents. Performance is slow.

Distinctions between Levels III and IV

Children in Level III manage to use easily handled objects independently for short periods. They perform actions with few subcomponents, and the actions take a long time to perform.

At best, children in Level IV can perform simple actions such as grasping and releasing easily handled objects that are offered in an adapted position. They need constant help.

Distinctions between Levels IV and V

Children in Level IV perform individual actions with a very limited selection of objects and need constant help.

At best, children in Level V perform simple movements in special situations. For example, they can press a simple button or hold single, simple objects.

Hand function- 4 years and over

MACS

What do you need to know to use MACS?

The child's ability to handle objects in important daily activities, for example during play and leisure, eating and dressing.

In which situation is the child independent and to what extent do they need support and adaptation?

I **Handles objects easily and successfully.** At most, limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities.

II **Handles most objects but with somewhat reduced quality and/or speed of achievement.** Certain activities may be avoided or be achieved with some difficulty; alternative ways of performance might be used but manual abilities do not usually restrict independence in daily activities.

III **Handles objects with difficulty; needs help to prepare and/or modify activities.** The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted.

IV **Handles a limited selection of easily managed objects in adapted situations.** Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.

V **Does not handle objects and has severely limited ability to perform even simple actions.** Requires total assistance.

Distinctions between Levels I and II
Children in Level I may have limitations in handling very small, heavy or fragile objects which demand detailed fine motor control, or efficient coordination between hands. Limitations may also involve performance in new and unfamiliar situations. Children in Level II perform almost the same activities as children in Level I but the quality of performance is decreased, or the performance is slower. Functional differences between hands can limit effectiveness of performance. Children in Level II commonly try to simplify handling of objects, for example by using a surface for support instead of handling objects with both hands.

Distinctions between Levels II and III
Children in Level II handle most objects, although slowly or with reduced quality of performance. Children in Level III commonly need help to prepare the activity and/or require adjustments to be made to the environment since their ability to reach or handle objects is limited. They cannot perform certain activities and their degree of independence is related to the supportiveness of the environmental context.

Distinctions between Levels III and IV
Children in Level III can perform selected activities if the situation is prearranged and if they get supervision and plenty of time. Children in Level IV need continuous help during the activity and can at best participate meaningfully in only parts of an activity.

Distinctions between Levels IV and V
Children in Level IV perform part of an activity, however, they need help continuously. Children in Level V might at best participate with a simple movement in special situations, e.g. by pushing a button or occasionally hold undemanding objects.

Communication

Definition of terms:

Communication occurs when a **sender** transmits a message *and* a **receiver** understands the message. An **effective communicator** independently **alternates as a sender and a receiver** regardless of the demands of a conversation, including settings (e.g., community, school, work, home), conversational partners, and topics.

All methods of communication performance are considered. E.g. use of speech, gestures, behaviours, eye gaze, facial expressions, and all forms of augmentative and alternative communication e.g. pictures communication books and devices.

Communication Function Classification System (CFCS) for Individuals with Cerebral Palsy

I **Effective Sender and Receiver with unfamiliar and familiar partners.** The person independently **alternates between sender and receiver** roles with most people in most environments. The communication occurs easily and at a **comfortable pace** with both **unfamiliar and familiar conversational partners**. Communication misunderstandings are quickly repaired and do not interfere with the overall effectiveness of the person's communication.

II **Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners.** The person independently **alternates between sender and receiver** roles with most people in most environments, but the **conversational pace is slow** and may make the communication interaction more difficult. The person may need extra time to understand messages, compose messages, and/or repair misunderstandings. Communication misunderstanding are often repaired and do not interfere with the eventual effectiveness of the person's communication with both **unfamiliar and familiar partners**.

III **Effective Sender and Receiver with familiar partners.** The person **alternates between sender <u>and</u> receiver roles with familiar** (but not unfamiliar) conversational partners in most environments. Communication is **not consistently effective** with most **unfamiliar partners**, but is **usually effective** with **familiar partners.**

IV **Inconsistent Sender and/or Receiver with familiar partners.** The person does **<u>not</u>** consistently alternate **sender and receiver** roles. This type of inconsistency might be seen in different types of communicators including: a) an occasionally effective sender and receiver; b) an effective sender but limited receiver; c) a limited sender but effective receiver. Communication is **sometimes effective** with **familiar partners.**

V **Seldom Effective Sender and Receiver even with familiar partners.** The person is limited as both a **sender and a receiver**. The person's communication is difficult for most people to understand. The person appears to have limited understanding of messages from most people. Communication is **seldom effective** even with **familiar partners.**

Hidecker et al (2011). Developing and validating the Communication Function Classification System (CFCS) for individuals with cerebral palsy, Developmental Medicine and Child Neurology. 53(8), 704-710

D7: Interview topic guide

Research Question: What are parent's experiences of standardised assessments for their child with cerebral palsy, with health professionals?

Thank you and house keeping

Just to remind you that I will be recording todays interview but your and other names will be de-identified and that our discussion today will remain confidential. Do you have you any questions regarding this? Audio started.

Background introduction to assessment

The topic we are talking about today is assessment and I'm interested in your experiences of assessment with therapists (OTs, PTs and SPs) that you have been involved with up until now.

When talking about assessment, I mean the way we gather and use information to help make judgments and decisions about things like therapy goals, therapy programmes or services for (name), or to monitor (name)'s progress with a therapy programme or goals related to aspects of (name)'s mobility, self-care, behaviour, social skills and communication.

Typically therapists would collect this information through; discussion with you and your child; observing him/her in different settings; but also by using more formal methods such as specific tests, measures or scales. Some common examples of these tests would include things like; goniometry to measure joint movement, or a walking assessment that's been timed or videoed, or where your child is asked to do a series of set tasks and a score sheet is used to record his/her performance e.g. Gross Motor Function Measure (GMFM), Assisting Hand Assessment (AHA), or a language assessment, or you might be asked to fill out responses to a list of questions e.g. Pediatric Evaluation of Disability Inventory (PEDI), or prioritise goals using numbers e.g. Canadian Occupational Performance Measure (COPM) or Goal Attainment Scaling (GAS).

1. **Before we start talking about assessment specifically, can you tell me a bit about (name of child)?**

    Probes:

    ☐ *How is a typical day for your child?*
    ☐ *What things or activities does your child engage in?*
    ☐ *What particular problems or issues does your child encounter?*

2. Can you tell me about what comes to mind when you reflect on your experiences of assessment?

Probes:
- ☐ *Who is involved? What happens?*
- ☐ *How do you find assessment generally?*
- ☐ *How is it for your child?*

If experiences of standardised assessment are not referred to, then prompt with …

I would like to go on now and talk more specifically about your experiences of formal types of assessment.

3. Can you think back and describe for me in detail your experience of a formal assessment for (child's name); perhaps the last time or another time that you can remember?

Probes - will be used as needed, depending on the participant's story…. *Can you tell me about…*

- ☐ *What happened? Where did it happen? Who was there?*
- ☐ *How did the assessment come about?*
- ☐ *How (in what ways) were you involved in the assessment for [child's name]?*
- ☐ *What did you hope to get from the assessment?*

- ☐ *Can you tell me about how the assessment process was for you, as the parent?*
    - o *What went well?*
    - o *What didn't go well (if anything)?*
- ☐ *How do you think (child's name) found the assessment, or finds assessments generally?*

- ☐ *How was the information from the assessment used?*
- ☐ *What did you (or your child) get from the assessment?*
- ☐ *How did you feel about this information?*
- ☐ *What did you do with this assessment information?*
- ☐ *Who else was able to use the information?*
- ☐ *Explore relationship to goal setting- related to? before-after?*

- ☐ *What value do you place in assessments? How important is it to you that your child receives formal assessment?*
- ☐ *To what extent do you think your child's therapists value assessments?*
- ☐ *How would you prefer to be involved in formal assessments for your child? Why?*

Wrapping Up *We have talked in detail about a very specific assessment experience, is there anything else you'd like to share with me about you and your child's assessment experiences?*

D8: Email communication with parents for member checking

From: Bridget O'Connor
Sent: Wednesday, 25 July 2018 10:18 AM
To:
Subject: Re: Parent experiences of assessment_study findings

Dear _____,

Thank you for speaking to me about your assessment experiences with_____ in _____. As I mentioned to you during the interview, I am providing you with a copy of the early findings from the study. I am sharing these to give you the opportunity to review and comment on them before progressing further.

Over the past 5 months I have spoken with 14 parents from across Southern NSW and Victoria. All of the interviews were typed up by a transcription service and returned along with our every "um" and "aah" (mostly mine!). Then I went through a process of careful analysis looking for shared and related thoughts and experiences of assessment.

Seven main topics with underlying themes were derived from the data. The summary is in the attached pdf document. The topics are arranged in a "Steering Wheel" starting at the central hub, and then filling in the four radiating spokes and outer rims. Each diagram has a brief description below.

I have arranged the findings in the Steering Wheel to show how the topics relate to each other and as a guide for therapists and parents to think about when using assessments. Generally, the further out in the wheel you go, the more collaborative assessment becomes. The outer rim of collaborative assessment is what we can aspire to.

I am interested to know:
- If you can see your experiences represented somewhere (you don't need to say where) in the descriptions and the Steering Wheel?
- Does the story described by the Steering Wheel "ring true" for you or perhaps for others you know?
- Is there anything in the wheel or the descriptions that you find awkward or uncomfortable?

I would really value any comments you might have about these questions along with any other thoughts you might have about assessment experiences. Even a brief message to let me know you have received the information would be great if running short on time.

If possible, could you please send your comments within the next two weeks - by Tuesday, August 7th - as then I will be able to continue with the work.

Again, thank you for your involvement in the study and your commitment to improving the experiences of other families and children. It was a privilege to have the opportunity to listen to your insights and thoughts about assessment, and their impact and worth to you and your family. I will forward the final paper to you when completed.

Warm regards,

Bridget O'Connor,

PhD candidate, School Allied Health, Australian Catholic University

D9: Participant member checking responses

Parent Nº Contact	Details
Par#1 Phone call notes taken following discussion	**Sub-theme discussed- Adjustment- reconciling** • *Stated that compliance and resignation are more reflective descriptions - parents never reconcile assessment. Your child is regularly judged or assessed as part of therapy and in addition to the mainstream school reports and NAPLan tests.* • *Although we talk about assessing what they 'can do' assessment is a reminder of what they 'can't do'. Every time you go through an assessment it's 'back in your face'. It brings it home every time. Parents feel guilty like any parent when something goes wrong, but the bandwidth is wider. Feel more highs and the lows from these events and they are ongoing. Parents are fragile, tired, emotionally fatigued every day -Ax can tip the scales on a fragile day. Takes a while to get on top of it again. Assessment has an impact.* **The Steering wheel concept discussed** • *Really liked the idea/concept. We discussed the wheel and who was holding the wheel. Interpreted this as the therapist as the driving instructor. Not all parents are the same and need different approaches at different times. Sometimes parents need lots of instruction and to hold the wheel (therapist needs to have two hands on the wheel) – or four hands- therapist and parent hold the wheel- or sometimes therapist guides and lightly touch the wheel (2 parent hands), sometimes the parent can take the wheel and therapist alongside or in backseat!* • *Therapists also need to teach child/student to take the wheel especially in adolescence- so can make decisions have near miss experiences like other kids that they can draw non as part of their experience.* • *Assessment early on is confronting but easier to implement strategies. Later much more difficult to implement and parents left stranded - parent reported being very glad she didn't ditch her own professional career!* • *Main point for her that didn't come through related to involvement theme was the idea of parents as instructors and educators of therapists about their child- very important for parent to help train therapists both for their child and other children to come. Parents are in a difficult role sometimes with new therapists – how to do this without undermining therapist confidence. Trained novice therapists to listen to parents and be guided. Parents 'bobbing around' but so are therapists. Therapists and parents guiding and training each other and working together.* **Theme discussed - Protection and diagnosis legacy** • *Less of an issue for this mother but a big issue for her ex-husband. When discussing problems for their child at 14 years – recaps the diagnosis– she had a bleed on the ultrasound- refers back to the script 'they always said there would be problems. We knew that life was going to be just shit.'*

	• ***Theme discussed - Representation***- *not so much misrepresented but her and many children fall between the cracks. Other issues become a priority, not able to deal with increasing tight arm-may regret this when a young woman.* **Recommendation** • *Use formal assessment judiciously* • *Therapists to be aware of the impact assessment can have at any stage.* • *Assess each parent re capability and capacity to manage assessment* • *Check in with parents – Say to parents I want you to let me know where you are at- generally but also today. What can they manage today?*
Par #2 Email	*Sorry Bridget this has been sitting in my to do folder for too long!* *You have done terrific work. I love the idea of the steering wheel being representative of the journey we are taking with our kids...without you actually using the good old word journey!* *I like the way you have layered the pieces over the wheel to build the collection of ideas.* *Trust stands out as being particularly important to achieve effective and useful assessment.* *I really don't have anything more to add. Thanks for the opportunity to be involved.*
Par #3	Email reply but no follow up
Par #4 Email	*Thanks for sharing that Bridget.* *I don't feel like the whole representation applies to us, but there are definitely bits I can relate to. It does seem an appropriate summary of the issues faced by parents.* *Thank you for doing this research, I hope it doesn't get lost in the dusty corners of academia.*
Par #5 Email Face-to-face	*I've just read through your study findings again. What a HUGE amount of work and time it must have taken you, definitely your forte! Anyway I can see where I think I am, assessment wise on the steering wheel and of course have comments but I'm not sure if it's what you're after so is it ok if we chat about it on Monday as you suggested just to make sure you get everything you need. I'm honoured that I am a participant and just want to do a good job for all your efforts. .... Many thanks* *Parent reported she could see where he was on the Wheel diagram and how she has progressed in her taking greater control of the wheel. Feels she needs to start afresh with new therapists. Has found it very useful in beginning to advocate for her child with NDIS. Has recently written her first email written to therapy team outlining preferences for behaviour medication.*
Par #6 Email	*I have had a look through the summary. There is something in every section that I am able to relate to. Well done!!*
Par #7	No reply
Par #8	No reply

Par#9 Email	*Thank you so much Bridget for sharing your study. I really liked the steering wheel concept. I found it both easy to follow and very interesting reading the 7 main topics. Thanks again for sharing.*
Par #10 Email	*Sorry for the delayed response, little …. has been unwell so we are a bit all over the place at the moment.* *In response to your questions, I can see my responses represented in your diagram/descriptions. Some of the information rings true for us and some doesn't, however the parts that don't match our scenario, I have definitely heard through other families telling their stories. Looks like that would have been a huge job for you, putting it all together in this format, well done!*
Par #11 Email	*I have read the study findings and I can honestly say that it all rings true - in all areas of the steering wheel. It either captures our own personal experiences or my feelings toward the process. Nothing in these findings is awkward or uncomfortable - just very relevant.* *Again, I just wanted to say that much of our experience has been positive which I attribute to having the time and resources to devote to assessment for Dane. I feel that another person's experience could be quite different if they are stretched for time/resources (e.g. work long hours, don't have support to care for other children). I imagine assessment would become far more stressful (and perhaps viewed negatively) if you are trying to fit it into an already hectic life.* *Let me know if you need any other feedback. Well done on your analysis - I feel you really captured my thoughts!*
Par#12 Email	*Apologies again for the delay with my feedback.* *The steering wheel appears to 'ring true'. There is great detail in this document Bridget and my experience is represented, not in all aspects of the wheel, but it is in there. The picture of what we are all striving for is noted well.* *I agree standardised assessments sometimes have difficulty picking up the nuances of the our kids, but understand that if all options are incorporated the standardisation becomes more difficult. There are certainly less relevant assessments in the later primary and adolescent years.* *Assessments or the medical appointments in general were historically often negative in nature or focus on what the child can't do, so positivity, highlighting possibilities and having clear strategies or goals coming from the assessment are important to make the time, monetary and emotional commitment worthwhile. This has been shifting in the last decade focussing on achievements and optimising these.* *Good luck with the next stages of your PhD. All your hard work will be worth it in the end. Please let me know if I can help further.*
Par #13	No reply
Par #14 Email	*Thanks for sending through a copy of your findings.* *I must admit, I wondered if I would be able to understand what you might have written – but I am happy to say that I did!! I did find that my thoughts were represented in your report – and I could also think of conversations with other parents that I have had along our journey. Well done! – and all the best with the final stages of your study.*

*Verbal consent gained from this parent to incorporate ideas discussed into analysis. Theme heading *mentee* replaced with *mentee-mentor.*

Appendix E: Permissions to use published works in this thesis

E1: Approval to reproduce artwork image in this thesis, published paper and book chapter

25 March 2019

To whom it may concern,

Left Bank
Spinningfields
Manchester M3 3ER
Tel/fax 0161 838 9190
info@phm.org.uk
www.phm.org.uk

People's History Museum hereby grants non-exclusive reproduction rights to **Bridget O'Connor** for the below images to be incorporated into the research manuscript **'Steering towards collaborative assessment: A qualitative study of parents' experiences of evidence-based assessment for their child with cerebral palsy'** for publication in the journal *Disability and Rehabilitation* and Ms O'Connor's published PhD thesis.

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The images:

1995.35.8 – Labour Party Poster, 'Mothers Vote Labour'

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Yours Sincerely,

Sam Jenkins

Collections Officer

E2: Permission to include Knowledge-To-Action diagram in Figure 1.1

E3: Permission to include published Paper 1

Dear Bridget
I am pleased to confirm that we are happy for you to reproduce your paper:

O'Connor B, Kerr C, Shields N, Imms,C. A systematic review of evidence-based assessment practices by allied health practitioners for children with cerebral palsy. Dev Med Child Neurol. 2016;58:332-347.

in your PhD thesis as long as full citation to the paper is given, and you have the agreement of your co-authors.

I wish you all the best with your thesis!

Kind regards
Ann-Marie

Ann-Marie Halligan
Managing Director

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On Mon, Apr 29, 2019 at 12:50 PM Bridget O'Connor <bridget.oconnor2@myacu.edu.au> wrote:

Dear Editorial Office,

I am currently preparing my doctoral thesis and am seeking your permission to insert my paper published with you in 'Developmental Medicine & Child Neurology' into my thesis by publication.

The details of the paper are as follows:
O'Connor B, Kerr C, Shields N, Imms,C. A systematic review of evidence-based assessment practices by allied health practitioners for children with cerebral palsy. Dev Med Child Neurol. 2016;58:332-347.

I look forward to hearing from you when convenient.

Kind Regards,
Bridget

Bridget O'Connor
PhD candidate, School Allied Health
Australian Catholic University E: bridget.oconnor2@myacu.edu.au

E4: Permission to include published Paper 1 Commentary

Subject **RE: Permission to include commentary article in PhD thesis Appendix**
From Ann-Marie Halligan
To Bridget O'Connor
Cc Andrew Booth; DMCN Journal
Sent 10/06/2019 6:32:32 PM

Dear Bridget
I am happy to grant permission for you to use the commentary in your thesis in print and online, with the same conditions as previously, that full citation to the article is given as you cite below.
Kind regards
Ann-Marie

Ann-Marie Halligan
Managing Director

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From: Bridget O'Connor <bridget.oconnor2@myacu.edu.au>
Sent: 10 June 2019 01:33
To: Ann-Marie Halligan <Ann-Marie.Halligan@mackeith.co.uk>
Cc: Andrew Booth <andy.booth@mackeith.co.uk>; DMCN Journal <dmcn@editorialoffice.co.uk>
Subject: Re: Permission to include commentary article in PhD thesis Appendix

Dear Ann-Marie,

I am wondering if it would be possible to steer me in the right direction in relation to seeking permission to include a commentary for a paper I have published with Developmental Medicine and Child Neurology for which you have granted permission for me to use (see below).
I would like to seek permission to include this commentary in the Appendix of my PhD thesis that I am collating. The thesis will be in print format but an electronic copy also needs to be provided to the University. I tried going through the permissions link at the article online however RightsLink declines permission when I enter print and electronic.
I am wondering whether it would be possible to obtain your permission to use this commentary article in this manner.

> Oeffinger, D. (2016). Use of standardized outcome measures should be common place in the clinical care of children with cerebral palsy: why isn't it? *Developmental Medicine and Child Neurology, 58*(4), 321. doi:10.1111/dmcn.13031

Thank you for your consideration,
Kind Regards,
Bridget O'Connor
PhD candidate, School Allied Health
Australian Catholic University
E: bridget.oconnor2@myacu.edu.au

E5: Permission to include accepted manuscripts for Paper 2 and Paper 3

[https://protect-us.mimecast.com/s/YKsKCxkVlDi1kOZZBH8oxCH?
domain=taylorandfrancis.my.salesforce.com]

Dear Author,

Thank you for your email.

As an author of the original article you have the right to include the Accepted Manuscript in a thesis or dissertation that is not to be published commercially, provided that publication is acknowledged using the following text:

This is an Accepted Manuscript of an article published by Taylor & Francis in Journal of XXX on DATE, available online: https://protect-us.mimecast.com/s/C9S9CyP6mEtrZnYYJUMFaFK?
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domain=apc01.safelinks.protection.outlook.com>

Best regards,

Christian Dominic Fontanilla

On behalf of the Taylor & Francis Journals Helpdesk

Subject: Permission query
Sent by: boconnor@hotmail.com.au
Sent on: 25/06/2019

Dear Taylor and Francis support and author queries,

I am wondering if you could assist me with the following.
I am due to submit my Doctoral thesis in 3 weeks and I was wondering if you could assist me with advice on how I might be able to gain permission to include the two published articles (Listed below), for which I am the primary author, in my thesis within this timeframe.
The permission request for the first article was placed 4 weeks ago on the 29th May. The automatic reply for the first article was placed 4 weeks ago so I am hoping to hear back soon.
The second article listed below was published on line yesterday (24 June 2019) and a permission request with Taylor and Francis submitted for this today with a 6 week response time indicated for a reply.

I appreciate the heavy demand and load to process these requests but wondered if there might be any possibility of these requested being considered in a time frame that enables me t include the published papers in my doctoral thesis.
I would also like to confirm that I have undertaken the appropriate procedure in my lodgement of these requests.

I thank you kindly for your consideration of this request, if possible,

Kind Regards,
Bridget O'Connor

Request placed 29 May 2019
O'Connor, B., Kerr, C., Shields, N., & Imms, C. (2019). Understanding allied health practitioners' use of evidence-based assessments for children with cerebral palsy: a mixed methods study. Disability and Rehabilitation, 41(1), 53-65. doi:10.1080/09638288.2017.1373376

Request placed 25 June 2019
O'Connor, B., Kerr, C., Shields, N., Adair, B., & Imms, C. (2019). Steering towards collaborative assessment: a qualitative study of parents' experiences of evidence-based assessment practices for their child with cerebral palsy. Disability and Rehabilitation, 1-10. Retrieved from doi:10.1080/09638288.2019.1629652

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[https://protect-us.mimecast.com/s/yeoBCERZP5f3LPBBnHBKKZu?
domain=taylorandfrancis.my.salesforce.com]

E6: Approval to include book chapter, checklist and vignette in this thesis

From: Lucy White <lucy@mackeith.co.uk>
Sent: Thursday, 6 June 2019 10:22 PM
To: Bridget O'Connor
Cc: Christine Imms
Subject: RE: Enabling Participation - Copyright Transfer Agreement

Dear Bridget

Thank you for your e-mail. We are happy to give permission for inclusion of your book chapter in your thesis. Please just use the reference format as follows with the details currently available:

Townend G.S., Marschik P.B., Kaufmann W., Fabio R.A., Sigafoos J., Curfs L.M.G. (2017). Cognition, behavior and communication. In Kaufmann WE. (ed.) *Rett syndrome.* Ch.5, 50-61. London: Mac Keith Press.

Wishing you the best for the completion of your PhD!

Best regards
Lucy

Lucy White
Editorial and Marketing Assistant

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London SE1 3UW
 +44 (0)20 3958 7412
www.mackeith.co.uk

From: Bridget O'Connor <bridget.oconnor2@myacu.edu.au>
Sent: 04 June 2019 03:28
To: Lucy White <lucy@mackeith.co.uk>
Cc: Christine Imms <Christine.Imms@acu.edu.au>
Subject: Re: Enabling Participation - Copyright Transfer Agreement

Dear Lucy,
Thank you for sending the CTA document for signing.

Before signing I wanted to let you know that I was hoping to be able to include a pre-published version of Chapter 15 of the book and the Jack In the Box vignette in the Appendix of my PhD thesis. I am currently preparing the thesis for submission in July this year and would like to seek permission from Mac Keith Press to include this and wondered if you could advise me on the permission process at this point.

Kind Regards,
Bridget

Appendix F: Research Portfolio

F1: Statement of contributions to published works of joint authorship

Paper 1. I acknowledge that the following contributions have been made by myself and each of the listed co-authors to the paper 'O'Connor, B., Kerr, C., Shields, N., & Imms, C. (2016). A systematic review of evidence-based assessment practices by allied health practitioners for children with cerebral palsy. Developmental Medicine and Child Neurology, 58(4), 332-347.'

Bridget O'Connor (65%)

- Development of systematic review protocol
- Database and literature searches
- Study selection, quality assessment, data extraction and analysis
- Critical appraisal and discussion with supervision team
- Planning, writing and submission of manuscript for publication

Signed: Date: 9/7/19

Claire Kerr (15%)

- Development and review of systematic review protocol
- Database and literature searches
- Study selection, quality assessment, data extraction and analysis
- Critical appraisal and discussion of content
- Review and editing of draft manuscript pre-submission

Signed: Date:10/07/2019

Nora Shields (10%)

- Development and review of study protocol
- Critical appraisal of included studies and discussion of content
- Review and editing of draft manuscript pre-submission
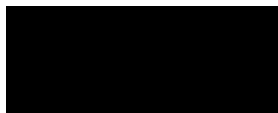
Signed: Date: 10/7/19

Christine Imms (10%)

- Development and review of systematic review protocol
- Critical appraisal of included studies and discussion of content
- Review and editing of draft manuscript pre-submission

Signed: ██████████ Date: 10 July 2019

Paper 2. I acknowledge that the following contributions have been made by myself and each of the listed co-authors to the paper 'O'Connor, B., Kerr, C., Shields, N., & Imms, C. (2019). Understanding allied health practitioners' use of evidence-based assessments for children with cerebral palsy: a mixed methods study. *Disability and Rehabilitation*, 41(1), 53-65.".

Bridget O'Connor (65%)

- Development of study design and protocol
- Review of data collection instruments, data collection and management
- Data analysis and interpretation of findings
- Critical discussion of findings with supervision team
- Planning, writing and submission of manuscript for publication

Signed: ██████████ Date: 9/7/19

Claire Kerr (10%)

- Development of study design and protocol review
- Data analysis, interpretation and critical discussion of findings consistent with supervisory role
- Review and editing of manuscript for publication

Signed: ██████████ Date: 10/07/2019

Nora Shields (10%)

- Development of study design and protocol review
- Data interpretation and critical discussion of findings consistent with supervisory role
- Review and editing of manuscript for publication

Signed: ▮▮▮▮▮▮▮▮   Date: 10/7/19

Christine Imms (15%)

- Development of study concept and design and protocol review
- Data collection tool design
- Data interpretation and critical discussion of findings consistent with supervisory role
- Review and editing of manuscript for publication
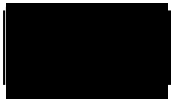
Signed: ▮▮▮▮▮▮▮▮   Date: 10 July 2019

Paper 3. I acknowledge that the following contributions have been made by myself and each of the listed co-authors to the paper 'O'Connor, B., Kerr, C., Shields, N., Adair, B., & Imms, C. (2019). Steering towards collaborative assessment: A qualitative study of parents' experiences of evidence-based assessment practices for their child with cerebral palsy. *Disability and Rehabilitation*, 1-10.'

Bridget O'Connor (80%)

- Development of study concept, design and protocol review
- Data collection and management
- Data analysis and interpretation
- Critical discussion of iterations with supervision team
- Writing and submission of manuscript for publication

Signed: ▮▮▮▮▮▮▮▮   Date: 9/7/19

Claire Kerr (5%)

- Contributed to development of study concept and design
- Review of protocol
- Data analysis, interpretation and critical discussion of findings
- Review and editing of manuscript pre-publication

Signed: Date: 10/07/2019

Nora Shields (5%)
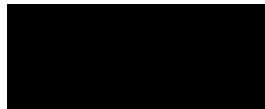
- Contributed to development of study concept and design
- Review of protocol
- Data analysis, interpretation and critical discussion of findings
- Review and editing of manuscript pre-publication

Signed: Date: 10/7/19

Brooke Adair (5%)

- Contributed to development of study concept and design
- Review of protocol
- Data analysis, interpretation and critical discussion of findings
- Review and editing of manuscript pre-publication

Signed: Date: 12/7/19

Christine Imms (5%)

- Contributed to development of study concept and design
- Review of protocol
- Data analysis, interpretation and critical discussion of findings
- Review and editing of manuscript pre-publication

Signed: Date: 10 July 2019

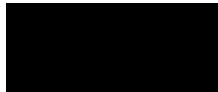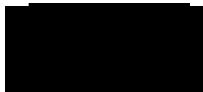**F2: Conference presentations and accepted abstracts related to the thesis**

O'Connor, B., Kerr, C., Shields, N., & Imms, C. (2016). A systematic review of evidence-based assessment practices by allied health practitioners for children with cerebral palsy. *Developmental Medicine and Child Neurology,* Vol 58 (S3) 47- 48 doi: 10.1111/dmcn.13069 Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) Adelaide, Australia.

O'Connor, B., Kerr, C., Shields, N., & Imms, C. (2016). Use of classification tools by allied health professionals for children with cerebral palsy: a survey of practice. Proceedings of International Conference on Cerebral Palsy and other Childhood onset Disabilities: Stockholm, Sweden.

O'Connor, B., Kerr, C., Shields, N., Adair, B., & Imms, C. (2018). Understanding allied health practitioner assessment behaviours for children with cerebral palsy: a mixed methods study. Developmental Medicine and Child Neurology, Vol 60 (S1) doi:10.1111/dmcn.13666 Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) Auckland, New Zealand 21 - 24 March 2018. Poster presentation

O'Connor, B., Kerr, C., Shields, N., Adair, B., & Imms, C. (2019) Parents' experiences of formal assessment for their child with cerebral palsy- a qualitative study. Proceedings of Victorian Allied Health Conference- Driving Change. Melbourne, Australia.

O'Connor, B., Kerr, C., Shields, N., Adair, B., & Imms, C. (2019) Steering towards collaborative assessment: A qualitative study of parents' experiences of evidence-based assessment for their child with cerebral palsy. Combined American Academy Cerebral Palsy and Developmental Medicine (AACPDM) 73rd Annual and IAACD 2nd Triannual Meeting. Sept 18-21, 2019 Anaheim, California, USA Accepted poster abstract

O'Connor, B., Smythe, T., Wright, V., & Rosenbaum, P. (2019) Knowingly or unknowingly complicit? Stigmatising health-care practices related to families and children with disabilities. Combined American Academy Cerebral Palsy and Developmental Medicine (AACPDM) 73rd Annual and IAACD 2nd Triannual Meeting. Sept 18-21, 2019 Anaheim, California, USA Accepted focused symposia

F3: Book chapter – joint publication

This chapter from page 390 of this thesis onwards was jointly written by Christine Imms and Bridget O'Connor. Bridget O'Connor developed the Steering Wheel checklist (Appendix F4) and the Jack in the Box vignette (Appendix F5).

Imms C., Jarvis J., Khetani M., O'Connor B. (2019). Part III Measuring participation and participation related constructs: Measurement challenges. In *Imms C and Green D* (ed.) *Enabling Participation in Childhood Onset Neuro-Disability* Ch.15, 1-15. London: Mac Keith Press.

Enabling Participation in Childhood Onset Neuro-Disability
Editors: Christine Imms and Dido Green
MacKeith Press

Part III, Measuring participation and participation related constructs

Authors:
Christine Imms [1], Jessica Jarvis [2], Mary Khetani [2] and Bridget O'Connor [1]
[1] Centre for Disability and Development Research, Australian Catholic University; [2] Department of Occupational Therapy, University of Illinois at Chicago;

Chapter 15: Measurement challenges

This chapter summarizes important challenges to measuring participation that must be addressed to advance participation focused work in clinical practice. At present, there are challenges to knowing what, when and where to assess participation, and to selecting the most appropriate instrument or process. Most importantly, we propose that clinicians need to be repeatedly challenged to reflect on and address how they implement assessment processes with children and their families.

Knowing what to assess, and where and when to assess it: the complexity of context

Our attempt to unpack contextual factors that shape children's participation has revealed that most studies to date focus on modelling children's participation as an outcome and employ gross estimates of extrinsic factors, excluding data on intrinsic factors altogether in their analyses. While these studies offer great value in establishing the role of a child's environment on their participation, this approach does not yield comprehensive and granular knowledge about the relative impact of specific contextual factors on participation.

Practitioners can benefit from knowing which contextual factors are more salient in shaping a child's participation across time. Most studies examine context through general environmental measures. Some studies emphasise select features of the child's environment (Clarke et al., 2011), others adopt a multidimensional assessment of environment (Albrecht and Khetani, 2017). In either case, researchers use one or more sum scores to capture environmental impact on participation (e.g., caregiver perceptions of home environmental support) (Albrecht and Khetani, 2017, Anaby et al., 2014, Khetani et al., 2018a). It might be more clinically meaningful to examine contextual factors as individual items, or by deriving multiple summary scores (e.g., summary scores representing micro-, meso-, and macro levels of environmental impacts), to build knowledge that can shape participation-focused interventions.

In addition to what we assess, when we assess is important to consider. Most studies to date examine contextual factors using cross-sectional study designs, providing limited guidance for practice. Future research would benefit from a longitudinal approach to understand how these factors influence each other over time as this knowledge is needed to guide practice. Few studies examine participation change (Anaby et al., 2012, Khetani et al., 2018a, Imms and Adair, 2017), and their follow-up period may have been too short to detect change (Khetani et al., 2018a). Technology-based approaches to data collection (Khetani et al., 2018b), particularly when integrated within electronic data capture systems, may be useful in harmonizing data collection for these needed studies (Khetani, 2016).

Longitudinal study designs also offer new analytic opportunities. Developmental scientists often frame studies using a person-process-context-time model and

transactional perspective (Bronfenbrenner and Morris, 2006, Sameroff and Mackenzie, 2003): novel methods for examining these relationships longitudinally. It is possible we can glean from approaches developed in this field (e.g., cross-lagged panel models, sequential cohort designs) the bidirectional linkages between intrinsic and extrinsic factors over time. These approaches capture intrinsic factors specific to the caregiver and child over time. One growing body of developmental studies examine reciprocal pathways between positive parent-child transactions and children's developing social-emotional adjustment (Lunkenheimer et al., 2013). While these studies acknowledge parenting occurs in the context of the home environment (Bradley, 2015), their home environment measure - cognitive stimulation and emotional support - may not be the most salient aspects for children with neurodisability. The methodological approach, however, remains useful for examining how intrinsic and extrinsic factors shape children's participation over time.

Accelerating knowledge about children's participation requires careful consideration regarding how to: measure both extrinsic and intrinsic factors and report contextual factors (e.g., individual items or summary scores). These decisions along with selection of appropriate study methodology (e.g., cross-sectional versus longitudinal), and consideration of analytic models for contextual variables (e.g., mediating variable, outcome variable) will advance the field.

Selecting the most appropriate tool, instrument or process

We are often guilty of measuring what we can measure rather than what we need to measure. This can be a problem because "..what we measure shapes what we

collectively strive to pursue" (Stiglitz et al., 2009, p. 9). For example, if our primary measure is at the level of body structure or skilled performance, that is what we tend to pursue. If we wish to pursue participation outcomes, then that should shape what we measure. A systematic review of measures of participation suggests we are trying to do this in childhood disability research and practice (Adair et al., 2018). Although the review identified 309 measures, few measures included the involvement construct. This is an immediate challenge. If what you measure is what you learn, and we do not have adequate measures of participation involvement, then we likely have inadequate understanding of the experience of involvement.

This assumption is supported by the fact that of the 11 'involvement' measures reviewed, over half measured enjoyment (Adair et al, 2018). While important, enjoyment does not sufficiently capture involvement, which has been defined as the experience of participation while attending, including elements of engagement, persistence, perhaps social connection and affect (Imms et al., 2017). The Participation and Environment Measures capture 'involvement', which at its peak is defined as *your child is actively engaged most of the time. He/she interacts and/or is helpful for most of the activity* (Coster et al., 2011, Khetani, 2015). In these measures, the word 'engaged' is used to define involvement, along with ideas about interactions with others. This suggests that 'involvement' and 'engagement' might be synonyms.

We have progressed our review of measures of 'engagement' that use observation of behavior as the assessment method, and which were designed for young children. Review of 13 of these measures that focus on engagement supports the notion that the construct of engagement has cognitive (thinking about what you are doing), affective

(how you feel about what you are doing) and behavioural (what you are doing) components.

Although this provides a more detailed understanding of what engagement entails, it is not yet clear whether the constructs of involvement and engagement are synonymous. Our reviews suggest involvement is a multidimensional construct describing the experience of participation that has elements of engagement which itself is multidimensional (e.g., orientation to, or action with, objects and/or people), persistence (e.g., time spent, sustained effort), perhaps social connection (interactions with others and/or a sense of belonging; but, you can also participate in activities all by yourself) and affect (which includes more than the idea of enjoyment).

The key questions going forward are:

- Is involvement as a construct observable?

  - At the level of the brain?

  - In individual behavior?

  - Between people?

  - Between ecological systems?

- Who should rate it and how? Or, how else should it be measured?

- What are the multiple dimensions, and how can they be rated in a way that gives credence to the complexity and importance of the construct?

Solving this measurement problem is crucial, as involvement is the fundamental participatory outcome. Of course, those with childhood onset neuro-disability should be able to attend the same situations as others, but, being involved while attending is the

element that makes the effort worthwhile and can shift the lived experience to being positive and growth enhancing.

In Chapter 9, therapy was described as one life situation that those with childhood onset disability might experience. The experience of assessment in practice is the third key challenge for us to address.

Approaching assessment from a strengths-based perspective: the challenge of '*how*'

The principles of family-centred care (King et al., 2006, King et al., 2002, King et al., 2004) are endorsed as 'how we should operate' as practitioners. Whether practitioners adopt a relational practice approach (Epse-Sherwindt, 2008; Taylor, 2008) or a participatory practice approach (Dunst et al., 2002), their use of a family-centered frame supports more positive outcomes for children and families (Moore et al., 2009, Trivette et al., 2010). This occurs by involving our clients - including the individual and family members - in ways that support their commitment and investment in care (Bright et al., 2015), and in ways that value and respect their goals and preferences.

One of the earliest opportunities for practitioners to enact family-centred care is during assessment. Information is gathered and interpreted to guide professional reasoning about priorities and recommendations for intervention (or prognosis). Assessment occurs routinely in practice, either using formal processes (and we may do this explicitly or not), or implicitly as we make observations and form judgements. In Chapter 14, the importance of making assessment explicit from a pedagogical perspective

was highlighted. Along with this key factor, lies the imperative that we undertake all assessment with great care.

Involvement in assessment is a transactional exchange among clinicians, children, parents, and the structures (activity, objects, time) of the assessment that impacts all those involved. We know that practitioner engagement in formal assessment is impacted by their level of comfort and confidence in engaging with parents around assessment (O'Connor et al., 2017). To understand this further, we conducted a qualitative study involving in-depth interviews with 14 parents who reflected on and described their experiences with allied health assessment (O'Connor et al., under review), resulting in the Steering Wheel for Collaborative Assessment (see Figure 15.1). The Steering Wheel has a central hub with four radiating spokes to an inner rim and outer rim. The hub contains two central themes: protection and framing assessment positively. Most central is protection where parents act to protect their child's being, identity and representation through assessment, along with their own psychological well-being during diagnostic and assessment processes.
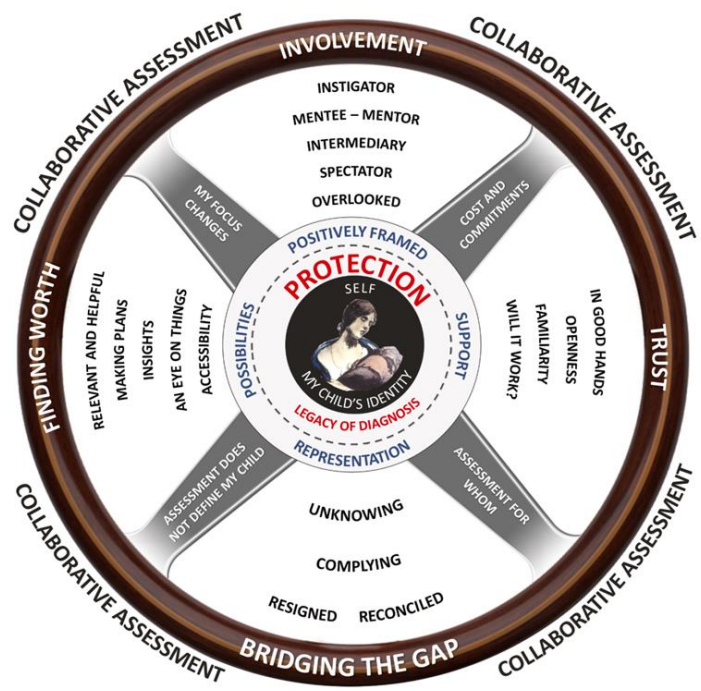
Figure 15.1. Steering Wheel for Collaborative Assessment.

In the Steering Wheel, framing assessment positively wraps around protection and is connected by a 'porous' line to indicate the potential influence of assessment on parents' need to protect. No matter *what* we choose to assess, *how* we assess the child is critical. We propose the way assessment and diagnosis is framed, strongly influences parents need to protect with enduring impacts on collaboration and building capacity with parents.

The themes illustrated that a parent's need to protect is magnified by negative assessment interactions that threaten their child's identity, revive feelings of grief and erode optimism, making collaboration with the therapist to enable involvement in the assessment process difficult. In these situations, parents may avoid assessment interactions or feel they can only participate as a resigned spectator of their child's

assessment. Assessment may hold little worth and decrease parent motivation to implement recommendations.

In contrast, positively framed assessment interactions, that focus on a child's strengths reduces the parent's need to protect; thereby opening opportunities for parents to be involved in the assessment process and develop a positive partnership. When framed positively, parents may reconcile the limitations of the assessment process, and feel able to choose how they want to be involved according to their circumstances, and priorities. Assessment in this instance is collaborative, and builds capacity, as represented by the outermost rim of the figure.

The Steering Wheel metaphor implies that the assessment process is driven, with choices made about where to go, and the route to be taken. Assessment determines the directions for therapy interventions - a process driven traditionally by the therapist or rehabilitation team. Within a capacity-building paradigm, one can ask who is holding the wheel and how tightly - the therapist, the parent and child, or, both? Assessment is a learning process for parents and their child that perhaps requires therapists to not only to let the child and family choose their desired destination, but to also loosen their grip on the wheel when navigating to a valued destination. If the Steering Wheel is shared, by making the assessment process transparent, parents may be empowered with relevant information that enables their job of parenting.

When thinking carefully about participation attendance and involvement in therapy as a life situation, it becomes apparent that therapy might not be 'mostly harmless'. Recent work focused on engagement in therapy provides an important set of principles and practices about how to engage with clients in therapeutic interactions

(D'Arrigo et al., 2017, D'Arrigo et al., 2018). Applying self-determination theory suggests we need to support autonomy, relatedness and competence in the individual and their family.

The notion of engaging in therapy as an affective (emotional connection, positive affect, enthusiasm), behavioural (asking questions to appraise recommendations prior to uptake) and cognitive (effort, readiness for change) commitment, describes a range of positive energising traits and efforts. These ideas are consistent with the stories of some parents in O'Connor et al. (under review) study who felt they were in good hands and could work together with their therapist and be involved in assessment to support the things they valued for their child. Those parents' experiences though, sat in contrast to others who felt an eroding sense of optimism and felt like spectators in a disconnected process of assessment that was done by and for the therapist and his or her professional team.

Despite advancements in implementing family-centred care, insufficient focus may have been given to 'how to' involve parents and children in formal assessment. The Pediatric Rehabilitation Intervention Measure of Engagement (PRIME) suite of measures were developed to support our understanding of engagement in therapy, including assessment (King et al., 2017). These measures have the potential to assist us in understanding our own contributions to optimal engagement. Focusing on how to engage with children and families in assessment is complex. The following checklist provides a list of questions that practitioners can reflect on when preparing for assessment with families that might support their positive involvement.

Steering Wheel checklist for collaborative assessment

FIRST CONSIDER

Do I know:

- Why I am gathering this assessment information e.g. early detection, diagnosis, surveillance, guide therapy, evaluate therapy?
- Who the assessment information is for - parent, therapist, service, funders, researcher?
- How the assessment information will be useful to parents and their child?

Am I aware of:

- The family's therapy 'ethos', current focus and aspirations for their child?
- Previous disempowering experiences (including diagnosis) in the health system?
- The possible emotional and pragmatic costs of attending?
- What the parent thinks and knows about formalised assessment?
- The potential harms from this assessment and how to mitigate these e.g. language, task administration, scoring and implications?
- How to positively frame the assessment process and findings from a strengths perspective i.e. positively represent the child, protect individual identity and the parent, identify possibilities, suggest ways forward and next steps?

THEN COLLABORATE

DECIDING TOGETHER   **BRIDGING THE GAP**

Have I

- Made time to specifically discuss assessment with the parent?
- Provided general information about what formal assessment is and why it is used?
- Asked the parent how they feel about their child being formally assessed?
- How their child manages and responds to being "tested"?
- Acknowledged that formal assessment can be emotionally difficult for some parents?

Have I

- Provided specific and easy to understand information about the assessment i.e. its name and what it assesses?
- Discussed the outcomes anticipated from the assessment?
- Given examples of the types of tasks their child will be asked to do, or types of questions if a parent questionnaire?
- Shown the parents (and child) the score sheets and how it is scored?
- Discussed how the assessment information can be interpreted (using common terms)?
- Discussed how the information is related to their child's therapy?
- Confirmed this assessment aligns with the parent's current focus, aspirations or goals?
- Identified aspects of the assessment that may be emotionally difficult e.g. deficit-based terms, images, pass-fail scoring, less than anticipated results?
- Reassured the parent that the assessment findings do not define who their child is?
- Provided written information about the assessment for parents to consider?
- Confirmed the decision: the parent is comfortable and mentally ready; would prefer it to be done later; or, not at all?

PLANNING TOGETHER   INVOLVEMENT

Have I

- Asked about any issues the parent might anticipate for their child during the assessment?
- Discussed strategies to make the assessment more manageable and enjoyable for the child and parent e.g. where, when, who is present, things they don't like, positions to avoid, use of visuals, fun things to include and ways to encourage?
- Asked about their child's behavioural cues that indicate pain, anxiety, stress, fatigue?
- Discussed what to bring e.g. clothing, hoists, transfer board, favourite toys or items, food and drink?
- Suggested practical ways the parent and child can be involved (if desired) that don't jeopardise reliability and scoring e.g. recording results; holding the infant during test?
- Gained consent for electronic material and who receives copies of the written report?
- Asked who the parent would like present when discussing the assessment and written report?

DOING TOGETHER   DEVELOPING TRUST

Have I

- Checked in to see if this is a 'good' day (for parent and/or child) to do the assessment?
- Given parent 'permission' to indicate if any concerns during the assessment?
- Clarified the child behavioural cues with the parent if unsure?
- Kept the score sheet visible to the parent while assessing?
- Been available to discuss or clarify questions with parent questionnaires?
- Found ways for the parent to stay close and involved during handling of their infant?
- Given older children or parents the option to be involved in the assessment when possible e.g. setting up items, recording scores, taking photos?
- Framed the assessment dialogue and items positively i.e.
    - Used strengths-based language i.e. highlighting what the child CAN do and interests.
    - Made items playful, fun, engaging, and efficient.
    - Ensured a sense of achievement with each item.
- Checked mid-way to see how the assessment is going for the parent and their child?
- Articulated what I'm doing and thinking while assessing whenever possible and appropriate?
- Drawn attention to the child's strengths?

DISCUSSING TOGETHER   FINDING WORTH

Have I

- Asked the parent (and child) about the assessment experience - what they noticed and thought?
- Discussed findings face-to face using everyday language that is positive and inclusive (not stigmatising)?
- Contextualised the findings from a strength (not deficit) perspective i.e. how the findings relate to their child's development, participation and the 6 F's (Function, Friends, Fitness, Fun, Family, Future)?
- Discussed findings in relation to;
    - parent goals and aspirations for their child.
    - child interests, home, school and community.
    - a therapy plan that accommodates family routines, resources and activities.
- Provided parents with a written summary or report that;
    - Uses understandable language and explains profession-specific terms and acronyms.
    - Includes a summary of the assessment purpose and findings
    - Interprets findings in terms of promoting child development
    - Explains how the findings contribute towards the parents' and child's priorities.

Box 15. 1. Reflecting on involving parents and children in the assessment process: A checklist for practitioners

Summary

Measurement of participation has come a long way since publication of the International Classification of Functioning Disability and Health (ICF) in 2001. Our focus now needs to be on measuring transactions among people in context over time, participation involvement as an outcome, and how we effectively and compassionately involve children and parents in the assessment process.

Key points

- Generating evidence for participation-focused practice requires a thoughtful approach to capturing involvement and contextual factors across time.

- Researchers and practitioners must find ways that involve the child and their parents in ways that support their commitment and investment in therapy.

- Positively framed assessments provide opportunities for parents to inform their child's therapy. In turn, this collaborative approach reinforces transparency and empowers parents with knowledge that enables their parenting self-efficacy.

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F5: Jack in the Box vignette

This powerful story places our role as practitioners in the assessment experience in the spot-light. No matter *what* we choose to assess, *how* we do it is critical. Every therapeutic exchange is a participatory transaction among those in the situation along with the contextual elements of objects, activities and time. No therapeutic exchange is more important than assessment where judgement is always implied or indeed highly evident. As you read, consider how the context (including practitioners) influences ongoing child and family involvement in assessment along with participation-related constructs such as sense of self.

Jack in the Box

Bridget O'Connor

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Fear and dread. This is what comes to mind when I think about assessment. I'm Jack's mother and Jack's my 5-year-old boy. Assessment unfortunately, brings back memories of the worst night of my life - the night Jack stopped breathing. We threw ourselves into the car and rushed to the hospital with no seat belts and no baby seat. The police pulled us over on the way, but we sped off towards the hospital, so when we arrived it was chaos - police and doctors everywhere, everyone huddled around my child except me, I couldn't see him, and nobody told us what was going on…and then our child was gone. Then the questions started. I slowly realised they thought we had done something terrible to our

baby and that we could lose our baby. They wouldn't let us out of their sight. It wasn't until after the MRI results came through that they realised his seizures were coming from a malformation in his brain, and we were no longer suspects. They showed us his damaged brain on the MRI, the tubes came out eventually and we left the hospital along with every ounce of trust we once had, and a sense of shame. All I knew was I would never lose control again.

Different therapists contacted us after we got home. They were all very nice, but I always felt on guard in our appointments, not knowing what was being judged and what this might mean for Jack and us. Each time, I felt the tension rising in me in the days before Jack's appointments - that fear of again being out of control. At these appointments the therapists were always looking, and I was always wondering - what were they looking for and what were they seeing and thinking? I hated handing him over, particularly when they took his clothes off and he was laying there half naked on the floor. I often felt like scooping him up and running out of those appointments, but I made myself stay, just in case there was something they said that might be helpful for Jack. I just sat on the edge of my chair looking on.

I remember an early assessment of Jack. It seemed like the therapist was trying to figure out what was inside a parcel that had arrived unexpectedly. They tapped Jack's knees, tugged and turned his little arms, tipped him this way and that way, trying to see what was inside my little Jack in the box. The therapist kept her sheet of paper and pen tucked in next to her on the other side, away from me. I couldn't quite see what was on it, but it looked like there were little stick figures of frogs with heads and legs bent in all different directions—sideways, forwards and backwards. She circled the little 'frogs' that didn't

bare any resemblance to my baby. Maybe she had a secret code that I wasn't meant to know about or wouldn't understand. Eventually Jack had had enough, and I had too. I leant forward and thankfully she passed my Jack in the box back to me. She gathered her frog pictures together and arranged our next appointment time. The only time available was when my partner had his next job interview, so again he couldn't come. I never knew what to tell him or my Mum about these assessments as I had no idea, really, what they had ascertained from it all. It was all so foreign to me. I guess I looked for different things – the smile of recognition, the relaxation of his body when I soothed him, the change in his cry that let me know he was hungry, the hand that recently caressed my hand while he drank – this was the Jack in the box I knew and loved, I didn't see the boy with a malformed brain.

A few months later we had an appointment to see our paediatrician - again the looming dread, but this time it was only to check his weight just like they do for all kids. My partner and I waited patiently in the consulting room with Jack on my lap while the paediatrician read a letter from our therapist. The therapist mentioned a letter she was going to send, but I hadn't received it yet. Now he's roaming the internet looking for things on the computer. As he scrolls down the screen he slowly nods at the screen and says "yes, I guess he does fit the description of cerebral palsy - he definitely has a disorder of posture and movement". He went on "It's a bit early to say how severe it will be but from the therapist's assessment and score (the frog one, I guess) he's likely to be a 4 or a 5". "What do you mean a 4 or a 5?" I asked. He swung the computer screen around for us to see. There were pictures of children in wheelchairs and frames, and others running upstairs. He pointed at the children in the wheelchair pictures next to the 4 and the 5. My Jack had been reduced to a number, I thought - that was very odd. My ears buzzed as I sat Jack on

my partner's lap. I stood up. I didn't know where I was going but I had to get out of there.

I felt so left out in the dark, like I was the last person to know and the lid had been closed

on my Jack in the box. I wasn't sure I could go on with this stuff and therapy anymore - it

just didn't seem worth it.