Understanding the assessment of language comprehension in children with severe motor and speech impairments due to cerebral palsy

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Lay abstract

Cerebral palsy (CP) is the most common cause of physical disability in children. CP is the result of an injury to the brain before, during, or after birth and before the age of one year. While effects of the brain injury are different for each child, for many children with CP the main effect is difficulty with voluntary movement, including fine movements of the lips and tongue to make speech. Some children with speech difficulties can communicate by pointing or making gestures, but others have such severe movement difficulties that they cannot make those gestures either. These children with severe difficulties might understand what others are saying, but tests of understanding usually require the child to respond with some type of movement, so those tests do not work for children with severe movement limitations.

The C-BiLLT, which is short for Computer-Based instrument for Low Motor Language Testing was developed to assess language comprehension in Dutch-speaking children with CP. The child who is being tested does not need to speak or to use other fine movements to respond. Instead, the child can respond using gross motor movements on a touch screen, input switches operated with anybody part, partner-assisted scanning and/or their own access method(s). The C-BiLLT could be useful for many children with CP around the world, but at present it is only available in Dutch and Norwegian.

The aim of this study was to make the C-BiLLT suitable for children in Canada. We translated the items from Dutch to English, and replaced some items of the Dutch version so that they were familiar to Canadian children. Our study told us that this new Canadian version of the test worked as well as the Dutch test. We also learned that clinicians liked the test, and used it for children with other disabilities as well. Some clinicians had difficulties using the test, and said they needed more practice. In the future we need to make sure there are

opportunities for clinicians to get more training, so they have the skills to give the test to any child who would benefit.

One question we still have is how families feel when their child is being tested with the C-BiLLT. Language testing should not be scary or stressful for families or children, and we need to make sure families feel comfortable with any test. Thus, as the last step of this thesis, we designed a future study to ask parents questions about their experiences. We will use results of that study to make the C-BiLLT even more child- and family-friendly.

Abstract

Children with cerebral palsy (CP) and severe motor and speech impairments face problems in communication. Their capacities may vary across all domains of functioning, including mobility, selfcare and communication, which means these should be assessed independently, using valid and reliable instruments. The assessment of an unobservable construct like language comprehension skills is complicated because the completion of commonly available tests requires speech and motor skills. Using such tests with children with severe motor and speech impairments does not yield a valid, reliable, or representative result. To fill the gap in language assessment instruments, the Computer-Based instrument for Low motor Language Testing (C-BiLLT) was developed in the Netherlands between 2009 and 2014, and introduced intro clinical care in 2015. This test provides an accessible alternative to traditional language tests, allowing participation of children who cannot speak, finger point, or manipulate small objects.

The overarching goal of the work in this thesis was to bring the C-BiLLT to Canada and to improve our understanding of the use of the C-BiLLT from a clinician and family perspective. To achieve this goal, the research described in this dissertation addressed objectives related to: 1) the cultural and linguistic adaptation of the test; 2) the psychometric properties of the new version; 3) the implementation of the test; and 4) the concept of family-centred care in relation to the C-BiLLT assessment.

Three empirical studies were completed. The adaptation processes (including a validation study) that resulted in the Canadian English version of the C-BiLLT (C-BiLLT CAN) are described in Chapters 2 and 3. To understand the unique implementation attributes of the C-BiLLT, Chapter 5 describes a survey among users about their C-BiLLT use, and Chapter 6 describes an interview study in which clinician behaviours are explored into more detail. Finally, Chapter 7 describes the protocol for a qualitative study using interpretive

description to understand parents' experiences of the C-BiLLT assessment for their child with cerebral palsy and severe motor and speech impairments.

The process to develop the C-BiLLT CAN comprised many phases, to ensure the linguistic and conceptual equivalence between the original C-BiLLT and the newly developed version. The benefits of a thorough cross-cultural adaptation process were confirmed by the results of the validity and reliability assessment of the C-BiLLT CAN in typically developing Canadian children. While future research is needed to confirm the feasibility and validity of the test for Canadian children with CP, our study showed that the new version is a robust instrument to assess spoken language comprehension and is available for use in clinical practice.

The C-BiLLT CAN is a scientific innovation. How scientific innovations can be best implemented into clinical practice is studied by implementation science. An implementation science lens was applied to the current use of the C-BiLLT in three countries where the test is currently available in clinical practice: The Netherlands, Belgium, and Norway. The survey study described in Chapter 5 demonstrated that clinicians use the test with children with CP (the C-BiLLT's target population), but also with children who have other diagnoses, including Down's syndrome and autism spectrum disorder. This study also reported on the barriers and facilitators related to use of the C-BiLLT. We categorized the reported barriers and facilitators into four groups: 1) factors inherent to the C-BiLLT (i.e., its hardware, software, and content); 2) factors related to the child; 3) factors related to the clinician; and 4) factors related to the environment.

To gain a better understanding of clinicians' implementation behaviour and what is needed to facilitate behaviour change, fifteen survey respondents were interviewed individually. The COM-B model (Capability, Opportunity, Motivation – Behaviour) of

behaviour change was the theoretical foundation for this study. This model describes how capability, opportunity, and motivation play a role in people's behaviour. This study taught us how these components of behaviour interacted for clinicians who use, or attempt to use the C-BiLLT in clinical practice. The study highlights the need for support for the clinicians who use the C-BiLLT with children with severe motor and speech impairments. Compared to clinicians who use it with children with other disabilities, this group of clinicians faces more and more complex barriers. The studies described in Chapters 5 and 6 underline the importance of appropriately addressing barriers to C-BiLLT use.

The growing emphasis on family-centred care in pediatric rehabilitation services inspired the conceptualization of the concluding study of this thesis, of which the protocol is described in Chapter 7. The aim of the described study is to advance Speech-Language Pathology (SLP) disciplinary knowledge around family-centred assessment for children with CP and severe motor and speech impairments. The protocol describes how we would like to address this aim by collecting parent experiences of their child's C-BiLLT assessment.

This thesis approached the C-BiLLT from the angles of cross-cultural adaptation, psychometrics, implementation, and family-centred care. The development of the C-BiLLT CAN provides the foundation for standardized and accessible assessment of spoken language comprehension for children with CP in Canada. Theory-informed knowledge translation strategies are suggested that align with real-world practice. Finally, suggestions for incorporating parents' perspectives into the assessment process help to increase the value of the assessment for children, their families, and clinicians alike.
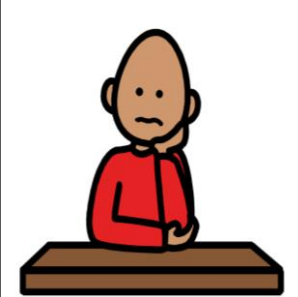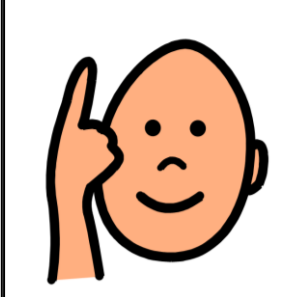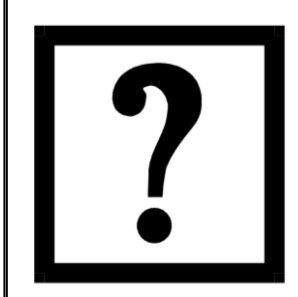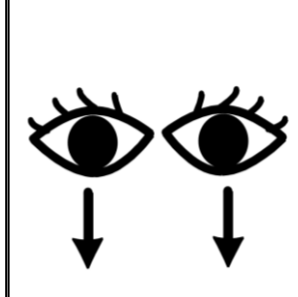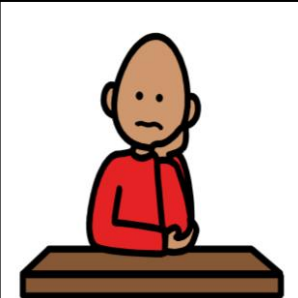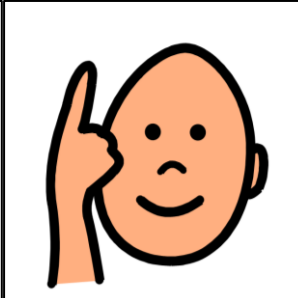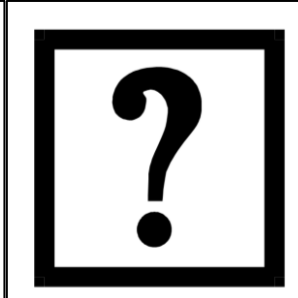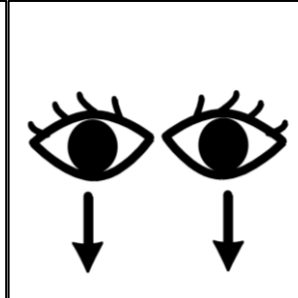
A practice in research and translation

Het kan lang duren voordat je weet wat je ziet.
Het kan zelfs lang duren voordat je weet wat er te zien ís.
Marjoleine de Vos
Original in Dutch (de Vos, 2020, p. 7).

It can take a long time before you know what you see.
It can even take a long time before you know what there is to see.
Translated from Dutch to English by Google Translate.

It may take a long time before you know what you see.
It may even take a long time before you know what there actually is to see.
Translated from Dutch to English by me.

Het kan lang duren	(voordat) je weet	wat	je ziet
It may take a long time	*(before) you know*	*what*	*you see*
Het kan (zelfs) lang duren	(voordat) je weet	wat	(er) te zien ís
It may (even) take a long time	*(before) you know*	*what*	*(there actually) is to see*

Translated from Dutch to Picture Communication Symbols by my former Speech-Language Pathology colleagues.

De Vos, M. (2020). *Je keek te ver.* Uitgeverij Van Oorschot.

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Vader J., papa Johns, Johnny: ik weet hoezeer jij in mij gelooft en hoe trots je bent. Wat kan ik me meer wensen? Een onuitputtelijke interesse in al mijn schrijfsels, een twee-mansboekenclub, jaarlijkse wandelvakanties door heel Europa, bijenhotels, chillen bij de open haard in casa Schellerberg? Bij alles wat ik doe hoor ik *"do kinst it wol, Jappie"* in mijn achterhoofd. Senks.

Lastly, I am indebted to all children and families who supported this thesis by showing up and sharing a piece of their lives. You matter most: thank you.

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List of Abbreviations

AAC	Augmentative and Alternative Communication
AIM	Acceptability of Intervention Measure
AUMC	Amsterdam University Medical Centres
C-BiLLT	Computer-based instrument for Low motor Language Testing
C-BiLLT CAN	Computer-based instrument for Low motor Language Testing Canada
C-BiLLT NOR	Computer-based Instrument for Low motor Language Testing Norway
CI	Confidence interval
CFCS	Communication Function Classification System
COM-B model	Capability, Opportunity, Motivation – Behaviour model
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments
CP	Cerebral palsy
CP-CaLL	Cerebral palsy – Communication and Language Learning
FCC	Family-centred care
FIM	Feasibility of Intervention Measure
EBP	Evidence-based practice
EFA	Exploratory factor analysis
GMFCS	Gross Motor Function Classification System
HAHSO	Hamilton Academic Health Sciences Organization
ICC	Intraclass correlation coefficient
ICF	International classification of functioning, disability, and health
IAM	Intervention Appropriateness Measure
ITC	International Test Commission
KTA framework	Knowledge to action framework
METC	Dutch: Medisch ethische toetsingscommissie (English: Medical ethics research committee)
NOR	Norway
NRDLS	New Reynell Developmental Language Scales
NLD	Netherlands
OT	Occupational therapist
PPVT-4	Peabody Picture Vocabulary Test – fourth edition
RED-Cap	Research electronic data capture
SD	Standard deviation
SLP	Speech-language pathology
VSS	Viking Speech Scale
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)

Children with severe motor and speech impairments

> The group of children with CP who need a wheelchair and assistance to move around and who need augmentative and alternative communication methods to express themselves. This group of children is often referred to as having complex communication needs, also in some of the manuscripts in this thesis. However, not all children with complex communication needs have cerebral palsy and the described combination of speech motor and non-speech motor disorders.

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". (O'Connor, 2020, p. xxi)

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 with severe motor impairments and complex communication needs. O'Connor, 2020, p. xxi)

Declaration of academic achievement

This thesis, presented in "sandwich" format, includes a general introduction, a chapter describing the adaptation process that was followed to arrive at the Canadian English C-BiLLT, the four independent manuscripts for which the candidate is the first author, and an overall discussion. At the time of the thesis preparation, Chapters 3, 5, and 6 were under review, and Chapter 7 was prepared for submission. The contributions of the candidate and all co-authors are outlined below for each manuscript.

CHAPTER 3

Reference:

Bootsma, J.N., Campbell, F., McCauley, D., Hopmans, S., Grahovac, D., Cunningham, B.J., Phoenix, M., Kraus de Camargo, O., Geytenbeek, J.J.M., Gorter, J.W. (2021) Psychometric properties of the English language version of the C-BiLLT evaluated in typically developing Canadian children. *Under review.*

Contributions

Conceived and designed the research: JNB, JJMG, JWG, OKC, DM

Funding: OKC, JWG

Management of the study: JNB, DM, JWG

Acquired the data: JNB, SH

Analysed and interpreted the data: JNB, DM, SH

Drafted the manuscript: JNB

Critical revision of the manuscript: CF, OKC, DM, SH, BJC, DG, JJMG, MP, JWG

CHAPTER 5

Reference:

Bootsma, J.N., Stadskleiv, K., Phoenix, M., Geytenbeek, J.J.M., Gorter, J.W., McCauley, D., Fiske, S., Campbell, F., Crews, N., Cunningham, B.J. (2022). Implementation of the C-BiLLT, an accessible instrument to assess language comprehension in children with limited motor and speech function: An international clinician study. *Under review.*

Contributions

Conceived and designed the research: JNB, BJC, DM

Funding: JNB, BJC, DM

Acquired the data: BJC, KS

Analysed and interpreted the data: JNB, NC, SF

Drafted the manuscript: JNB

Critical revision of the manuscript: KS, MP, JJMG, JWG, DM, FC, BJC

CHAPTER 6

Reference:

Bootsma, J.N., Phoenix, M.P., Geytenbeek, J.J.M., Stadskleiv, K., Gorter, J.W., Fiske, S., Cunningham, B.J. (2020). Implementing the language comprehension test C-BiLLT: a qualitative description study using the COM-B model of behaviour change. *Under review.*

Contributions

Conceived and designed the research: JNB, BJC, MP

Acquired the data: JNB, SF

Analysed and interpreted the data: JNB, MP, JJMG, KS, JWG, SF, BJC

Drafted the manuscript: JNB

Critical revision of the manuscript: MP, JJMG, KS, JWG, SF, BJC

CHAPTER 7

Reference:

Bootsma, J.N., Geytenbeek, J.J.M., Barendse, M., Ketelaar, M., Gorter, J.W. (2022). Parents' perspectives on the C-BiLLT assessment of spoken language comprehension for their child with cerebral palsy and severe motor and speech impairments: Protocol for a qualitative study. *Manuscript prepared for submission.*

Contributions

Conceived and designed the research: JNB, JWG, MP, MK, JJGM, MB

Funding: JNB

Acquired the data: Not applicable (protocol paper)

Analysed and interpreted the data: Not applicable (protocol paper)

Drafted the manuscript: JNB

Critical revision of the manuscript: JWG, JJMG, MB, MK

Chapter 1: Introduction

1.1 Prelude

My interest for the profession of speech-language pathologist grew after I had fallen ill with a neurological disease at age 19. I was hospitalized and unable to speak or myself clear in other ways. My family was with me 24/7 to support me to communicate my wants and needs and to advocate on my behalf. After my stay in the hospital, I spent the following six weeks at the in-person neurology ward of a rehabilitation clinic. I experienced the care and expertise of speech-language pathologists first hand and saw what they did for me and my fellow patients.

I made a full recovery, and after my training in linguistics and speech-language pathology I started working at the pediatric rehabilitation department of the VU medical centre (currently: Amsterdam University Medical Centre) in Amsterdam, the Netherlands. Here, I supported children and their families in finding the best ways to deal with problems that had to do with eating and drinking, speech, language and communication. It was a humbling experience to be a small part of the lives of these families. Motivated by my own experiences of the importance of the role of my family, I was determined to put families first. However, the work could also be frustrating when I realised how little I had to offer, or how much of what I had learned in school, played out so differently in real life. All in all, it made me eager to learn more.

Clinicians and researchers at the hospital had progressed far with the development of a test that promised to dramatically improve care for children who cannot speak and their families, by facilitating accessible measurement of their language comprehension. Through years of successful and pleasant partnerships (and sheer coincidence) I ended up working on a grant application towards the adaptation of this test for use in Canada. This grant was awarded

and that allowed the start of my PhD journey at McMaster University, of which this
dissertation is the result.

1.2 Background

All of us communicate, regardless of age or capacity (Mcleod, 2018) and communication is
often described as that what makes us human. Technically speaking, communication is the
exchange of information and meaning between two or more people (International
Communication Project, 2014). In large parts of the world, the most common forms of
communication are speech and written language. This thesis is about children for whom these
forms of communication are not easily available, or not at all. They will need support to
develop their communication capacity in alternative ways, and they deserve an environment
that acknowledges, respects, and fosters their forms of communication.

Communication is a fundamental human right, of which the first enunciation dates
back to 1948 (United Nations, 1948). In 2014, a collaboration between several Speech-
Language associations put together the Universal Declaration of Communication Rights
(International Communication Project, 2014). In there is a pledge which says:

> We recognize that the ability to communicate is a basic human right.
> We recognize that everyone has the potential to communicate.
> By putting our names to this declaration, we give our support to the millions of people
> around the world who have communication disorders that prevent them from
> experiencing
> Fulfilling lives and participating equally and fully in their communities.

We believe that people with communication disabilities should have access to the support they need to realise their full potential.

Among those "millions of people" referred to in the pledge are children who face barriers to communication because of cerebral palsy (CP). CP may cause speech motor control issues, language, cognitive and/or sensory impairments, which can all impact a child's ability to communicate. As alluded to in the pledge, communication disorders can have an immense impact on a child's life. This is especially true for the children this thesis is about: those with severe motor and speech impairments.

Typically, several professionals, including Speech-language pathologists (SLPs) and occupational therapists, are involved in supporting children with CP and severe motor and speech impairments to develop and achieve their language and communication abilities. Forms of Augmentative and Alternative Communication (AAC), such as communication boards with photographs, or speech generating devices, are often used to help children take a full and active role in communication (Pennington, 2008). The delivery of such communication care is multidisciplinary teamwork (Loncke, 2014; Romski et al., 2015; Romski & Sevcik, 2005). In the current therapy services for children with CP, assessment plays a central role in clinical reasoning and decision making. Assessment is used to initiate, plan, monitor and evaluate interventions. Assessment in rehabilitation intervention is defined by Laver Fawcett 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 (2013, p. 5).

The assessment of abilities related to communication, like language comprehension, can be challenging to do well with children who have difficulties with movement and speaking. This is because the tests that are typically used to test such cognitive abilities require motor and/or speech responses. For instance, the participant may be asked to finger point to select their answers, or to manipulate toys in a certain way. Even small fine motor impairments may impact scores on such tests and thus lead to an underestimation of the participant's ability (Sherwell et al., 2014). The impact of more severe motor and speech impairments on assessment participation is even bigger (Yin Foo et al., 2013), to the point where standardized instruments are not used with these children at all (Stadskleiv, 2020). Instead, their cognitive abilities are estimated, for instance by clinical judgement (Horber et al., 2019) or degree of motor impairment (Hutton et al., 2002). These methods are unlikely to provide an accurate representation of the child's true abilities (Andersen et al., 2008; Smits et al., 2011). Such a lack of reliable and valid information poses risks to the quality of subsequent decisions and interventions (Hollon, 2017). For instance, children could receive developmentally inappropriate interventions, which leads to limited interaction and will not help them to reach their communicative capacity.

The work undertaken for this thesis explored different aspects of the assessment of spoken language comprehension using the *Computer Based instrument for Low-motor Language Testing* (C-BiLLT) with children who have CP and severe motor and speech impairments (Geytenbeek et al., 2014). This assessment instrument was developed in the Netherlands specifically to facilitate accessible standardized assessment of spoken language comprehension for this group of children. The C-BiLLT is successfully implemented in Dutch pediatric rehabilitation care, with licensed clinicians in every rehabilitation centre and rehabilitation department (in academic hospitals). Its use is recommended in the national guidelines for the care of children with spastic CP, the most common type of CP leading to

increased muscle tone (*Richtlijn Spastische Cerebrale Parese Bij Kinderen*, 2015). Dissemination efforts (e.g., publications in international peer reviewed journals, presentations at international conferences) about the development of the C-BiLLT have been successful in reaching researchers, clinicians and families from all over the world who also struggled with the issue of non-accessible language assessment tools. This has led to adaptation processes in several countries. To date, the C-BiLLT is introduced into clinical care in the Netherlands, Belgium, and Norway. Countries that are currently working on the adaptation and validation of new versions include Sweden, the United Kingdom, Ireland, Germany, Romania, Slovenia, Spain, France, Australia, and Italy.

In the different chapters of this thesis, the following topics are discussed: a) the cross-cultural adaption process from the original Dutch version to a Canadian-English version of the C-BiLLT, and the psychometric properties of the Canadian English version; b) clinicians' assessment practices with the C-BiLLT; and c) families' experiences of language assessment with the C-BiLLT for their child. The development of the Canadian C-BiLLT facilitates access to standardized language assessment for Canadian children with severe motor and speech impairments, whose primary language is English. Together with an increased understanding of implementation and family-centred assessment, this will improve the quality of assessment for these children and their families, and thus has the potential to improve the supports they receive and transform their lives.

This introductory chapter provides an outline of the research field and the purpose of the described research. It describes how CP can impact a child's communication abilities, outlines three important frameworks that guide current best practices in pediatric rehabilitation care, describes the group of children this thesis is about into more detail, and describes the conceptual background and psychometric properties of the original C-BiLLT. An outline of the research purpose, objectives and thesis structure ends this chapter. As a note

to the reader: Throughout this thesis, different terminology is used. I recognize the diversity in perspectives and preferences regarding language use about disability. Language use is ever changing and there is a need to revise language on an on-going basis.

1.3 Cerebral palsy and communication

With estimates ranging between 1.5 to more than 4 in 1000 live births, CP is the most common physical disability manifesting in childhood worldwide (Odding et al., 2006; Oskoui et al., 2013; Paneth et al., 2006; Surveillance of Cerebral Palsy in Europe, 2002; Winter et al., 2002). The diagnosis of CP is a clinical description (i.e., there is no definitive diagnostic test) and does not provide information about the cause, pathology or prognosis (Stanley et al., 2000). CP occurs due to an injury of the developing brain which can have different causes and may impact different brain regions and structures. There is a large variation in clinical features and functional abilities in individuals who share the diagnosis. While the underlying brain lesion/disturbance is, by the CP definition, non-progressive (i.e., will not change or worsen over time), the associated disturbances may have a changing impact on the person's functioning and wellbeing throughout the course of their life. There is a large variation in clinical features and functional abilities in individuals who share the diagnosis. This heterogeneity complicates epidemiological and clinical goals.

Since the nineteenth century, many attempts were made to define the disorder and to classify patients according to etiological, clinical and/or functional features (Morris, 2007). However, these systems were complex and could be rather confusing, hindering the diagnostic process, reliable estimates of prevalence of CP, and they would muddle communication between professionals, patients, and families (Graham, 2005).

In 2000, the group of the Surveillance of Cerebral Palsy in Europe (SCPE) published a definition of CP that included five key points. According to this definition, CP: (1) is an umbrella term; (2) is permanent but not unchanging; (3) involves a disorder of movement and/or posture and of motor function; (4) is due to a non-progressive interference, lesion, or abnormality; and (5) the interference, lesion, or abnormality is in the immature brain (Surveillance of Cerebral Palsy in Europe, 2000). This definition, however, did not fully capture the fact that these key features are often accompanied by other clinical problems. The most recent definition which is now generally used worldwide includes a description of the variety of aspects of functioning that may also be affected (Rosenbaum et al., 2007):

> Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems.

It is important that these other clinical problems are mentioned in the definition, because their effects on the functioning and participation of the person with CP may be extensive and they therefore require scientific and clinical attention. To be able to further the specify a child's functioning, several classification systems, e.g. for gross and fine motor abilities, communication, and speech have been introduced.

The communication development and abilities of children with CP can be impacted in several ways. Children may have sensory, speech, language, cognitive and motor impairments that

can lead to difficulties in both producing and receiving communicative messages. Different modes of communication include speech, body movements, gestures, writing and all of these may be impacted directly, or indirectly because the language, sensory, or cognitive development of the child is delayed or deviant.

To start, the motor impairments of children with CP can impact their ability to explore the world around them and interact with it. In typically developing children, gross and fine motor abilities are correlated with language comprehension, and learning to walk is associated with receptive and productive vocabulary growth (Anderson et al., 2013; Houwen et al., 2016). Early motor impairments in children with CP are associated with poorer communication outcomes at school age (Coleman et al., 2013, 2015). In general, more motor impairments are associated with more communication restrictions. Of children with CP who are unable to walk, 85 to 100% have communication problems (Voorman et al., 2009). The motor disorders associated with CP often impact speech production abilities as well. The child may lack control over the systems that are involved in speech production such as respiration and articulation. These motor speech problems, together called *dysarthria*, can range from mild (*e.g.,* a slight slurring or a breathy voice), to severe, when the child is not able to produce recognizable words at all (*anarthria*). It is estimated that 30 to 50% of children with CP have dysarthria, and one in four cannot speak at all (Andersen et al., 2010; Nordberg et al., 2013; Novak et al., 2012).

Sensory impairments are common in children with CP. One in 25 has major hearing impairment or is deaf (Novak et al., 2012). Hearing impairments negatively impact a child's language and communication functioning and development (Eisenberg, 2007; Luckner & Cooke, 2010; Moeller, 2007). Vision problems are widespread as well: approximately two-thirds of children with CP have visual defects indicative of cerebral visual impairment (CVI) (Philip & Dutton, 2014; Schenk-Rootlieb et al., 2008). One out of ten children has severe

vision impairments or are blind (Novak et al., 2012). This has implications for the development, assessment and intervention of language and communication functioning (Tadić, Pring, & Dale, 2010; Vervloed et al., 2014).

Children with CP have an increased risk of cognitive impairments, with estimates of children with an IQ of less than 70 varying between 30% to 40% in Western countries (Andersen et al., 2008; Himmelmann et al., 2007; Sigurdardottir et al., 2008). However, the study of cognitive functioning in CP is challenged by the same barriers that are present in language comprehension assessment (Stadskleiv, 2020): a lack of reliable, valid and accessible assessment instruments and thus of representative samples in research studies.

The research on language impairments in CP, when diminished language functions cannot be explained by lower cognitive function but instead appear in isolation, is relatively scarce and inconclusive (Bottcher, 2010). A plausible interpretation is that the language development of children with reduced world experience, such as children with CP and speech and motor impairments, is delayed because of their lack of interaction with the world around them (Bottcher, 2010; Pennington, 2008).

1.4 Important frameworks in current pediatric rehabilitation practice

Three theoretical frameworks are dominant in current pediatric rehabilitation research and clinical practice for children with CP: The International Classification of Functioning, Disability, and Health (the ICF model, WHO, 2001), evidence-based practice (Sackett et al., 1996), and family-centred care (Espe-Sherwindt, 2008; Rosenbaum et al., 1998).

1.4.1   International Classification of Functioning, Disability, and Health (ICF)

The way societies define and conceptualize impairments and disabilities has impact on the lives of peoples who live with impairments and who are disabled. In the footnotes of the pledge at the beginning of this chapter it states that *"disability/disabilities may be a consequence of a disorder, depending on personal and environmental contextual factors. Disability refers to the cumulative effect of a person's impairments (or disorders), their activity limitations, participation restrictions, and contextual factors (i.e. environmental and personal)"* (International Communication Project, 2014). This understanding of disability is rooted in the ICF model (International Classification of Functioning, Disability, and Health: ICF, 2001). This framework was developed in response to two earlier and very distinct understandings of disability: the medical and the social model. The medical model views disability as the causal result of an impairment. Consequently, disability resides in the individual, who should be cured or helped by trained professionals and through medical interventions. Diametrically opposed are social models of disability, which claim that disability is not natural or individual, but socially constructed. In social models, impairment and disability are separated from each other. Instead of the causal inevitable relation between impairment to disability, these models identify social, cultural, historical, economic, relational and political factors that *dis*able people (Goodley, 2017). The ICF aims to be a synthesis between these models of disability: the biopsychosocial model. It consists of four components (Figure 1): (1) body structures and functions, (2) activities and participation, (3) environmental factors and (4) personal factors. The bidirectional arrows between the domains represent the ongoing interactions among between the components. Within the body structures and function component, a person's physical and cognitive strengths and limitations can be grouped. The activities and participation components encompass all life areas and associated activities. The component of environmental factors can be used to describe the physical, social and attitudinal factors that play a role in the individual's lives, either as

facilitators or barriers to the individual's functioning. A person's personality traits, race, gender, age, spirituality, etcetera are considered in the personal factors. The ICF framework recognizes individual disablement arising from interactions between an individual's health condition and their environment. This system is dynamic and non-hierarchical, which is different from the linear approach (i.e., impairment leads to disability). This means that interventions to improve an individual's functioning and participation can start anywhere in the model, and changes at one level of functioning (e.g., activity) may influence one or more other areas (e.g., body structure and function) (Rosenbaum & Stewart, 2004). Current recommended practice is for rehabilitation treatments to focus on goals that facilitated a child's participation in valued activities (Novak et al., 2019), whereas previously the emphasis of treatment would be to fix or improve body structure and function.
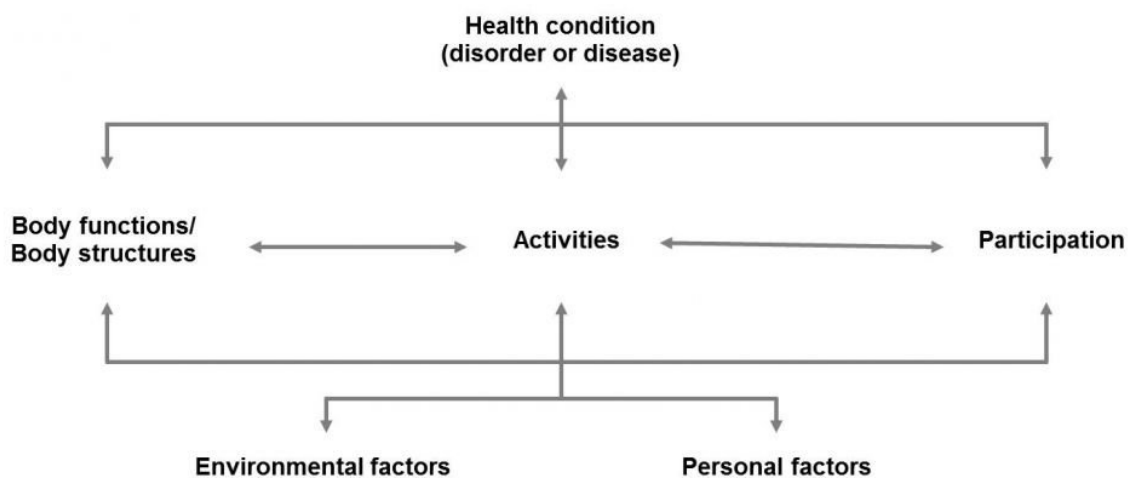
Figure 1. International Classification of Functioning, Disability, and Health (ICF) Framework (International Classification of Functioning, Disability, and Health: ICF, 2001).

1.4.2   Evidence-based practice

The services that clinicians provide are supposed to be the result of an integration of information and knowledge from different sources. A current guiding framework is that of evidence-based practice. Evidence-based practice builds on evidence-based medicine and is comprehensively described as "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett et al., 1996). Four elements are considered and valued in the decision-making process: best available clinical research evidence; individual clinician expertise (proficiency developed from clinical practice); patient values and preferences; and locally available resources (Sackett et al., 1996). Consideration of assumptions of evidence-based practice has been prominent in (research regarding) treatment interventions from the start of the conceptualization of the approach.

More recently, the concept of evidence-based *assessment* has started to emerge as part of the evidence-based practice (Danielson et al., 2019; Hollon, 2017; Youngstrom et al., 2017). This involves a shift from informal and intuitive methods of assessment, like personal observations and judgements to a process of assessment that involves all elements of evidence-based practice. For the purpose of this thesis, evidence-based assessment is understood 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" (O'Connor, 2020).

1.3.3 Family-centred care

Family-centred care is an approach to service delivery that includes an emphasis on child and family strengths, family choice and control, and collaborative partnerships between families and service provides (Espe-Sherwindt, 2008). Two complementary components characterize family-professional collaboration: 1) relational practice (e.g. active listening, showing respect,

honesty, and trust), and 2) participatory practice (e.g. engaging families in the therapeutic process, incorporating their needs and priorities) (Blue-Banning et al., 2004; Dunst & Trivette, 2009). Family-centred service leads to better outcomes than traditional service models. Studies report an increase in the child's participation in family/recreational activities (McCoy et al., 2020), decrease of parental stress (Dunst & Trivette, 2009), and increase of family satisfaction with family-centred services (Järvikoski et al., 2015; Law et al., 2003). However, clinicians may struggle with how to implement family-centred care in their services (Gorter et al., 2010). Especially the participatory practice component of actually involving families in decision making can be challenging, for instance because clinicians are unsure of how it may impact their relationship with families (O'Connor, 2020).

1.5 Children with cerebral palsy and severe motor and speech impairments

The work described in this thesis is focused on a specific group of children with CP, who will be referred to as having "severe motor and speech impairments". This description may sound vague, because what exactly is *severe* and how do these two features make these children a specific subgroup of children with CP? However, this description was chosen because it explicates in easy to understand language why these children need more services and better support than they currently often receive. It is the combination of the speech and motor impairments that results in a) these children often being excluded from research studies; b) an inability to complete standardized assessment tools; and c) more severe activity limitations and participation restrictions compared to children who only have impairments in one domain or the other. These are far-reaching consequences that can result in a status-quo where there is

too little evidence to improve access to communication and participation for children who need that support most.

1.5.1 Children with severe motor and speech impairments experience more and larger activity limitations and participation restrictions

As previously explained, motor and speech impairments correlate with communication restrictions. An increase in motor impairments often means more communication restrictions, and of the children who are unable to walk, 85 to 100% has communication difficulties (Voorman et al., 2009). Children who face both severe motor *and* severe speech impairments, have the lowest participation at home, at school, and in the community (Clarke et al., 2011, 2012; Noreau et al., 2007; Raghavendra et al., 2012). They engage in fewer activities at school and have fewer friends compared to typically developing children or children with physical impairments only (Raghavendra et al., 2012). Strikingly, over seventy percent of children with CP and severe motor and speech impairments in the US are denied the opportunity to participate in appropriate general education and instead receive most of their instruction outside the regular education classroom (National Center for Education Statistics, 2013). The impact of such exclusion is staggering: up to 90% of children who rely on AAC enter adulthood without functional literacy skills (Foley & Wolter, 2010).

AAC interventions are effective in alleviating the developmental and participatory risks of these children by providing access to functional speech (Branson & Demchak, 2009; Romski et al., 2015). However, not children who could benefit from AAC are reached. Even in high resource countries, estimates of AAC use among children with CP and severe motor and speech impairments range from 15 to 55% (Andersen et al., 2010; Pirila et al., 2007; Sigurdardottir & Vik, 2011).

1.5.2 Children with severe motor and speech impairments are often unable to complete existing standardized assessment tools

Because most tests require the participant to manipulate small objects, finger point, and/or speak (Geytenbeek et al., 2010), this group of children is often excluded from available language assessments in clinical practice (Smits et al., 2011; Stadskleiv, 2020; Stadskleiv et al., 2018). In a Norwegian registry-based study, only 29% of children with CP received formal testing (Andersen et al., 2008), and the group with severe motor and speech impairments was excluded most often (Sherwell et al., 2014; Sigurdardottir et al., 2008). This reality is at odds with the evidence-based practice paradigm, that expects the use of evidence-based tools as part of the assessment process (Majnemer, 2010; Speech-Language & Audiology Canada, 2010). Unsurprisingly, the inability of children with complex needs to complete the assessment with existing tests is the most highly reported barrier to meeting this expectation (Craig 1999; Douglas, Swanson, Gee, & Bellamy, 2005; Hanna et al., 2007; Stokes & O'Neill, 2008).

1.5.3 Children with severe motor and speech impairments are often excluded from research studies

There is growing evidence that alternative access forms, such as a multi-choice answer format combined with gaze pointing or partner-assisted scanning, are reliable methods for the completion of cognitive tests (Geytenbeek et al., 2014; Kurmanaviciute & Stadskleiv, 2017; Warschausky et al., 2012). Applying these alternative forms of access would reduce barriers to assessment with standardized tests. Currently however, the majority of studies of cognitive

and language functioning still excludes this group of children. Even in studies that aim to include a representative sample of the population of children with CP, they are often left out (Romeo et al., 2011; Smits et al., 2011) or described as non-assessable (Gosling, 2017). This results in a dearth of information about these children, and an incomplete or incorrect understanding of their abilities, development, and impairments.

1.6 The Computer-Based Instrument for Low Motor Language Testing

The Computer-Based instrument for Low motor Language Testing (C-BiLLT) is an assessment instrument that aims to capture a child's understanding of spoken words and sentences. A higher score on the C-BiLLT reflects a better ability to understand spoken language. The test can be administered by clinicians such as Speech-language pathologists (SLPs), psychologists, and occupational therapists (OTs) after a certification training.

The majority of the test is web-based and is administered on a device that is connected to the internet, *e.g.* a touch screen, a tablet, or an individual's speech generating device. Prior to the web-based sections of the test, a pre-test section is included to assess whether the participant is able to express a choice between two options. The tester will start by showing eight of the child's own familiar items (a pre-defined set of objects, including pieces of clothing, a book and a bottle or cup) in sets of two, and asks the participant to select one by looking at, reaching for it, nodding to it, etc. This is repeated with a set of eight photographs of the same, but then generic, items. Once a child has correctly identified at least five out of eight items in either the section with the objects or the section with the photographs, they progress to the web-based sections of the test (Geytenbeek, 2014).

The 86 items of the web-based part of the test are read aloud by the tester and the participant is then required to select the corresponding photo in the screen (from a choice of

two or four). The test starts with 30 single word vocabulary items and progresses to complex

compound sentences as the most difficult items. The single word vocabulary items are

presented on the screen alongside one distractor. To account for the possibility of scoring by

chance, the tester is required to re-assess, in a different order of presentation, each 10-item

section if a participant gave an incorrect response to one or more of the items of that section.

Only items that are answered correctly in both assessments will count towards the total score.

The remaining sentence items are presented with four images on the screen and do not include

the extra sections.

1.6.1 The conceptual framework of the C-BiLLT

The C-BiLLT was developed with children with cerebral palsy and speech and language

impairments in mind. This focus manifests two important ways: the accessibility of the test,

and the content of the items.

The C-BiLLT is the first evidence-based standardized assessment tool that allows

clinicians to assess a child's spoken language comprehension without requiring a verbal

response or the use of fine motor skills. Instead, participants need minimal motor skills and

can select their answer using any method that suits their needs, including direct access

methods (e.g., touch screen, eye gaze), or indirect (e.g., input switches). As an example of

what the assessment may look like, Figure 2 shows a C-BiLLT set up where the child

responds using an infrared eye-tracker mounted just below the computer screen. The eye-

tracker detects her eye gaze on the screen, and lets her select her answer by holding her gaze

at a target for a personalized amount of time (e.g., 600 ms). To select the most appropriate

access method(s) for the participant, a training module is incorporated at the start of the test.

The participant can experiment with responding to the training items on the screen and the tester can observe and adjust access, if needed.

Figure 2. Assessment with the C-BiLLT *(Figure by S. Dong)*

The content selection of the test's items was guided by what is known about children with CP. Children with severe motor and speech impairments are restricted in exploring the world around them and interacting with it (Pennington, 2008). This may shape the world experience of these children. Concretely, they may never kick a ball at a soccer field or climb a tree and thus may not know these concepts. The content of the items of the C-BiLLT is adapted to reflect objects and situations that these children realistically may encounter in their daily lives. Additionally, care was taken to ensure that the images were clear depictions of the concept, even for children with mild vision impairments (e.g., sharp contrast and no small distracting details).

1.6.2 The psychometric properties of the original Dutch C-BiLLT

Assessment instruments can be assessed for their reliability and validity, among other characteristics. The concepts of validity and reliability will be defined and explained below, supported with the psychometric properties of the Dutch C-BiLLT. The definitions of the different psychometric properties are taken from the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN, (Mokkink et al., 2010), a leading international initiative to advance the science and application of outcome measurements.

An assessment instrument may yield variation in scores. This variation can be expected and meaningful, for instance because a participant improved in the skill that is being tested. Unwanted variation can arise as well, from several sources: the measurement instrument itself, the persons performing the measurement, or the circumstances under which the assessment was done. The reliability of a test is about the amount of error (i.e., unwanted variation) there is in the measurements obtained with the test. The extended definition of reliability of an assessment instrument is given by COSMIN as: "the extent to which scores for patients who have not changed are the same for repeated measurement under several conditions: e.g., using different sets of items from the same multi-item measurement instrument (internal consistency); over time (test-retest); by different persons on the same occasion (inter-rater); or by the same persons (i.e., raters or responders) on different occasions (intra-rater)" (Mokkink et al., 2010).

For the C-BiLLT, two sources of possible variance were examined through calculation of the intraclass correlations: test-retest reliability (0.97) and interrater reliability (0.97) (Geytenbeek et al., 2014). Additionally, the internal consistency of a 75-item version of the Dutch C-BiLLT was calculated. Internal consistency is a special type of reliability and examines the extent to which responses to test items are consistent. For the 75-item version of the Dutch C-BiLLT, internal consistency was found high a sample of 806 typically developing children and in sample of 87 children with CP (Geytenbeek et al., 2014).

Validity concerns how well the construct that the instrument aims to measure is captured by it. It can be assessed in several ways. Preferably, a new instrument is compared to a gold standard, which is considered to represent the true state of the construct. If a gold standard is not available, COSMIN recommends validity assessment using construct validation. Since there was no gold standard for assessing language comprehension, construct validation was used to provide evidence of validity of the C-BiLLT.

Construct validity is defined by the COSMIN panel as "the degree to which the scores of a measurement instrument are consistent with hypotheses, e.g. with regard to internal relationships, relationships with scores of other instruments or differences between relevant groups" (Mokkink et al., 2010). It can be further divided into three aspects: structural validity, hypothesis testing, and cross-cultural validity (Mokkink et al., 2010). Structural validity is expressed by the degree to which the scores of an instrument are an adequate reflection of the dimensionality of the construct to be measured. For the Dutch C-BiLLT, this was estimated through exploratory factor analysis (EFA) on 75 items within a sample of participants with and without cerebral palsy. EFA yielded a unidimensional factor solution with an explained variance of 76% (Geytenbeek et al., 2014).

The next step in validity testing on the original Dutch version was taken by testing hypotheses about the correlations between C-BiLLT scores and scores on similar tests (convergent validity, hypothesized to be high), and between C-BiLLT scores and scores on unrelated tests (discriminant validity, hypothesized to be lower). Convergent validity was assessed by calculating correlations between C-BiLLT scores and the Peabody Picture Vocabulary Test (r=0.88) and the Dutch Reynell Developmental Language Scales (r=0.93), tests for receptive vocabulary and receptive language development, respectively. Discriminant validity was estimated through correlations between the C-BiLLT and the Raven's progressive matrices, a test for non-verbal reasoning (r=0.43) (Geytenbeek et al., 2014).

These correlations suggest that the C-BiLLT measures what it claims to measure, while not measuring a construct that was not intended to measure.

1.6.3 Cross-cultural adaptation of the C-BiLLT

As described in paragraph 1.2, the C-BiLLT sparked interest in researchers, clinicians and families from around the world. In Canada, interest was shown by CanChild, a centre for childhood disability research at McMaster University dedicated to maximizing the quality of life of children with developmental conditions through evidence-based clinical and health services research. This interest was the beginning of a collaborative grant application towards developing a C-BiLLT for English raised Canadian children.

Instead of developing an accessible English receptive language test from scratch, adapting an existing instrument can have many advantages. It is potentially an efficient and cost-effective way to access a tool that has proven reliable and valid in the source language and culture (Jeanrie & Bertrand, 1999). It is important to differentiate between *test translation* and *test adaptation*. Test translation has a more limited meaning of moving the instrument from one language to another, with no regard for educational, psychological, or cultural equivalence (International Test Commission, 2017). Test adaptation is a broader term. It refers to all activities that are involved in moving a test from one language and culture to another. To date, the C-BiLLT has one published adaptation: the C-BiLLT NOR, a Norwegian version of the test (Fiske et al., 2020), of which the measurement properties are described in Chapter 3. Chapter 3 also describes the assessment of the psychometric properties of the Canadian English version of the C-BiLLT, C-BiLLT CAN, a major outcome of this dissertation.

1.7 Research Aim and thesis outline

The overall aim of this thesis was to generate a body of knowledge that can facilitate the evidence-based assessment of language comprehension in children with cerebral palsy and severe motor and speech impairments, in a way that aligns with current best practice. The work in this thesis a) furthers the evidence base for accessible language assessment for children with CP and severe motor and speech impairments in Canada, b) increases the understanding of the implementation of assessment tools in clinical practice, and c) facilitates child- and family centred assessment practice. Specifically, the objectives of the research program were:

1. To adapt the Dutch C-BiLLT for use among English speaking Canadian children with cerebral palsy. This objective was met by carefully following best-practice guidelines for the adaptation of tests from one language and culture to another (Chapter 2) through a cross-sectional study of the validity and reliability of the C-BiLLT CAN in a sample of 80 typically developing children, and an exploration of its feasibility in the Canadian health care context (Chapter 3).

2. To assess the implementation process to date of the C-BiLLT in clinical practice. This objective was met through a survey study among 90 Dutch, Belgium, and Norwegian clinicians in which they reported about their professional backgrounds, caseload characteristics, practice contexts, and details of their experiences with the test (Chapter 5). The results of the survey study were complemented by a qualitative description study in order to achieve a more in-depth understanding of clinicians' contextualized evidence-based assessment behaviours (Chapter 6).

3. To design and conduct a study to understand parents' experiences of language assessment with the C-BiLLT for their child growing up with cerebral palsy and complex communication needs. A qualitative research design using interpretive description was used to meet this objective (Chapter 7).

This thesis is comprised of a general introductory chapter, a chapter that introduces part 2 of this thesis about the implementation of the C-BiLLT, five chapters that include both published and unpublished work, and an overarching discussion chapter. Chapter 2 describes the work that was done to develop the C-BiLLT CAN. Chapter 3 includes a submitted manuscript about the evaluation of the psychometric properties of the C-BiLLT CAN in typically developing Canadian children. This manuscript is preceded by a description of how our team pivoted recruitment and data collection in response to the Covid-19 pandemic. Chapter 4 describes how the three different languages (i.e., English, Dutch, and Norwegian) in the implementation studies were dealt with. Chapter 5 includes a submitted manuscript that describes our international survey study. Chapter 6 starts with an introduction about implementation science in SLP and includes a submitted manuscript that describes our in-depth interview study with C-BiLLT clinicians. Chapter 7 is a manuscript prepared for publication that describes the protocol for a qualitative study about parents' experiences with the C-BiLLT assessment for their child with CP and severe motor and speech impairments. A final overarching discussing chapter (Chapter 8) provides a synthesis of the work.

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Chapter 2: The adaptation process of the C-BiLLT for use in Canada

2.1 Background

Cerebral palsy (CP) is the leading cause of childhood-onset physical disability, affecting approximately 1 in 500 infants. It is estimated that 80% of individuals with CP experience difficulty expressing and/or understanding language, due to the cognitive, language, speech, sensory or motor impairments that can be part of the disorder (Novak et al., 2012). Because the language comprehension abilities of these children can develop independently from their motor and speech skills (Geytenbeek et al., 2015; Stadskleiv, 2020; Stadskleiv et al., 2018), it is essential to have tools to reliably assess the different aspects of their language development. However, traditional language assessment tools tend to fail this group of children, because they require verbal responses or fine motor abilities, for instance finger pointing to an answer (Geytenbeek et al., 2010). This excludes children with motor and speech impairments from participation in these tests. A promising tool to evaluate spoken language comprehension abilities that requires no verbal responses and only a minimum of motor skills was introduced in the Netherlands in 2014, the Computer Based instrument for Low-motor Language Testing (C-BiLLT; Geytenbeek et al., 2014). The C-BiLLT was developed in Dutch and therefore cannot be used with children growing up in other languages. However, instead of developing a new English assessment instrument to test spoken language comprehension in Canadian children with CP, adapting the C-BiLLT was preferred.

Choosing an existing instrument over the development of a new instrument can have many advantages. It can be an efficient and cost-effective way to access a tool that has proven reliability and validity in the source language and culture. To ensure the instrument will measure the same phenomenon in the target language and culture as it does in the source language and culture, a careful and thorough cross-cultural adaptation process is

recommended (de Vet et al., 2011; International Test Commission, 2017; Sousa &

Rojjanasrirat, 2011). In this chapter I describe the process that was followed to arrive at the

Canadian English version of the Computer-Based instrument for Low Motor Language

Testing (C-BiLLT CAN). Funding to support the development of the C-BiLLT CAN was

available from the Hamilton Academic Health Sciences Organization (HAHSO, #18-03).

Test adaptation is a complex process. First, it is important to note the difference

between *test translation* and *test adaptation*. Test translation has a more limited meaning of

moving the instrument from one language to another, with no regard for educational,

psychological, or cultural equivalence (International Test Commission, 2017). Test adaptation

is a broader term. It refers to all activities that are involved in moving a test from one

language and culture to another, such as consideration of the equivalence of the construct that

is measured, the selection of the translation design(s) and the translators, considering

necessary accommodations, modifying the test format if necessary, evaluating the equivalence

of the resulting test in the target language, and estimating the psychometric properties of the

new version (Dale, 2015). The development of a high-quality, psychometrically sound new

version of a test can be a long and elaborate task in which test translation is only one part of

the process (Gudmundsson, 2009; International Test Commission, 2017; Merenda, 2006).

Test adaptation and the concept of equivalence are even more complex if the construct

that the instrument purports to measure is related to language (Dale, 2015). What is needed is

not just a translation of the test items, but a new instrument "which bears the same

relationship to the overall language" (Dale, 2015, p. 3). In this case, a new test that bears the

same relationship to Canadian English as the original C-BiLLT does to the Dutch language.

That means that the fundamental content must change, because not all Dutch words will be

relevant for Canadian children, or words that are needed in the Canadian version to

adequately cover the construct are not available in Dutch and therefore were not included in

the test. So even though the construct of verbal language comprehension is likely to be represented the same way in both Dutch and English language and culture (i.e., the ability to understand the different elements of spoken language), the linguistic features of form, content and use and their developmental trajectories may vary considerably (Dale, 2015; Haug, 2011).

There are guidelines available to support researchers to adequately adapt psychological tests from one language and culture to another. The goal of the International Test Commission (ITC) is the advancement of good practices in the construction, distribution, and use of psychological tests and it has published several guidelines to help researchers. We used the ITC guidelines for translating and adapting tests in the adaptation of the Dutch C-BiLLT to ensure that sufficient attention was given to all steps of the adaptation process. The guidelines for translating and adapting tests are organized into six categories (number of guidelines included in the category): pre-condition (3), test development (5), confirmation (4), administration (2), scoring and interpretation (2), and documentation (2) (International Test Commission, 2017). This chapter describes the pre-condition and test development stages, addressing guidelines 1 through 7, which resulted in a Canadian English version of the C-BiLLT that could be assessed for its psychometric properties. The guidelines and the way they were operationalized for the C-BiLLT adaptation are shown in Table 1.

Table 1. ITC Pre-Condition and Test Development Guidelines and Operationalization

Stage	#	*ITC Guideline*	Operationalization
Pre-Condition	1	Obtain the necessary permission from the holder of the intellectual property rights relating to the test	Protect the intellectual property rights of the creators of the C-BiLLT and

		before carrying out any adaptation.	obtain permission for the adaptation.
	2	Evaluate that the amount of overlap in the definition and content of the construct measured by the test and the item content in the populations of interest is sufficient for the intended use (or uses) of the scores.	The construct of 'comprehension of spoken language' should be understood in the same way in Dutch and English.
	3	Minimize the influence of any cultural or linguistic differences that are irrelevant to the intended uses of the test in the populations of interest.	Assess the impact of the linguistic and cultural distance between the Netherlands and Canada on the C-BiLLT content.
Test Development	4	Ensure that the translation and adaptation processes consider linguistic, psychological, and cultural differences in the intended populations through the choice of experts with relevant expertise.	A multidisciplinary team was put together with knowledge Dutch and Canadian English language and culture, language comprehension (assessment, development), and cerebral palsy.
	5	Use appropriate translation designs and procedures to maximize the suitability of the	Multiple translation designs were used (forward and concurrent translation) and several rounds of translations

		test adaptation in the intended populations.	were applied to ensure optimal translations and adaptations.
	6	Provide evidence that the test instructions and item content have similar meaning for all intended populations.	A pilot test with 9 Canadian children with and without cerebral palsy was undertaken to test and obtain feedback on the instructions and new item content.
	7	Provide evidence that the item formats, rating scales, scoring categories, test conventions, modes of administration, and other procedures are suitable for all intended populations.	Incorporated in the earlier steps.

2.2 Pre-condition guidelines

This paragraph describes how the three guidelines pertaining to the pre-condition phase were addressed in this project.

Guideline 1: Obtain the necessary permission from the holder of the intellectual property rights relating to the test before carrying out any adaptation.

An adapted test that mimics an existing test but with new items, which is the case here, is potentially a breach of the original intellectual property rights and therefore needs careful consideration. Guideline 1 was addressed in our project because the lead

developer of the original C-BiLLT and co-holder of the intellectual property rights was part of the team that created the C-BiLLT CAN. She granted the team full permission to adapt the Dutch C-BiLLT, with respect for the structure, scoring system, format and material of the original test.

Guideline 2: Evaluate that the amount of overlap in the definition and content of the construct measured by the test and the item content in the populations of interest is sufficient for the intended use (or uses) of the scores.

This guideline was addressed by considering the construct of spoken language comprehension among the research team members. The construct of language comprehension is well-defined and -researched for Dutch and English and overlaps sufficiently if not completely. Evidence can be found in the many English language comprehension tests that are adapted for use in Dutch, e.g. the Peabody Picture Vocabulary Test-III-NL (L. M. Dunn et al., 2005), and the Dutch version of the MacArthur Communicative Development Inventories (Zink & Lejaegere, 2002), among many others.

Guideline 3: Minimize the influence of any cultural or linguistic differences that are irrelevant to the intended uses of the test in the populations of interest.

This guideline was addressed throughout the different stages of adaptation process by discussion between the different experts in linguistics, psychology, and speech-language pathology.

2.3 Test development guidelines

The guidelines 4 through 7 are all part of the development phase of the adaptation process. Guidelines 4 and 5 are concerned with the adaptation of the test's content and they are

described together first. In the following section a description of the pilot study that addressed guidelines 6 and 7 is given.

2.3.1 Adaptations

Guideline 4: Ensure that the translation and adaptation processes consider linguistic, psychological, and cultural differences in the intended populations through the choice of experts with relevant expertise.

Guideline 5: Use appropriate translation designs and procedures to maximize the suitability of the test adaptation in the intended populations.

Guidelines 4 and 5 were addressed during multiple phases: a literal forward translation, and analyses of content, linguistic, and conceptual equivalence between the two versions by individual researchers and in group meetings, described below.

The first phase, the literal translation of the Dutch test items into English, was done by several speakers of Dutch with near-native English language abilities. Some features, such as instructions and trial items, were directly translated into the English language. Phase 2 was carried out by individual review of written materials, as well as in group meetings. A team of native English-speaking researchers in linguistics, psychology, and speech-language pathology were provided with the written translated items and with the screen shots of the pictures of proposed items. They reviewed the translations in writing and provided feedback and suggestions for alternative translations or concepts for items.

To review and discuss the results of this process, a multidisciplinary expert group meeting was held in June, 2018, at CanChild Centre for Childhood Disability Research. Members of the group were Dutch and Canadian linguists, SLPs, physiatrists, and pediatricians. They were presented with the visual items of the Dutch test, together with the

different proposed English translations from phase 1. Items of the test that were beyond the one-word level were presented with linguistic glossing (see Ex. 1 and Figure 1). This was done to facilitate discussion about their (morpho-)syntactic complexity.

Ex. 1: Het doek-je lig-t en één van de pot-ten jam staat in de mand.

the cloth-DIM lie-3SG and one of the jar-PL jelly stand.3SG in the basket

(note DIM, diminutive; PL, plural; 3SG, third person singular)

Figure 1: item example

The group investigated conceptual and linguistic equivalence by reviewing each C-BiLLT item. They were invited to share their comments with one another and to reconcile any differences if possible. These discussions were moderated by me.

Often times in the translation of an instrument, a back translation of the items is undertaken to examine the adequacy of the translation (Brislin, 1986). However, since we relied on multiple translation and adaptation strategies, the back-translation method was not expected to add valuable information. To illustrate, review the item in Example 2:

Ex 2.: Waar is de lamp?

Where is the lamp?

During Phase 1, this item was translated into the very straightforward translation: "Where is the lamp?". However, during the expert meeting, several child language experts argued that

"Where is the light?" could be a better translation. Their rationale was that in early English language development, the concept of 'illuminating', was understood by the word 'light' rather than by the word 'lamp'. This intuition is supported by data from Wordbank, a database that archives data from the Mac-Arthur-Bates Communicative Inventory (Fenson et al., 2007), see Figure 2. Based on the experts' opinion and the supporting data we decided to pilot both possible translations of this item. Relying on a back translation (English 'lamp' translated back to Dutch 'lamp') would not have identified this issue.
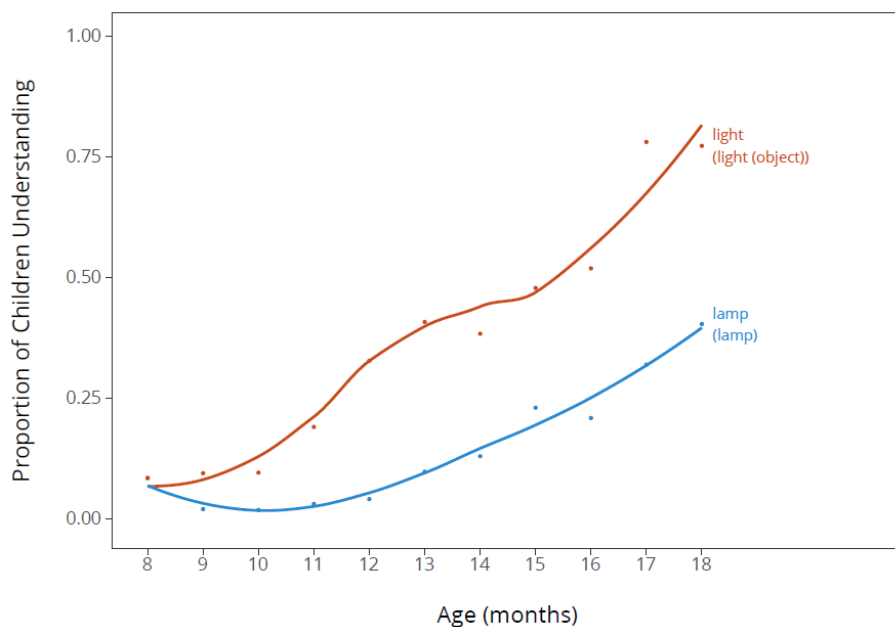
Figure 2: Comprehension of the spoken word 'light' versus 'lamp' for children aged between 8 - 18 months (figure reproduced from www.wordbank.standford.edu).

An example of a cultural difference that came to light in this meeting was about the item "Where is the vacuum (cleaner)?", with a picture of a standard portable vacuum cleaner which is presented next to 3 distractor pictures. In the meeting the Canadian participants argued that this item would not be recognizable to all Canadian children because: a) a central vacuum system is more common in Canada; and b) it is possible that low-income families do

not possess a vacuum of any type. They suggested to either change the picture to an image of a (part of a) central vacuum system, or to change the item altogether.

Tables 2, 3, and 4 show the outcomes of Phases 1 and 2 of the adaptation process. The tables list the items that needed to be modified to be relevant and appropriate for the Canadian English version of the C-BiLLT. The different reasons included grammar, culture, modernization of the image or the concept of the item, visibility of the item, or the need for rephrasing. Table 2 shows the items that needed a new target, to ensure they would be culturally relevant, up to date, or to match the other items in a given section. Table 3 shows the items that were identified as potentially needing a new picture, either because they were outdated or because experts shared concerns about the visibility of the current image. Table 4 shows the items that needed rephrasing, for a variety of reasons.

Final decisions on the items that were used in the pilot test were made based on consensus meetings with the research team. Selection of possible new items was guided by the following two requirements: high imageability, and relevancy to children who grow up with severe motor disorders and with little to no functional speech. Suggestions for possible pilot options were based on the expert opinions, data on comprehension of early words from Wordbank (Frank et al., 2016), a database that archives data from the Mac-Arthur-Bates Communicative Inventory or on items from age equivalent sections of the Peabody Picture Vocabulary Test – 4 (Dunn et al., 2015).

Table 2: Items that needed a new target for grammatical or cultural reasons or for the purpose of modernization and the options that were considered for the pilot test.

Item	Dutch (*literal English translation*)	Adaptation Type	Reason	Options to pilot (*used in pilot test*)

Pretest item 8	Waar is de DVD/video? (*Where is the DVD/video?*)	New target; conceptual	Modernization (conceptual): modern day children are likely to watch comics, shows and movies through services such as Netflix or YouTube, instead of from a DVD or video cassette.	Spoon or *toothbrush*
26	Waar is de stofzuiger? (*Where is the vacuum cleaner?*)	New target; cultural	Cultural: many Canadian households have a central vacuum system. Moreover, low income households may not possess a vacuum of any type.	Pencil, carrot, cookie, or *mouth*
32	Waar is de brievenbus? (*Where is the mailbox?*)	New target; conceptual	Modernization (conceptual): mail is rapidly digitalizing; thus, mailboxes are much more unfamiliar to children than they were ~10 years ago.	Toe, belt, fire, castle, shoulder, or *gift*
65	Een stuk kaas is voor de helft	New target: cultural	Cultural: a big piece of cheese is a lot less familiar to children	Watermelon, cracker, *toast*

| | opgegeten. (*Half of a piece of cheese has been eaten.*) | | growing up in Canada compared to Dutch children. | |

Table 3: Items that may need an update of the picture, to improve visibility or for purpose of modernization and the options that were considered for the pilot test.

Item	Dutch (*literal translation*)	Adaptation Type	Reason	Options to pilot
5	Waar is de lepel? (*Where is the spoon?*)	New picture	Visibility: Current spoon may be unclear	Compare current spoon to a(stock) photo of different spoon
6	Waar is de tv? (*Where is the TV?*)	New picture	Modernization (visual): Current TV is old fashioned	Compare current TV to a (stock) photo of more modern TV
8	Waar is de schoen? (*Where is the shoe?*)	New picture	Visibility: Current shoe has detailed embroidery	Compare current shoe to a (stock) photo of a plain shoe
9	Waar is de pan?	New picture	Cultural: Current pot would be called differently	Compare two (stock) to a (stock) photo of a Canadian pot

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| | | | | and is less familiar than the pot we aim to test | |

Table 4: Items that may need rephrasing and the options that were considered for the pilot test.

Item	Dutch (*literal translation*)	Adaptation Type	Reason	Options to pilot
7	Waar is de lamp? (*Where is the lamp?*)	Rephrasing; development	Child development: 'Light' is understood earlier than 'lamp'	Compare lamp to light
10	Waar is de sleutel? (*Where is the key?*)	Rephrasing; grammar	Grammar: To keep the structure of all the questions in the pretest consistently singular.	Compare current set of keys to (stock) photo of a single key
36	Waarin kan je rijden? (*What can you ride?*)	Rephrasing; linguistic	In the English language, a wheelchair is not something you ride. If changed to 'where can you sit?', the picture of the bed could also be correct.	Compare: What can you ride? + change target image Where can you sit? + change image of the bed to something else
43	Wie heeft er boodschappen gedaan? (*Who*	Rephrasing; linguistic	No consensus reached in expert meeting on best phrasing.	Who went shopping? Who was running errands?

	went grocery shopping?)			Who went grocery shopping?
86	Omdat bijna alle borden al zijn opgestapeld heeft Joost de geschilde appel en de bananen niet op de stapel neergelegd. (*Because almost all of the plates have been stacked, Josh hasn't put the peeled apple nor the bananas on the pile.*)	Rephrasing; linguistic		Compare: Almost all of the plates have been stacked, but Josh hasn't put the peeled apples or the bananas on the pile. OR: Because almost all plates are already stacked, Josh didn't put the peeled apple and the bananas on the pile.

2.3.2 Pilot test

A pilot test was carried out to address guidelines 6 and 7. A convenience sample of 9 children (5 females) was included in this study. Eligibility criteria for participants were: age between 4 and 8.5 years (mean age 6.5 years), typically developing (n= 6) or diagnosed with cerebral palsy (n= 3). If a diagnosis of cerebral palsy was present, children were eligible to participate if they were able to verbalize their thoughts, had no severe sensory impairments that would prevent them from observing the screen or hearing the instructions, and had sufficient gross motor skills to move independently (operationalized as levels I to III on the Gross Motor Function Classification System (GMFCS), (Palisano et al., 1997)). The age range was based on the assumption that children at this age would have sufficient metalinguistic and metacognitive skills to reflect on their own thought processes, guided by the session facilitator (Chaney, 1992; Whitebread et al., 2009). The study protocol received ethics approval from the Hamilton Integrated Research Ethics Board #5152 at McMaster University.

2.3.3 Pilot Test Materials and Procedures

The pilot test visits were set up as 'think aloud'-sessions. After informed consent was obtained from a parent of the participant, and informed assent for participants over the age of 7 years old. The session facilitator and the participant sat next to each other, facing a touch screen. Parents were allowed to be present if they so wished. The session facilitator would build rapport with the child and create a friendly and cooperative atmosphere. Sessions were videotaped with two cameras: one pointed at the session facilitator and the participant and one pointed at the screen.

All test items were presented in the regular C-BiLLT order, on the original online C-BiLLT platform. Items that were piloted were presented using a PowerPoint presentation. The

session facilitator switched between the browser, where the C-BiLLT was displayed, and the PowerPoint presentation that contained the pilot items.

Participants were encouraged to engage with the session facilitator when they reviewed. The participant and the session facilitator approached the items as co-investigators. This means that even though the session facilitator initially asked the participant to respond to each item, she also gave direct feedback about the participant's answers to the items. When the participant answered conform what the team expected, the session facilitator responded with an affirmative 'mm-hmm' or 'uh-huh'. If the participant's answer was different than expected, they were asked for explanation in an investigatory manner, e.g. *"that's interesting, you pointed at this picture, while in fact we had this picture in mind. What made you choose that picture?".* The participants were encouraged to think aloud while answering the questions. Throughout the session, the session facilitator would respond to the participant by asking for clarification, explanation, suggestions, or continuation, to make sure she understood the participant correctly (Zhao & McDonald, 2010).

The sessions were discontinued after 8 consecutive wrong answers. This was done to prevent frustration for the participant, and to avoid a situation in which a participant was asked to reflect on items they were developmentally not yet able to understand. Sessions lasted 30 minutes at most. Participants received a $20 gift card and a certificate for being a junior scientist to thank them for their participation.

2.3.4 Pilot Test Analysis

Data from the pilot test were analyzed using an approach inspired by template analysis (Brooks & King, 2012). Template analysis is a flexible technique that allows to define themes or categories in advance of the analysis. Because there were particular perspectives that needed to be incorporated into the analysis, the approach of template analysis fit with our

objectives. A priori defined categories that were expected to be found were: *unfamiliarity, confusion, dislike* and *suggestion* with regard to the concept, picture, and/or phrasing of each item.

The first step of the analysis was a review of the videotapes. In principle, only the comments and feedback on the piloted items were analyzed into detail. However, in case a participant verbally or non-verbally expressed confusion or dislike concerning an item that was not originally planned to be under investigation, this discourse was also transcribed and analyzed. Comments about the items were grouped into the pre-defined categories. No other categories were needed.

2.3.5 Pilot Test Results

Results from the feedback that was collected in the pilot test are summarized in Table 5.

Table 5: Piloted item, proposed type of adaptation, and pilot test result.

Piloted item	Type of adaptation			Result
	Conceptual	Image	Phrasing	
Where is the TV?		*		New image of a TV
Where is the pot?		*		New image of a pot
Who is cutting?		*		New image of a person cutting
Where is the vacuum cleaner?	*			Where is the mouth?
Where is the phone?		*		New image of a phone
Where is the mailbox?	*			Where is the gift?
Who is walking the dog?			*	Who is going to walk the dog?

Who used to play outside but doesn't anymore?			*	Who used to play outside but now has to go to work?
Half of the piece of toast has been eaten.		*		Half of the glass of juice is finished.
A small jar of jam is next to the red jar of jam.			*	A small jar of jam is beside the red jar of jam.
Where is the spoon?	n/a			Item remained unchanged.
Where is the lamp?	n/a			Item remained unchanged.
Where is the shoe?	n/a			Item remained unchanged.
Where are the keys?	n/a			Item remained unchanged.
Who went grocery shopping?	n/a			Item remained unchanged.

Two examples of participant feedback are shown below. In the first, two images of TV were piloted: the original image from the Dutch C-BiLLT showing an old TV model, and a stock photo of a flat screen TV.

> SF: Where's the TV?
> PAR: TV... they're both TVs.
> PAR: This one seems a bit more common though (points to the image of a modern flat screen TV).
> SF: This one?
> PAR: Yeah this one, the one on the... right.
> SF: Uh-huh.

SF: And what about this one? (points to the image of an older model TV)

PAR: That one? Still seems a bit common. A bit... I don't want to say *old*, or *vintage*, but yeah.

Note: SF, session facilitator

In the second example the phrasing of the item, shown in Figure 4, was piloted. An unforeseen result was confusion about the phrasing of the item "a small jar of jam is next to the red jar of jam". Some participants pointed at the bottom right picture. After consultation with the team the phrasing was changed to "a small jar of jam is beside the red jar of jam".

Figure 4: Participants expressed confusion about the phrasing of the item "a small jar of jam is next to the red jar of jam."

2.4 Conclusion

The ITC guidelines (International Test Commission, 2017) facilitated the planning and execution of the adaptation process. The guidelines supported planning because they allowed us to consider the different steps that we needed to take and gave an idea of how elaborate those steps would be in terms of time, and the number and different backgrounds of experts. The guidelines supported our thinking about the importance of thoroughly considering the cultural equivalence of the test items. It is possible that without the guidelines, we would not have included an in-person meeting with such a large, multidisciplinary, and international

group of experts into the process. While it would have been easier, less expensive, and faster to rely on written feedback from a handful of experts, the meeting brought concerns to the surface that would have likely been overlooked otherwise.

Based on the year-long project, which included the multiple rounds of translation and adaptation of individual experts, a multidisciplinary group meeting, and pilot testing, the items for the C-BiLLT CAN were finalized. This version was used in the validation study described in the next chapter of this thesis, Chapter 3.

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Chapter 3: Evaluation of the psychometric properties of the C-BiLLT CAN

3.1 Introduction

This chapter presents the research undertaken to meet the first objective of this thesis: To adapt the Dutch C-BiLLT for use among Canadian children with cerebral palsy (CP), whose primary language is English. The validity and reliability of the Canadian English version of the C-BiLLT (C-BiLLT CAN) were examined cross-sectionally in a sample of 80 typically developing children. This study also contained an exploration of the test's feasibility in the Canadian healthcare context using a sample of nine children with CP and severe motor and speech impairments. This introduction contains a section that provides background information for the study (section 3.2), and a final section about the strategies that were developed to mitigate the challenges with recruitment and data collection in response to the Covid-19 pandemic (section 3.3). The two sections are followed by the manuscript about this study. The amendment summarizing the changes to the study protocol to enable the virtual study visits can be found in Appendix 1.

3.2 Background

This study received funding from the Hamilton Academic Health Sciences Network in Hamilton, Ontario (#18-03, principal investigators Drs. Jan Willem Gorter and Olaf Kraus de Camargo) and commenced in 2018. The awarded project grant described three projects: 1) the adaptation of the Dutch C-BiLLT towards a Canadian English C-BiLLT; 2) the evaluation of the psychometric properties of the Canadian C-BiLLT; and 3) an exploration of the C-BiLLT CAN's feasibility in the Canadian healthcare context. The adaptation of the Dutch C-BiLLT (project 1) has been described in Chapter 2 of this thesis. The current chapter describes

projects 2 and 3: the evaluation the convergent validity, internal consistency, test-retest reliability, and measurement error of the newly developed C-BiLLT CAN (project 2), and its feasibility in the Canadian healthcare context (project 3).

The research team included clinician-scientists from pediatric physiatry, speech-language pathology, and developmental pediatrics, a family research partner, a research coordinator, and a research development officer. Additionally, study visits of the typically developing children were led by ten graduate students in Speech-Language Pathology from the School of Rehabilitation Science from McMaster University. They were trained and supervised by Jael Bootsma and Sarah Hopmans. Several of the students contributed to the project as a part of their clinical placement, practicing their assessment skills.

3.3 Transition to virtual study visits in response to the Covid-19 pandemic

From March 14 2020 onwards, all in-person research study visits needed to be cancelled due to the Covid-19 pandemic. At that point in time, we had included 52 children in the study, 65% of the project's target inclusion of 80 children. We found some encouraging evidence that remote administration of psychological tests via videoconferencing could yield results comparable to in-person administration (Brearly et al., 2017). In an attempt to continue our research project, we decided to transition our recruitment and data collection strategies to virtual visits that complied with the social distancing regulations.

The preparation for this transition comprised four different steps: 1) identification of digital versions of the language and cognition tests that were included in the study; 2) selection of a user-friendly online videoconferencing platform; 3) consideration of technical aspects; and 4) pilot testing of the feasibility of the new set up. The steps are described below.

Step 1. The tests that were included in the original study visits are the C-BiLLT CAN, and the pen and paper versions of the Peabody Picture Vocabulary Test-4th edition (PPVT-4; Dunn et al., 2015), the New Reynell Developmental Language Scales (NRDLS; Edwards et al., 2011), and the Raven's 2, a test of non-verbal intelligence (Raven, 2018). In the study visits, each participant started with the C-BiLLT CAN, and progressed with some or all of the other tests, depending on their age. The C-BiLLT has been developed to be completed on a computer, so this test was already fit for remote administration. Our team was able to quickly identify the digital versions of tests that are published by Pearson, which were the PPVT and the Raven's 2. These tests could be accessed, administered and scored in Q-Global, Pearson's web-based system for assessments (https://www.pearsonclinical.ca/en/q-global/main.html). This meant that the PPVT and the Raven's 2 were digitally available to our team. However, the NRDLS was not available online, and therefore this test could no longer be used in our project. The total number of children who were assessed with the NRDLS pre-pandemic and that we could use in our analysis was 41.

Step 2. The digital versions of the PPVT and the Raven's 2 were now available, meaning the tests could be completed on a computer and there were no longer materials involved such as booklets and score sheets. However, we still needed to find a way to remotely administer these tests in a standardized way, overlooked by a tester. To that end, step 2 of the process involved the identification of an online videoconferencing platform that could be used. We decided to pilot the Zoom platform, because we had good experiences with it for our research meetings and McMaster University had a subscription to it, which allowed us to use it free of charge.

Step 3. In this step of the process, we needed to conceptualize the virtual study visits. The tester would initiate a Zoom call with the participants, most of whom would need some assistance from an adult family member. The tester would access Q-global, or the C-BiLLT

website, and then share their screen with the participant. Zoom has a feature of 'remote control' which allows the participants in the call to exchange power over the other party's screen. Thus, the tester would allow the participant to take control over their screen, which displayed either the C-BiLLT, the PPVT, or the Raven's 2. Then, the participant could select their answers on the screen, guided by the tester in in the Zoom call. The participant's responses would be collected through the tests' platforms, either the C-BiLLT website or Q-Global, that were accessed through the tester's computer.

Step 4. Our team pilot tested this approach until everyone felt comfortable with the new procedures. We decided to record all sessions using the Zoom feature, in case something unexpected would happen that we wanted to review later. A new protocol was developed for the virtual visits, and a document for participating families were created. This document included information about what to expect during the study visit and some tips for using Zoom, and was sent to families in advance of the study visit. Once the study visit was completed, the gift card and junior scientist certificate were e-mailed to the participants. An amendment was submitted to the ethical committee to explain the new procedures and privacy measures, which was approved (Appendix 1).

Excitingly, the shift to remote recruitment and data collections allowed us to recruit participants from all over Canada if they met our eligibility criteria, and they possessed a computer, laptop or a tablet that could be connected to the internet. Recruitment resumed in early July 2020, roughly three months after the start of the pandemic. We were able to reach our inclusion target of 80 participants in October of 2020. To get an impression of how acceptable the virtual study visits were to families, we created a short survey asking about their experiences with the study visit. This survey included questions such as "How easy was it for you and your child to participate in the virtual C-BiLLT study?", and statements such as "The virtual assessment was acceptable for my child", with 5-point Likert scale answering

options and space to provide free text responses. Responses to this survey ($n = 16$ out of 29 remote assessments) show that for the majority of families ($n = 14$) it was easy or very easy to participate in the virtual visits. Most parents ($n = 14$) said the virtual assessment was very much acceptable to their child. Free text responses included the following statements:

> *"We didn't have to travel anywhere. My daughter is shy and happier in her home environment."*
>
> *"Easy communication between my son and the tester. Easy setup, quick start up and easy to do from home."*
>
> *"Duration was a bit high for a four-year-old, but the option of breaks made it manageable."*

We have learned a couple of lessons through this unexpected turn of events. There were setbacks as well as windfalls that came with the transition to virtual study visits. Setbacks included that some devices (e.g., Google Chromebooks) did not support Zoom's remote control function at the time of our data collection. Therefore, participants who only had access to such a device could not participate. A more fundamental issue with our new method of data collection was the bias that it may have brought, because of the necessity of a computer or a tablet with a stable internet connection. While our team looked into the possibilities of recruiting families without such resources and then lending them the equipment, this proved unfeasible in reality. This access barrier may have caused bias with our sample to be of a higher socioeconomic status. Lastly, our hypothesis testing approach to assess the construct validity of the C-BiLLT required correlational analyses based on the tests' raw scores. However, we were unable to obtain raw scores from the Raven's 2 assessments, because the scores were automatically entered into Q-Global's scoring algorithm. Our team made contacts

with the publisher to try if there was a way to retrieve the raw scores, but these efforts were to no avail. Therefore, the assessment of the C-BiLLT's discriminant validity could only be based on the sample of 33 participants that had completed the Raven's 2 during the in-person study visits.

Windfalls of the virtual study visits included the previously mentioned extension of the geographical recruitment area. Additionally, parents' feedback on the virtual visits taught us that for some children participating from their home environment was more comfortable. They also mentioned that, during this first lockdown which included school closures as well, children were happy to have something to do. Ultimately, the transition to remote study visits made it possible to complete our study in a timely manner.

3.4 Psychometric properties of the English language version of the C-BiLLT evaluated

in typically developing Canadian children

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Psychometric properties of the English language version of the C-BiLLT evaluated in

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Abstract

Purpose: This study aims to 1) investigate the convergent and discriminant validity, internal

consistency, and test-retest reliability of the Canadian English version of the Computer-Based

instrument for Low motor Language Testing (C-BiLLT-CAN), and 2) to explore feasibility of

the C-BiLLT assessment for children with cerebral palsy (CP) and complex communication

needs in the Canadian health care context.

Methods: Eighty typically developing children between 1.5 and 8.5 years of age completed

the C-BiLLT-CAN, the Peabody Picture Vocabulary Test-IV (PPVT-4), the receptive

language sub-test of the New Reynell Developmental Language Scales (NRDLS), and/or the

Raven's 2. Correlations between raw scores were calculated for estimates of convergent and

discriminant validity. Internal consistency was calculated for all items, and separately for

items pertaining to vocabulary and grammar. To calculate the standard error of measurement

(SEM) and intraclass correlation coefficient (ICC), 33 participants were re-tested with the C-

BiLLT within three weeks. Feasibility was explored with nine participants with CP.

Results: C-BiLLT-CAN's convergent validity was good to excellent (Spearman's rho >0.78)

and discriminant validity was higher than hypothesized (Spearman's rho >0.8). Internal

consistency (Cronbach's alpha .96), test-retest reliability (ICC >0.9), and measurement error

(SEM <5%) were excellent. Preliminary data demonstrated some technical and practical

barriers for using the C-BiLLT in children with CP in Canada.

Conclusion: The C-BiLLT-CAN demonstrates good to excellent psychometric properties in a

sample of typically developing children, indicating it is an adequate test for measuring

language comprehension in English-speaking Canadian children.

Introduction

Cerebral palsy (CP) is caused by a disturbance of posture and movement due to a non-progressive brain lesion acquired during early brain development (Rosenbaum et al., 2007). It affects approximately 1 in 500 live births, and due to population growth and increased life expectancy, the number of Canadians living with CP is expected to increase in the coming decades (Amankwah et al., 2020; Oskoui et al., 2013). Considerable variation in motor, cognitive, perceptual and communicative functioning exists in children who share this diagnosis (Andersen et al., 2008; Krägeloh-Mann et al., 2007; Rosenbaum et al., 2007; Stadskleiv, 2020). Approximately 16% of children born with CP have extremely limited motor function (Hollung et al., 2018), restricting mobility and speech considerably (Nordberg et al., 2013). CP puts children at risk for intellectual disability and/or specific cognitive impairments, and therefore, timely and frequent assessment of functioning across all developmental domains is warranted (Schiariti et al., 2018; Wright & Majnemer, 2014). With regards to cognitive and language functioning, however, many children with CP are excluded from assessments (Smits et al., 2011; Stadskleiv et al., 2018) because of the verbal and motor responses that standard assessment instruments require (Geytenbeek et al., 2010; Sherwell et al., 2014). While there is growing evidence that the adaptation of response modes (e.g. gaze pointing instead of finger pointing) yields reliable results (Ballester-Plané et al., 2016; Fiske et al., 2020; Spillane et al., 1996; Stadskleiv et al., 2018; Visser et al., 2013), these access methods are rarely incorporated, with serious consequences for research and practice.

In research studies investigating cognitive functioning in children with CP, those with complex communication needs are often either excluded from the sample (Ashwal et al., 2004; Hutton et al., 2002; Majnemer et al., 2010; Sherlock et al., 2005), or their abilities are judged based on clinical observation instead of standardized assessment (Andersen et al., 2008). This paints an incomplete or inaccurate picture of cognitive functioning in this group

of children. While correlations exist between severity of motor and cognitive impairments, there is no absolute correspondence (Sigurdardottir et al., 2008; Stadskleiv, 2020) and average to gifted cognitive functioning is present across the entire spectrum of motor and speech functioning (Sigurdardottir et al., 2008; Stadskleiv et al., 2018). The same is true for the development of language comprehension abilities, which may develop typically even if speech is absent (Geytenbeek et al., 2015).

This implies that children's language comprehension (particularly morphology and syntax) must be accurately assessed so interventions can be tailored to incorporate the individual child's strengths and address their specific communication challenges (Romski & Sevcik, 2005; Theodorou & Pampoulou, 2020). However, for children with severe CP, decisions are often made based on observations and clinical judgements (Andersen et al., 2010), which can result in under- or overestimating language comprehension, causing children to receive services that do not help them to reach their full communicative potential.

Originally developed and validated in the Netherlands, the Computer-Based instrument for Low-motor language Testing (C-BiLLT) was designed to overcome the challenges associated with testing children with CP who have low motor and speech function (Geytenbeek et al., 2014). Its validity and reliability were assessed in samples of 806 typically developing Dutch children and 87 children with CP and complex communication needs (aged 1;6-12 years old). In the group of children with CP, mean C-BiLLT scores varied widely across the different age groups, but overall the validity hypotheses and reliability parameters were excellent (Geytenbeek et al., 2014).

The current study is part of a larger project examining the cross-cultural validation of the Canadian C-BiLLT (C-BiLLT-CAN), which consisted of the following phases: 1) translation and cultural adaptation of the test, 2) psychometric testing in a sample of typically developing children, and 3) estimating the feasibility of the C-BiLLT-CAN in children with

CP and complex communication needs. Phase one was completed prior to the psychometric and feasibility testing according to the guidelines for translating and adapting psychological tests from the International Test Commission (Hambleton et al., 2004) and included three steps: (a) forward translation Dutch to English; (b) analysis of content and equivalence of the adapted version by experts and discussion in interdisciplinary group meetings; (c) initial pilot testing of the face-validity with Canadian children. The outcome of phase 1 was the C-BiLLT-CAN that could be used for further testing for its psychometric properties. This paper reports results from phases two and three.

Methods

A cross-sectional design was used to estimate validity properties, and a test-retest design was used to estimate the test-retest reliability of the C-BiLLT-CAN in a sample of typically developing children. Feasibility of the Canadian C-BiLLT was explored using a cross-sectional sample of children with CP.

Ethics

The study protocol received ethics approval from the Hamilton Integrated Research Ethics Board #5152 at McMaster University. Ethical approval to recruit through the Hamilton-Wentworth Catholic District School Board was also received. Parents of all participants provided written informed consent. Participants older than 7 years provided written assent.

Participants

Participants for the validation study were recruited via flyers, social media and through day care centres and schools in Hamilton, ON, Canada. Between January 2019 and March, 2020, all assessments took place in-person at McMaster University. Due to the COVID-19

pandemic, the protocol was adapted to allow for virtual assessments via Zoom, which took place between July and November, 2020. By adding the option to conduct virtual assessments, recruitment could be broadened to allow assessment from across Canada.

Children were eligible for this study if they: (1) were between 1.5 and 8.5 years of age; (2) spoke English; and (3) had at least one parent/caregiver who spoke English as their first language. Participants were excluded from the study if they had: (1) a history of speech and/or language delay or disorder; (2) a history of auditory and/or visual impairment; (3) a developmental delay or disorder; and/or (4) a neurological or chronic disorder. Data from one participant in the lowest age group were removed because the participant obtained a score of zero, due to distractibility. The sample of typically developing children thus was comprised of 80 children (Table 1). The majority of participants were assessed in-person (n=50, 62.5%).

Participants for the feasibility study were recruited through clinics at Hamilton Health Sciences. Children were eligible to participate if they were between 1;6 – 16;0 years of age, had a diagnosis of CP, had no functional speech, and were classified as level III-V on the Gross Motor Functioning Classification System (GMFCS). At the start of the COVID-19 pandemic, data collection was abruptly discontinued because of the need for in-person assessments with these participants. The final sample therefore included nine children with CP (Table 1).

Table 1. Demographic data of the sample.

	TD ($N = 80$)	CP ($N = 9$)
Sex		
Female	45	5
Male	35	4
GMFCS level		

III		n/a	1
IV		n/a	2
V		n/a	6
Language exposure			
	English only	43	4
	English & French	14	1
	English & other	11	3
	≥ 3 languages	12	1
Annual household income			
	≤ 49.999	6	2
	50.000-99.999	13	2
	100.000-149.999	23	1
	≥ 150.000	34	2
	Don't know	0	2
	Prefer not to answer	4	0

Notes: GMFCS, Gross Motor Functioning Classification System; TD, typically developing; CP; cerebral palsy

Measures

     Use of the different measures depended on the eligible ages for the additional tests, and the type of study visit. Therefore, sample sizes for the different analyses varied (Table 2).

Table 2. Sample characteristics for the different analyses.

Analysis	# of participants (Female)	Age (years;months) min-max
Internal Consistency	80 (45)	1;6 – 8;6
Test-retest reliability and SEM	33 (19)	1;9 – 8;6
Convergent validity		
NRDLS	41 (24)	2;1 – 7;5
PPVT-4	70 (44)	2;6 – 8;6
Discriminant validity		
Raven's 2	33 (20)	4;1 – 8;6
Feasibility	9 (5)	3;2 – 10;6

Notes: NRDLS, New Reynells Developmental Language Test; and PPVT, Peabody Picture Vocabulary Test – 4th edition. SEM, standard error of measurement.

C-BiLLT

The Computer-Based instrument for Low-motor Language Testing (C-BiLLT) is an 88-item test that assesses a child's understanding of spoken language, with a higher score indicating better language comprehension (Geytenbeek et al., 2014). The C-BiLLT consists of web-based software that can be combined with several different access methods. Access methods using direct selection include a touch screen, and eye gaze computer control. Indirect selection methods include input switches and partner assisted scanning. Administration of the C-BiLLT follows three parts: a pre-test on which the child is first asked to identify concrete familiar objects held up by the assessor in sets of two, and then identify the same objects presented as photographs. The next two parts are the computer-based components of the assessment, which test vocabulary, morphology, and syntax by asking the participant to select the picture from a choice of 2-4 that matches the item orally presented by the examiner (e.g., which one is the …).

Measurement properties of the Dutch and Norwegian C-BiLLT (C-BiLLT-NOR) show good construct validity, excellent internal consistency, and optimal reliability in samples of typically developing children, and in Dutch children with CP (Fiske et al., 2020; Geytenbeek et al., 2014). For the Dutch C-BiLLT, exploratory factor analysis (EFA) of a former 75-item version resulted in one factor, labelled comprehension of spoken language, explaining 76% of the variance. For the C-BiLLT-NOR, EFA resulted in a two-factor solution (receptive vocabulary and receptive grammar) that explained 68.6% and 16.6% of the variance in the data, respectively.

The Dutch C-BiLLT was translated into English and adapted for use in Canada. To ensure the instrument would measure the same phenomenon in the target language and culture (*i.e.* was equivalent to the original measure) a careful and thorough cross-cultural adaptation process was completed (Sousa & Rojjanasrirat, 2011). Guidelines provided by the International Test Commission (International Test Commission, 2017) were followed during the translation process.

Peabody Picture Vocabulary Test – 4th edition (PPVT-4)

The PPVT-4 (Dunn, L. M., Dunn, D. M., Lenhard, A., Lenhard, W., & Suggate, 2015) is a widely used untimed instrument to measure single word receptive vocabulary in individuals aged 2.5 to 90+ years. The examiner orally presents a word and the participant is asked to identify the corresponding picture from a choice of four pictures. For the online study visits, the digital version of the PPVT-4 was used with participants of eligible age.

New Reynell Developmental Language Scales (NRDLS)

The NRDLS (Edwards et al., 2011) is a clinical instrument designed to measure comprehension and production of spoken language in children aged 3 to 7.5 years. It is

comprised of ten subtests, of which eight (also) measure comprehension. In the present study, these eight subtests were administered to participants of eligible age. The test uses both toys and a picture booklet to elicit responses. There is no digital version of the NRDLS, so this test was not administered during online study visits.

Raven's 2

The Raven's 2 (Raven, 2018) assesses non-verbal reasoning in individuals aged 4-90 years. It consists of visual geometric designs of increasing difficulty, each with a missing piece. The participants over the age of 4 years were asked to identify the missing piece from a choice of five options. For the online study visits, the digital version of the Raven's 2 was used. However, only scores obtained during in-person study visits could be included, as the digital version did not yield raw scores.

Procedure

To avoid a learning effect, test sessions started with the C-BiLLT-CAN for all participants. Depending on their age, participants were administered one to three additional measures. Following the C-BiLLT-CAN, measures were presented in two different test orders, to which participants were randomly assigned. Parents could be present during the study visit. Participants received a junior scientist certificate and a $20 gift card for their participation. Thirty-three participants were retested with the C-BiLLT-CAN within 3 weeks of the original test date. Participants with CP were assessed with the C-BiLLT-CAN, and if time permitted and a reliable response (e.g., by pointing) was achievable, also with the PPVT-4.

Examiners

Examiners for the assessments of typically developing children were speech-language pathology graduate students from McMaster University ($n = 10$), who were trained in the administration of standardized language tests and received a minimum of two hours of additional training on the specific tests included in this study. The assessments of children with CP were done by an experienced speech-language pathologist familiar with Augmentative and Alternative Communication (initials co-author).

Assessment of measurement properties

Validity is defined as "the degree to which an instrument truly measures the construct(s) it purports to measure" (De Vet et al., 2011). The C-BiLLT attempts to measure an individual's comprehension of spoken language, from single word vocabulary to complex compound sentences. Because of cognitive and linguistic growth in typically developing children, a significant positive linear trend for age and C-BiLLT-CAN scores was hypothesized. Hypotheses for convergent and discriminant validity were based on the Dutch validation study (Geytenbeek et al., 2014). Expected were: a high correlation (*i.e.,* ≥ 0.8) between the C-BiLLT-CAN and the NRDLS, that aims to measure the same construct, and a slightly lower correlation (*i.e.* 0.6-0.7) between scores on the C-BiLLT-CAN and the PPVT-4, a measure of receptive vocabulary. Discriminant validity was assessed using the Raven's 2, a measure of non-verbal reasoning. A correlation of 0.6 between scores on the C-BiLLT-CAN and the Raven's 2 was hypothesized.

For a measure to be useful it must demonstrate sufficient absolute and relative reliability (De Vet et al., 2006). Relative reliability refers to the degree to which a measure is free from error and remains consistent across administrations, and is expressed in the intraclass correlation coefficient (ICC) (De Vet et al., 2011). Absolute reliability, expressed in the standard error of measurement (SEM), refers to the systematic and random error of a

measure that is not attributable to true change (De Vet et al., 2011). SEM is expressed in the same units as the original measurement and represents the confidence interval around a single measurement. This study estimates the relative reliability and absolute measurement error of the C-BiLLT-CAN in typically developing children by retesting participants within three weeks of the first assessment, under the assumption that their level of language comprehension would remain stable over this period. A test-retest reliability (i.e., an ICC of $\geq$ 0.8) was expected, but an ICC of $\geq$ 0.6 would be acceptable. A SEM <10% was considered an acceptably small measurement error.

Statistical analyses

Data were assessed for normality by visual inspection of QQ-plots and tests of skewness and kurtosis. In many age groups there was moderate skewness and kurtosis, in some age groups (e.g., 5;6 – 5;11 and 6;6 – 6;11) they were high.

Because of these distributions and the small sample sizes per age group, non-parametric measures were deemed more appropriate. Therefore, Spearman's rho was used to assess validity, and the Jonckheere-Terpstra test was performed to assess the hypothesized trend between increasing age and C-BiLLT-CAN scores. For validity hypothesis testing, one-tailed tests set to a 0.1 significance level were performed and 99% lower bound estimates were based on Bonett and Wright (Bonett et al., 2000). Because of the two-factor solution that was found in the Norwegian C-BiLLT, Cronbach's alpha was calculated for items pertaining to grammar and vocabulary separately. The intraclass correlation coefficient (ICC) was calculated using a two-way random effects model with absolute agreement. Absolute reliability was calculated as SD-$\sqrt{(1-ICC)}$. All statistical analyses were performed using SPSS version 26.

Results

Participant sample sizes and sex distribution for the different analyses are presented in Table 2. Mann-Whitney U tests showed that the distribution of C-BiLLT-CAN scores did not significantly differ between males (*Mdn* = 72) and females *(Mdn* = 72), *U* = 730, *z* = -.558, *p* = 0.577,* nor was there a difference between scores for children who participated in virtual (*Mdn* = 73) versus in-person study visits *(Mdn* = 71.5), *U* = 776.5, *z* = .264, *p* = 0.792.

The sample performed substantially above the population mean on the PPVT-4, mean (SD) Z-score = 1 (0.83). On the NRDLS and the Raven's 2, the sample obtained a mean (SD) Z-score of 0.53 (0.89), and 0.13 (1.38), respectively.

Table 3 shows the distribution of C-BiLLT-CAN scores per age group. A Jonckheere-Terpstra Test determined that there was a statistically significant increasing monotonic trend in C-BiLLT-CAN scores, p < 0.0005, Kendall's τ_b = .751.

Table 3. Median, minimum, maximum, mean (M) with 95% confidence intervals (CI), standard deviation (SD), skewness, and kurtosis per age group of raw scores on the C-BiLLT-CAN.

Age group[a]	*n*	Median (min-max)	M(SD)	95% CI for mean	Skewness	Kurtosis
1;5- 1;11	4	41.5 (37-43)	40.8(2.9)	36.3 - 45.3	-0.86	-1.29
2;0 - 2;5	6	44 (26-70)	46.2(13.5)	31.0 – 61.4	0.53	1.56
2;6 - 2;11	5	60 (52-65)	58.6(5.1)	52.2 – 65.0	-0.17	-1.17
3;0 - 3;5	8	62 (47-67)	60.3(7.2)	54.3 – 66.3	-0.92	0.12
3;6 - 3;11	5	68 (64-73)	67.8(3.6)	63.4 – 72.2	0.60	-0.23
4;0 - 4;5	5	70 (64-74)	69.4(3.7)	64.8 – 74.0	-0.48	0.59
4;6 - 4;11	7	72 (64-78)	70.6(4.4)	66.5 – 74.7	0.27	0.67

5;0 - 5;5	5	73 (71-82)	74.8(4.4)	69.3 – 80.3	1.39	1.58
5;6 - 5;11	5	75 (67-79)	74.6(4.7)	68.7 – 80.5	-1.25	1.66
6;0 - 6;5	8	76.5 (71-81)	75.1(3.4)	73.3 – 79.0	-0.29	-0.72
6;6 - 6;11	6	81 (71-83)	79.7(4.6)	74.9 – 84.4	-1.80	3.45
7;0 - 7;5	5	82 (78-83)	81.2(2.3)	78.5 – 83.9	-0.91	-0.74
7;6 - 7;11	5	76 (74-80)	76.8(3.0)	73.0 – 80.6	0.32	-3.08
8;0 - 8;5	6	82.5 (80-86)	82.7(2.3)	80.4 – 84.9	0.46	-0.30

Notes: CI, confidence interval; [a]Years;months

Convergent and discriminant validity

To estimate convergent and discriminant validity, one-tailed Spearman's rank-order correlations were run to assess the relationship between scores on the C-BiLLT-CAN, NRDLS, PPVT-4 and Raven's 2 (Table 4).

Table 4. Spearman's rho correlations (99% lower confidence bound) of raw scores on the C-BiLLT-CAN, NRDLS, PPVT-4, and Raven's 2.

	NRDLS	PPVT-4	Raven's 2
C-BiLLT-CAN	0.780* (0.451)	0.845* (0.630)	0.871* (0.604)
NRDLS		0.627* (0.292)	0.681* (0.257)
PPVT-4			0.747* (0.359)

Notes: C-BiLLT-CAN, Computer Based instrument for Low-motor Language Testing-Canada; NRDLS, New Reynells Developmental Language Test; and PPVT, Peabody Picture Vocabulary Test – 4th edition

*p < .001

Internal consistency

Cronbach's alpha of the C-BiLLT-CAN was calculated for all 88 items (0.960), and separately for the 34 vocabulary items (0.875) and the items pertaining to morphology and syntax (0.948).

Test-retest reliability and SEM

Thirty-three participants were retested with the C-BiLLT-CAN within approximately 3 weeks of their first test (range 5-26 days, mean: 14 days). Mean score at baseline was 68.9 (*SD*=13), and mean score at the retest was 75.8 (*SD*=10). ICC was .96 (95% CI .88-.98), which indicates excellent reliability (Portney & Watkins, 2009), and a SEM of 2.3 points, which is <5% of the possible total score of 88.

Feasibility

The C-BiLLT-CAN could be fully completed for four out of nine participants with CP (three within a single session), and partially completed for the other five. For two, a second session was required, but could not be scheduled due to COVID restrictions, and for one participant a reliable access method for the computer-based parts of the assessment could not be determined. For the two remaining participants with whom the assessment could not be completed in one or two sessions, a second or third session was deemed too burdensome and was therefore not scheduled.

The nine participants used several different access methods including: touch screen (*n*=3), eye tracking technology (*n*=1), switch buttons (*n*=2), finger, eye and/or body part pointing with target selection confirmed by examiner (*n*=3), head mouse with target selection confirmed by examiner (*n*=1). Two participants used more than one access method to complete the C-BiLLT: one switched from touch screen to pointing with target selection confirmed by the examiner after fatiguing, and one participant started with eye gaze, then

used the switch button, and ended with pointing with target selection confirmed by the examiner.

Discussion

This study estimated construct validity, internal consistency, test-retest reliability, and measurement error of the C-BiLLT-CAN in a sample of typically developing Canadian children. Feasibility of the instrument in the Canadian context was explored in a small sample of children with CP and complex communication needs.

The hypotheses about construct validity were partially confirmed. Convergent validity was excellent between the C-BiLLT-CAN and the NRDLS, indicating the test can be regarded as a valid measure of language comprehension. The higher than expected correlations between the C-BiLLT-CAN and PPVT-4 (vocabulary) may be explained by the age of the sample. In young children, cognitive abilities are less well differentiated and do not develop in isolation (Karmiloff-Smith, 2009; Tideman & Gustafsson, 2004). Comprehension of vocabulary and sentences can best be characterized as a single construct in young (pre-kindergarten to grade 3) typically developing children (Farquharson & Murphy, 2016; Justice et al., 2018). This could also explain the high correlation between scores on the Raven's (non-verbal reasoning) and the C-BiLLT. Furthermore, because of the small sample size (*i.e*., only scores of participants who completed the paper version of the Raven's 2 could be used, n = 33), this analysis may have been underpowered (Portney & Watkins, 2009).

The sufficiently high test-retest reliability indicates that the C-BiLLT-CAN results are consistent for participants whose abilities have not changed over time. The C-BiLLT-CAN's good internal validity indicates that the different test items measured the same construct in the sample.

The findings of the feasibility study are limited because of the need to abruptly terminate this project due to COVID-19 restrictions in 2020. However, the data that were collected do suggest the need to carefully consider the local context when 'moving' an assessment instrument from one language, culture, and country to another. While health care services may be comparable between Canada and The Netherlands, the geographical (and thus travel times to clinics), organizational, and clinical differences are large. As an example of a geographical consideration: Assessments in this trial were done at one clinic, which meant many child participants had to travel for hours. This may have caused fatigue to the extent that the assessment had to be done in two sessions, or could not be completed at all. In the Netherlands, many of the children with CP were assessed in their own schools or day care centres, which was feasible for administrators because of the short distances. An example of a clinical practice difference is that the head mouse is a popular access method in Canada. This feature is not yet part of the C-BiLLT's access repertoire as head mouse access is prescribed much less frequently in The Netherlands. To promote the uptake and use in clinical practice of the C-BiLLT-CAN, the team has proposed an implementation study to explore the factors that will support or hinder effective use of the test in Canadian clinical practice.

There are several strengths of the current study. *A priori* levels of acceptable and desired construct validity and test-retest reliability were provided upon which to base the interpretations. In response to the COVID-19 pandemic, the project was quickly adapted to virtual data collection, which allowed for completion of most of the project as intended. This study also has some major limitations. The validity of an assessment tool should be estimated if the tool is applied in a new situation or for another purpose (De Vet et al., 2011). Here, the new situation was the new language and cultural adaptation of the C-BiLLT. To test if this new version measured what it purports to measure, the C-BiLLT CAN was validated on a sample of 80 typically developing English speaking Canadian children. In the adaptation

process, care was taken to select items and images that were present in the world of Canadian children with CP and complex communication needs, to ensure that the items would be familiar to them. However, it is important to recognize that validity of the C-BiLLT CAN in the population of children with CP and complex communication needs has not yet been assessed directly. It should be noted however that this will be evaluated by this team as part of a recently funded study and that we feel reassured by the validity parameters for the original Dutch C-BiLLT with a sample of 87 children with CP and complex communication needs. The said four-year research project commences in 2022 and aims to (1) understand Canadian clinicians' and families' perceived barriers and facilitators to using the C-BiLLT, and how they would use results to inform service delivery and education plans; (2) modify and test the C-BiLLT's accessibility with Canadian children to ensure all children have access to a reliable assessment of their language comprehension; and (3) develop and pilot training materials, and methods to support implementation in Canada.

The same limitation is present for the assessment of the C-BiLLT's reliability. Reliability of an instrument depends highly on the distribution of the characteristic (i.e., language comprehension) in the population (i.e., children with CP). It is possible that language comprehension abilities are distributed differently in a population of typically developing children, and that therefore the reported reliability of the C-BiLLT CAN in this study may differ if tested in a sample of children with CP. Future research will also assess reliability of the C-BiLLT CAN in a sample that reflects the test's target population.

Despite efforts to recruit a balanced sample, the typically developing participant group had above average cognitive functioning, potentially limiting the generalizability of the findings. Furthermore, it is unfortunate that the assessments for children with CP could not be adapted in response to the pandemic. The necessary health safety precautions and in person guidance during the assessments with these participants could no longer be provided in

accordance with the COVID-19 regulations. As part of the proposed implementation study, local pediatric therapists will be trained to collect data by administering the test to children on their caseloads. This could circumvent the children's exposure to unknown clinicians and extra study visits. Additionally, feasibility of the C-BiLLT-CAN was evaluated in children with CP older than 3 years. Because of the cognitive challenges associated with indirect access (e.g., attention, timing) it is important that future studies will look at younger children with CP as well.

This study's findings add to the accumulating evidence and need of translated and adapted versions of the C-BiLLT instrument, and are highly anticipated by scientific, clinical, and family stakeholders (Molinaro et al., 2022; Morgan, 2015; personal communication).

The assessment of measurement invariance of the different versions of the C-BiLLT by confirmatory factor analysis or using item response theory techniques is a logical next step for psychometric testing. Knowing the different versions of the C-BiLLT function similarly would allow for interesting international comparisons. Results from the feasibility study also call for explicit consideration of the context in which testing is meant to happen, so while there is scientific and clinical evidence of the validity and reliability of the C-BiLLT in Dutch, Norwegian and now Canadian children with CP, further research is needed to examine its validity and reliability among children with complex communication needs from different language and cultural backgrounds.

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Appendix 1: Summary of changes Amendment May 15 – 2020

Chapter 4: Cross-language implementation research of the C-BiLLT

4.1 Introduction

The aim of the second part of this thesis was to develop a contextualized understanding of the implementation of the C-BiLLT in the Netherlands and Norway. The body of Chapter 5 comprises the manuscript of a survey study among 90 clinicians from both countries. Chapter 6 contains the interview study that was conducted with 15 clinicians, 9 from the Netherlands, and 6 from Norway. Both studies are examples of cross-language research, because of the language differences between the researchers and the participants. Cross-language research refers to research studies where a language barrier is present, and where interpreters or translators are involved to reduce these barriers (Temple, 2002). Cross-language research brings unique challenges to the research process. This introduction describes how the language barriers in these research projects were addressed.

The Netherlands and Norway have a published version of the C-BiLLT in their official languages, respectively Dutch and Norwegian. According to the 2021 English Proficiency Index the Netherlands ranks first, and Norway ranks fifth in the English-speaking proficiency of the general population (Education First, 2021). This implies that we probably could have used an English language survey and interview guide for all respondents. However, we wanted to allow them to express themselves in their primary language. We reasoned that respondents would feel more comfortable answering questions in their most accessible language (and that this could be a decisive factor for their participation), and that it would yield the richest data, minimizing potential semantic losses (Premji et al., 2020). That is the reason why we wanted to bring together an international team of researchers to complete these projects.

4.2 Language situation of the research team

The languages that were involved in the two projects were Dutch, English, and Norwegian. In the research team, all members had one of those three languages as their primary language. Those members whose primary language was Dutch ($n = 3$) or Norwegian ($n = 2$) spoke English at a near-native level. To further specify, four levels of language competence can be considered in the context of translation. For research purposes, translators must possess at least sociolinguistic competence in the second language (Squires, 2008). Sociolinguistic competence is the term for a non-native speaker who integrates understanding of cultural norms into communication processes, and whose oral and written communication functions on a sophisticated level. They are able to express and negotiate the meaning of words and phrases according to the culture using the language (Savignon, 1976). The language used for the communication in the research team (e.g., in research meetings, shared documents, and e-mail conversations) was English. When the Dutch and Norwegian researchers worked in mono-lingual teams, their communication happened in their primary languages.

4.3 Language situation during the study design phase

The survey and interview projects were part of the doctoral studies of the first author (JB), which are completed at McMaster University in Hamilton, Canada, which is an English language institution. The projects were supervised by BJ Cunningham, an associate professor at Western University in London, Canada, which is an English language institution as well. The grant application to fund the research was written in English and submitted to CanChild, an English language research centre at McMaster University.

While the projects were coordinated out of Western University, the interviews were conducted by two team members (JB, Dutch-speaking, and SF, Norwegian-speaking) in the Netherlands and Norway, respectively. Ethical approval was sought from the Office of Human Research Ethics at Western University, which was done in English. The necessity for additional ethical approval was checked in the Netherlands and Norway countries, which was done in Dutch and Norwegian, respectively. After a consultation with the Dutch Central Committee on Research Involving Human Subjects, no additional ethical approval was required for the research studies in the Netherlands (J. Bootsma, personal communication, December 15, 2020). However, the Norwegian Centre for Research Data did need to evaluate the study. This meant that all necessary documents regarding the projects needed to be translated and adapted to the Norwegian context for approval.

4.4 Language of study materials

Materials for this study, including participant communication (e.g., recruitment materials and instructions on the completion of the survey), the survey, and the interview guides were conceptualized in English. The materials for participant communication were created by determining the necessary content together as a research team, and then the actual e-mails and survey instructions were developed in the target languages.

Hiring professional translators was not feasible because of the modest project budget. Therefore, the survey and interview guide were created with English as the source language and then translated to Dutch and Norwegian by the team members. The survey contained many items that could be translated in a straightforward way, like questions about when the respondent had participated in the training and how often they administered the C-BiLLT. Some items required cultural adaptation, because of the way the healthcare system works in

the respective countries. Some practice settings where the C-BiLLT is used in Norway do not exist in the Netherlands, for instance. These adaptations were discussed in research team meetings. This often meant that the team members not only had to explain to the rest of the group the meaning of certain words, but also their countries' healthcare infrastructure.

Pilot testing of a translated version of study materials is considered best practice in the field of cross-language research to make sure the translation function (Squires, 2008; Temple, 2002).The Dutch and Norwegian surveys were pilot-tested in the two target languages by two researchers who were not involved in this project, but who knew the C-BiLLT. The survey also included three short tools to measure an intervention's acceptability, appropriateness, and feasibility (Weiner et al., 2017). Fortunately, these English measures were already validated in both target languages and available for us to use (Engell et al., 2018; Simon et al., n.d.). The interview guide for the semi-structured interviews was created following the same route as used for the surveys.

4.5 Language situation during data collection and analysis

The survey could be accessed by the respondents through RedCap (Harris et al., 2019), an electronic survey tool hosted at Western University. Most of the survey items were (multiple choice) closed-ended questions, but there were also a couple of open-ended questions included. The responses to the closed-ended questions could be managed easily by a monolingual English research assistant (NC). The responses to the open-ended questions were translated to English by the Norwegian and Dutch team members. In some cases, more explanation was needed for the research team to be able to interpret the translated responses. These discussions highlighted the value of team effort in cross-language research.

At the end of the survey, respondents were asked if they were willing to participate in the interview study. Willing and eligible respondents were contacted via e-mail in their own language by the two team members who would also conduct the interviews. Interviews took place over Zoom. They were recorded and transcribed verbatim. Interview transcripts were translated into English. These English versions were then analysed following the process outlined in the study's main manuscript: in two rounds. In the first round of deductive coding, a codebook was developed based on the COM-B model of behaviour change. Coding was done by the (Dutch) lead author, and an English-speaking research assistant. In the second, abductive, round of analysis, the researchers moved back and forth between the theory and the data. In this phase, the Dutch and the Norwegian team members who conducted the interviews would take a step back from the coded English data from the first round, to analyse the language's dataset (i.e., all interviews in that language) as a whole. This practice allowed the team members to integrate the culturally informed conceptualizations of the contextual meaning of the participant's words. It brought back the nuance to the analysis that had somewhat disappeared from the data in the first round of analysis, for instance about the way healthcare is structured in the Netherlands and Norway. The research team met at least monthly to discuss the ongoing analysis and to clarify any issues.

The approach we took to overcome the challenges in cross-language research allowed for a broader perspective on the implementation of the C-BiLLT. It led to a more contextualized understanding of the influencing factors, which will be beneficial to future implementation efforts.

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Chapter 5: C-BiLLT use in practice: An international survey among BiLLT users

5.1 Introduction

Chapter 5 addresses the second objective of this thesis: to assess the C-BiLLT's current implementation status. To date, the explicit use of theories and frameworks is still largely lacking in implementation science in Speech-Language Pathology (Douglas et al., 2022; O'Connor, 2020). In our research about the unique implementation characteristics of the C-BiLLT, we wanted to make sure that our study would add to the implementation science literature in general by grounding it in theory. Therefore, the body of this chapter, the C-BiLLT survey study, was informed by the knowledge to action framework (KTA; Graham et al., 2006), which was intended to 'address the need for conceptual clarity in the KTA field and to offer a framework to help elucidate what we believe to be the key elements of the KTA process' (Graham et al., 2006, p. 14).

5.2 Implementation of the C-BiLLT, an accessible instrument to assess language comprehension in children with limited motor and speech function: an international clinician survey

Bootsma, J.N., Stadskleiv, K., Phoenix, M., Geytenbeek, J.J.M., Gorter, J.W., McCauley, D., Fiske, S., Campbell, F., Crews, N., Cunningham, B.J. (2021)

Implementation of the C-BiLLT, an accessible instrument to assess language comprehension

in children with limited motor and speech function: an international clinician survey

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Abstract

This study assessed implementation of the Computer-based Instrument for Low-motor

Language Testing (C-BiLLT). The C-BiLLT is an accessible language comprehension

assessment tool originally developed for children with cerebral palsy and complex

communication needs (i.e., those with significant motor and speech impairments). An online

survey was distributed to rehabilitation clinicians working in the Netherlands, Belgium, and

Norway via email. Participants reported their professional background and their use of the C-

BiLLT. They also assessed acceptability, appropriateness, and feasibility of the C-BiLLT, and

reported their perceived barriers and facilitators to using it. There were 309 invitations sent

and complete responses were received from 90 clinicians. The C-BiLLT was used most often

with children with cerebral palsy, and those under 12 years of age, but it was also used with

various other populations and age groups, including with children who did not have motor or

speech impairments. Acceptability, appropriateness, and feasibility were rated highly. The

main implementation facilitator was clinicians' high motivation, and the main barriers were

related the required resources and complex cases. Findings suggest implementation of new

assessment tools is an ongoing process that should be monitored following initial trainings to understand the clinical context in which a tool is being used. Identified barriers and facilitators can be used to further support the use of new assessment tools in practice.

Keywords: Cerebral palsy; Computer-based instrument for Low motor Language Testing; evidence-based assessment; implementation; speech-language pathology

Introduction

Cerebral palsy is the most common cause of childhood-onset physical disability worldwide (Oskoui et al., 2013). Children with cerebral palsy are at high risk of having communication disorders, which can be due to motor, sensory, language, and cognitive impairments associated with cerebral palsy (Mei et al., 2016; Pennington et al., 2004; Rosenbaum et al., 2007). Language impairments affecting comprehension of vocabulary and grammar are found in children with cerebral palsy across the entire spectrum of motor functioning (Pirila et al, 2007; Stadskleiv et al., 2018; Vaillant et al., 2020; Voorman et al., 2009; Vos et al., 2014). Motor speech disorders are also common and lead to reduced intelligibility or even the absence of functional speech (Andersen et al., 2010; Hustad et al., 2014; Sigurdardottir & Vik, 2011). Such communication impairments often have a pervasive and detrimental impact on children's social, educational, and emotional well-being and development (Clarke et al, 2011, 2012; Raghavendra et al., 2012). There are many other neurodevelopmental disorders that also commonly have associated communication disorders where motor and/or speech skills are affected, including but not limited to autism spectrum disorder and Down syndrome. In children with cerebral palsy, gross motor function is typically described using the Gross Motor Function Classification Scale (GMFCS; Palisano et al., 1997), a classification tool that categorizes children's motor function into one of five levels (I-III able to move independently, IV-V, need assistance or powered devices). Children's communicative function is often described using the parallel Communication Function Classification Scale (CFCS, Hidecker et al., 2011), on which children in levels I-III function best and those in levels IV-V function least well in terms of their communication. In many cases where both motor and speech skills are impacted, children have complex communication needs and require augmentative and alternative communication (AAC).

AAC interventions should be used for children with cerebral palsy who have complex communication needs to give them access to more expressive language, which, in turn, supports more effective and efficient communication (Branson & Demchak, 2009, Romski et al., 2015). Depending on the child's needs, AAC may be something simple like choosing an activity by indicating one of two graphic symbols, but it can also be something very complex such as a high-tech speech-generating device with thousands of graphic symbols available and operated by eye-tracking software. There is substantial evidence that AAC interventions tailored to children's individual needs enable critical communication skills such as turn-taking, requesting, commenting, and narrating (Branson & Demchak, 2009; Machalicek et al., 2010). Furthermore, AAC can expand children's expressive vocabularies and enable them to learn to read and write (Barker et al., 2013; Sennott et al., 2016; Solomon-Rice & Soto, 2014). High tech AAC devices may also be used to support children's development in displaced talk (i.e., communication about something outside the here and now), which could for instance be done by using the device to take a photo of something to talk about it later (Light et al., 2019). In addition to supporting children's expressive communication, the augmented and often visual input from AAC methods can support children's understanding of spoken language (Drager et al., 2010).

In order to prescribe appropriate AAC systems, children's language comprehension must be accurately assessed so that interventions can be tailored to incorporate the child's individual strengths and address their specific communication challenges. Ideally, assessment should be done using a multidisciplinary approach so that AAC interventions address both the child's current abilities and future needs (Andersen et al., 2010). If language comprehension is underestimated, the child will receive an AAC system that is too limited, which will not only keep the child from expressing themselves at a level comparable to what they understand but may also hinder their developmental process. On the other hand, if a child's abilities are

overestimated, they will receive a device that is too difficult for them to use. In both cases, the child is unable to achieve their communicative potential, and opportunities for participation and social engagement are restricted.

Assessment with traditional language comprehension measures is challenging for many children with cerebral palsy and complex communication needs, because these tools require the child to speak, point to pictures, or manipulate small objects (Geytenbeek et al., 2010; Stadskleiv, 2020). Such requirements make it difficult for children to complete testing, and as such, clinicians will often rely on informal observation alone rather than incorporating the results of standardized testing when making decisions about AAC (von Tetzchner & Stadskleiv, 2016). This means children with more severe functional limitations are less likely than children with more typical motor functioning to receive a formal standardized assessment of their language comprehension (Smits et al., 2011; Stadskleiv, 2020; Stadskleiv et al., 2018). It may also mean that children receive services that fail to support them in achieving their full communicative potential.

An instrument has been developed to ensure language comprehension can be accurately and reliably assessed in children with cerebral palsy and complex communication needs (i.e., those with limited motor and speech skills): The Computer-Based Instrument for Low-motor Language Testing (C-BiLLT) (Geytenbeek et al., 2014). The C-BiLLT assesses a child's understanding of spoken language, and consists of web-based software that can be combined with several different access methods, both direct and indirect. Current access methods using direct selection include a touch screen and eye gaze computer control. Indirect selection methods include input switches and partner-assisted scanning. The uniqueness and innovation of the C-BiLLT is that children can respond using the access method that suits their needs (e.g., a touch screen operated by any body part such as the hand or nose; input

switch[es] that can be adjusted to any body part; independent eye gaze computer control with an eye control module).

The variety in access methods is intended to allow even children with the most complex needs to reliably and autonomously respond to test items. Administration of the C-BiLLT involves completing three test sections:

1. A pre-test, during which the child is first asked to identify five out of eight concrete familiar objects in sets of two, and then identify the same objects presented as photographs, to assess whether and how the child communicates a choice.

2. Part one of the computer-based test, during which pairs of items are presented visually on a monitor. The child is asked to select the picture that matches the vocabulary item verbally requested by the examiner (e.g., "Where is the …"). Items are presented in sets of two, in three 10-item sections. To deal with the risk of a chance effect, parallel versions of each 10-item section are started if a child answers one item incorrectly.

3. Part two of the computer-based test, during which children are presented with 56 items starting with items at the one-word level and progressing to complex compound sentences. This section tests comprehension of vocabulary, morphology, and syntax. Items are presented on the screen in sets of four. In part two, the test is terminated once the child completes five tasks incorrectly.

Measurement properties of the Dutch and Norwegian C-BiLLT show good construct validity, excellent internal consistency, and excellent reliability in samples of typically developing children, and in Dutch children with cerebral palsy (Fiske et al., 2020; Geytenbeek et al., 2015). The C-BiLLT has been available for use in the Netherlands since 2015 and is part of the Dutch best practice guidelines for pediatric rehabilitation for spastic cerebral palsy (Nederlandse Vereniging van Revalidatieartsen, 2015). A translated and validated version was introduced in Norway in 2019 (Fiske et al., 2020) and validation studies are currently being

conducted in Canada, Sweden, Germany, Romania, and the UK/Ireland. At present, clinicians wanting to use the C-BiLLT must participate in a one- or two-day instructional course through the XXX or XXX (masked). The course is run by C-BiLLT investigators, and clinicians who complete the course are provided with credentials to access the software via a website. The accompanying hardware required to administer the C-BiLLT is purchased separately. Initial efforts to implement the instrument into practice have included dissemination in scientific and clinical journals, conference presentations, and professional trainings. Prior to this study, a formal evaluation of implementation in Europe had not been conducted.

It is critical to understand how the C-BiLLT has been used in clinical practice thus far, as new interventions, procedures, and assessment instruments cannot be effective unless they are implemented well (Proctor et al., 2011; Straus et al., 2013). To be able to interpret the factors that influence C-BiLLT implementation, there is a need to understand its users and their practice contexts (de Veer et al., 2011). Barriers and facilitators to using the C-BiLLT in practice must also be identified so that implementation can be further supported.

The current study was informed by the knowledge to action framework (Graham et al., 2006), which can be used to conceptualize the process of moving new tools into practice. It comprises two distinct but related components: (a) knowledge creation, and (2) the action cycle, which can interact. The publication and validation of the C-BiLLT completed the knowledge creation component of the framework, with training materials being adapted to fit the local (European) context. This study explored the first two phases of the action cycle: adapt knowledge to the local context and assess barriers to knowledge use. Remaining phases (select and tailor interventions, monitor knowledge use, evaluate outcomes, and sustain knowledge use) will be addressed in future implementation work designed based on results from this study.

Recent reviews looking at gaps in knowledge translation suggest that a collaborative approach between researchers and clinicians could increase the acceptance and implementation of new techniques, tools, and practices (Campbell & Douglas, 2017; Olswang & Prelock, 2015). The purpose of the current study was to understand the current clinical contexts in which the C-BiLLT was used and to assess barriers and facilitators to implementation. Therefore, individual clinicians from the Netherlands, Dutch-speaking parts of Belgium, and Norway were asked about their experiences using the C-BiLLT. More specifically, this study aimed to understand clinicians' (a) professional background and training, characteristics of their caseloads, and details about their use of the C-BiLLT, (b) perceptions about the C-BiLLT's appropriateness, acceptability, and feasibility, and (c) perceived barriers and facilitators to C-BiLLT use in clinical practice.

Method

Participants

In the Netherlands and Belgium, clinicians who participated in a C-BiLLT training and obtained certification, and had provided their email addresses for future contact, were invited to complete the survey (n=177). In Norway, 76 clinicians who had participated in a C-BiLLT training and obtained certification were invited to complete the survey. Furthermore, 56 speech-language pathology divisions of Dutch pediatric rehabilitation centers, special education daycare centers, and centers for individuals with developmental disabilities were contacted once by email and asked to circulate the survey among their clinicians. Of the 309 invitations that were issued, 32 were undeliverable (25 to clinicians, seven to centers). A total of 114 clinicians agreed to participate, of whom 90 completed more than 50% of the survey items and were included in this study.

Most survey respondents were female (*n*=87, 97%); the male respondents (*n*=3, 3%) came from Norway; 38 respondents indicated a different practice setting than the ones listed on the survey. See Table 1 for complete demographic details.

Table 1

Professional Background of Respondents who Use the C-BiLLT in Their Practice

	Netherlands	Norway	Full sample
	n	*n*	%
Country and year of training			
2014	6		7
2015	11		12
2016	4		4
2017	10		11
2018	11		12
2019	15	6	23
2020	9	5	16
Do not remember	8	0	9
Did not participate in training	5	0	6
Profession			
SLP	78	1	88
Psychologist	0	4	4
Educator	0	5	6
Other	1	1	2
Practice setting			
Treatment center	33	3	40
Hospital	13	7	22
School	16	1	19
Private practice	6	1	8
Other: Facility for individuals with IDD	20	0	22
Other: Early intervention	3	0	3
Other: National competence center	1	3	1
Other: not defined	0	0	1
Years of work experience			
< 10	13	4	19
> 10	66	7	81

Note. SLP, speech-language pathologist; IDD, intellectual and developmental disability. Some numbers and percentages sum to greater than 100, as clinicians may have chosen more than one answer.

Research Design

An exploratory survey study was used to collect multiple data points at once from a relatively large sample of clinicians. Participation was voluntary and anonymous. Approval for this study was granted by the [masked Research Ethics Board] (ID [masked]).

Survey and Instruments

The online survey was developed specifically for this study to assess clinicians' use of C-BiLLT (Appendix 1). Survey items were developed within the knowledge to action framework (Graham et al., 2006) to understand the local contexts in which the C-BiLLT was being used (i.e., take a snapshot of current practices) and to assess barriers and facilitators to C-BiLLT use. The survey was designed in English, and then translated to Dutch and Norwegian. After pilot-testing with clinical colleagues who had C-BiLLT experience, minor adjustments to the wording of questions were made.

Respondents were first asked six questions about their demographics and C-BiLLT training, and whether they had used the C-BiLLT in practice. Those who had not used the C-BiLLT were asked to explain why and what would need to change in order for them to use it. Those who answered yes were asked closed-ended questions about their experiences (e.g., how often they used the C-BiLLT, what access method(s) they used, how long assessments typically took, and whether they were ever unable to complete administration), open-ended questions about what made it easy and difficult to use the C-BiLLT, and to list up to three things they would like to see changed about the instrument.

Three tools were used to measure acceptability, appropriateness, and feasibility of the C-BiLLT: The Acceptability of Intervention Measure (AIM), Intervention Appropriateness Measure (IAM), and Feasibility of Intervention Measure (FIM; Weiner et al., 2017). The AIM, IAM, and FIM were selected as the constructs of acceptability, appropriateness and feasibility are commonly used in research as indicators of implementation success (Weiner et al., 2017). Each measure has four items, is quick and easy to administer, and freely available. Respondents were asked to rate all items for each measure using a 5-point Likert scale that ranged from 1 (completely disagree) to 5 (completely agree).

Acceptability was defined as the perception that the C-BiLLT was seen as agreeable, palatable, or satisfactory (Proctor et al., 2009; Weiner et al., 2017). Appropriateness was defined as the C-BiLLT's perceived fit, relevance, or compatibility for a given practice setting, provider, or consumer; and/or its perceived fit to address a particular problem (Proctor et al., 2009; Weiner et al., 2017). Lastly, the C-BiLLT's feasibility was defined as the extent to which it could be easily used given the clinical context in which it is administered (Proctor et al., 2009; Weiner et al., 2017). These three implementation outcomes are closely related, yet some important distinctions can be made (Proctor et al., 2009). For instance, an innovation may be deemed appropriate (e.g., relevant to address a specific problem), but not acceptable (e.g., unacceptable to the clinician). An innovation could also be appropriate, yet not feasible due to training or resource requirements. In the present study, the Norwegian and Dutch adaptations of the three measures were used (Engell et al., 2018; Simon et al., n.d.).

Procedures

Data Collection and Analysis

The survey was open from February 15 to March 15, 2021, and responses were collected and managed using REDCap, an electronic data capture tool hosted at the last author's university. Survey responses were analyzed descriptively, including reporting of

counts and percentages. Demographic data were analyzed separately for the respondents from the Netherlands and Dutch-speaking parts of Belgium, and Norway. This was done to able to understand the backgrounds of the respondents from the different countries better. Caseload characteristics and user experiences were analyzed for all regions combined. Results for the AIM, IAM, and FIM were reported using means and standard deviations for Dutch and Norwegian respondents separately. Free-text survey responses were translated from Dutch and Norwegian into English by the first and seventh authors, who were fluent in both languages; and qualitative data were managed and analyzed using Dedoose, a web-based application for qualitative and mixed methods research (Dedoose Version 8.3.45, 2018). Within Dedoose, responses to the open-ended survey items about the barriers and facilitators to C-BiLLT use were analyzed using thematic analysis (Braun & Clarke, 2006), which involved the following steps:

1. Familiarization with the data.

2. Generation of initial codes.

3. Development of themes.

4. Review of themes and generation of a thematic 'map' of the analysis.

5. Generation of names and definitions of identified themes.

6. Producing a report of the analysis.

Steps 1 to 3 were done by the first author, and Steps 4 to 6 were done collaboratively with the entire research team. To ensure reliable coding, a trained graduate research assistant reviewed 10% of the free-text responses, during Steps 2-3. Cohen's κ was calculated to determine the agreement between two raters on these 52 excerpts, and there was almost perfect agreement between the two raters, $\kappa = .92$ (95% CI, .83 to 1), $p < .0005$ (McHugh, 2012).

<center>**Results**</center>

A total of 114 surveys were returned, 94 from the Netherlands and Belgium, and 20 from Norway. The exact response rate cannot be reported because it was not known how many individual clinicians at the rehabilitation sites received or completed the survey. The majority of the invitations were sent to clinicians in the Netherlands, and we had no way of differentiating respondents from the Netherlands versus Belgium, so responses from both countries were grouped and are reported under *Netherlands* in Tables 2 to 4.

Surveys that were less than 50% complete (n=24, 21%) were discarded, as a comparison of responses for completed and non-completed surveys yielded no difference in terms of sex (Fisher's exact test, $p = 1$) or years of work experience (Kruskal-Wallis H test, $\chi^2(3) = .064$, $p = .8$). The incomplete surveys included responses from eight clinicians who said they had never used the C-BiLLT in their practice. Six (four from Norway and two from the Netherlands) indicated they had participated in training but had not used the C-BiLLT for various reasons including (some respondents gave more than one reason) parental leave (n=1), COVID-19 pandemic (n=3), no eligible clients (n=1), lack of hardware (n=1), or no reason stated (n=2). Two clinicians answered the question about what would need to change in order for them to use the C-BiLLT. One indicated a need to get the right hardware and one cited COVID-19 mitigations. The two other non-users were Dutch respondents who had registered for an upcoming training and were not using the C-BiLLT yet. The final sample of C-BiLLT users included 90 respondents (79 from The Netherlands, 11 from Norway). Their results are presented next. Note that not all respondents answered all survey questions.

Aim 1: Understand Clinicians' Caseloads and C-BiLLT Use

C-BiLLT Users' Caseloads

Respondents worked in a variety of practice settings, and most had over 10 years of work experience. They reported using the C-BiLLT most often with children up to 12 years of age, and the majority of clinicians (58%) had used it with between three and 20 children at the time of survey completion. Most children with whom the C-BiLLT was used had a diagnosis of cerebral palsy, but the C-BiLLT was also being used with children who had other neurodevelopmental disabilities. Identified populations included children who would be physically able to participate in traditional language testing (e.g. Peabody Picture Vocabulary Test), which was also indicated by their gross motor function and communicative function, expressed by the GMFCS (Palisano et al., 1997) and CFCS (Hidecker et al., 2011). While the majority of children were classified as GMFCS and CFCS Levels IV or V (the intended population for C-BiLLT use), the test was also being used with clients who spanned the entire spectrum of motor and communicative functioning (see Table 2).

Table 2

Clinician Caseloads (n = 90)

Characteristics	Netherlands	Norway	Full sample
	n	*n*	*%*
Number of clients tested			
< 3 clients	4	6	11
3 – 10 clients	22	4	29
10 – 20 clients	25	1	29
> 20 clients	28	0	31
Age[a] (total n = 89)			
< 5 years	56	8	72
6 – 12 years	58	8	74
13 – 17 years	26	2	31
> 18 years	25	2	30
Diagnosis[a]			
Cerebral palsy	74	6	89
Down syndrome	31	1	36
Rett syndrome	27	0	30
Angelmann syndrome	19	0	21
Language disorder	43	5	53

Syndrome other than listed	22	0	24
IDD	17	0	19
ASD	16	3	21
Other (*e.g.*, ABI, metabolic, muscle or mitochondrial diseases)	13	4	19
Unknown	31	4	39
GMFCS[ab]			
I	28	5	37
II	29	2	34
III	39	2	46
IV	57	3	67
V	64	4	76
I don't know	2	2	4
CFCS[ab]			
I	9	1	11
II	21	2	26
III	48	2	56
IV	70	3	81
V	50	3	59
I don't know	2	2	4

Note. ASD, Autism Spectrum Disorder; ABI, Acquired Brain Injury; IDD, Intellectual or developmental disability; GMFCS, Gross Motor Function Classification System (Palisano et al., 1997b); CFCS, Communication Function Classification System (Hidecker et al., 2011).

[a] Numbers may sum to greater than 90 and percentages sum to greater than 100, as clinicians had the option to choose more than one answer.

[b] While these classification systems are validated for use in the CP population, we did not specify that respondents should limit their responses only to their clients with CP.

C-BiLLT Users' Assessment Practices

Most clinicians indicated that they used the C-BiLLT at least quarterly and that they used a variety of access methods (see Table 3). Duration and number of sessions needed to complete C-BiLLT assessment varied widely. Clinicians (n=84) indicated a mean minimum C-BiLLT administration time of 24 minutes (range: 1–90 min), and a mean maximum time of 56 minutes (range: 15–240 min). Respondents (n=42) indicated needing between one and five

sessions to complete the C-BiLLT (mode=3). Twenty percent of those 42 respondents (*n*=8) said it always took at least two sessions for them to complete the test. Despite the variation in time required to complete the C-BiLLT, clinicians did not identify time needed for the assessment as a barrier to using the test.

Over 60% of clinicians (*n*=56) indicated they had combined multiple access methods within one test session, with a preference for direct selection methods. Sixty-six percent (*n*=59) indicated they had on occasion been unable to complete a C-BiLLT assessment. For those that had been unable to complete the C-BiLLT, most reasons for non-completion related to the child's attention (*n*=46) or task orientation (*n*=48). Other reasons for non-completion included clinicians terminating the assessment because of doubts about the reliability of the child's responses (*n*=31), and difficulty finding a good access method (*n*=9).

Table 3

C-BiLLT Users' Assessment Practices

	Netherlands *n*	Norway *n*	Full sample *%*
Frequency of use			
Yearly or less	7	2	10
Half-yearly	15	3	20
Once every three months	25	5	33
Monthly	27	1	31
Weekly	5	0	6
Access method(s) used [a]			
Direct selection with pointing			
Touchscreen monitor	64	3	74
Tablet	29	7	40
Pointing without touching (finger or other)	53	3	62
Direct selection with eye gaze			
Eye gaze (no tech)	25	1	27
Eye tracker	31	2	37
Indirect selection			
Input switches	19	1	22
Head mouse	2	0	2

Partner assisted scanning	6	2	9
Child's own access device	24	0	27
Multiple access methods in one session			
Never	27	7	38
Sometimes	47	4	57
Usually	5	0	6
Ever unable to complete			
Yes	55	4	66
No	22	7	32
Reasons/causes for non-completion [a] (total n = 59)			
Issues re: access methods	8	1	15
Vision	13	2	25
Hearing	0	0	0
Attention	43	3	78
Behavior/compliance	12	2	24
Task orientation	45	3	81
Doubts re: reliability	30	1	52
Technical issues	16	2	31
Other	4	0	7

Note. [a] Numbers may sum to greater than 90 and percentages sum to greater than 100, as

clinicians had the option to choose more than one answer.

Aim 2: Assessing Acceptability, Appropriateness, and Feasibility of the C-BiLLT

Clinicians rated all three implementation outcomes highly. Acceptability was rated the

highest (*M*=4.35, *SD*=0.62 and *M*=4.39, *SD*=0.24 respectively in the Netherlands and

Norway). Feasibility and appropriateness received average ratings above 4 in both countries

as well (see Table 4).

Table 4

Users' Ratings of the C-BiLLT's Acceptability, Appropriateness, and Feasibility

Baseline characteristic	Mean (SD)	
	Netherlands	Norway

Acceptability of Intervention Measure	4.35 (0.62)	4.39 (0.24)
C-BiLLT meets my approval.	4.34 (0.55)	4.36 (0.67)
C-BiLLT is appealing to me.	4.35 (0.66)	4.27 (0.65)
I like C-BiLLT.	4.34 (0.66)	4.18 (0.75)
I welcome C-BiLLT.	4.37 (0.61)	4.74 (0.48)
Intervention Appropriateness Measure	4.08 (0.71)	4.16 (0.09)
C-BiLLT seems fitting for my clients.	4.11 (0.72)	4.09 (0.70)
C-BiLLT seems suitable for my clients.	4.08 (0.73)	4.18 (0.60)
C-BiLLT seems applicable for my clients.	4.06 (070)	4.27 (0.65)
C-BiLLT seems like a good match with my clients.	4.08 (0.69)	4.09 (0.70)
Feasibility of Intervention Measure	4.07 (0.64)	4.43 (0.16)
C-BiLLT seems implementable.	4.06 (0.67)	4.27 (0.65)
C-BiLLT seems possible.	4.12 (0.53)	4.36 (0.50)
C-BiLLT seems doable.	4.11 (0.62)	4.27 (0.65)
C-BiLLT seems easy to use.	3.92 (0.76)	4.00 (0.77)

Note. Scale from 1 (lowest) top 5 (highest); SD, standard deviation

Aim 3: Identifying Barriers and Facilitators to Using the C-BiLLT

A range of barriers and facilitators to C-BiLLT use were identified, with barriers being defined as factors that would limit use of the C-BiLLT, and facilitators being defined as factors that would help clinicians in using the C-BiLLT. The reported barriers and facilitators were grouped into four broad themes: (a) factors inherent to the C-BiLLT (e.g., the hardware, software, and test characteristics), (b) factors related to the children the C-BiLLT is used with,

(c) factors related to the clinician using the C-BiLLT and (d) factors related to the

environment the C-BiLLT is used in. These themes are illustrated in Figure 1, which depicts a

C-BiLLT administration using eye-tracking. The screen is tilted and mounted on a rolling

mount so that it is parallel to the child being tested. The identified barriers and facilitators

associated with each theme are presented next.

Figure 1

Barriers and facilitators related to C-BiLLT use
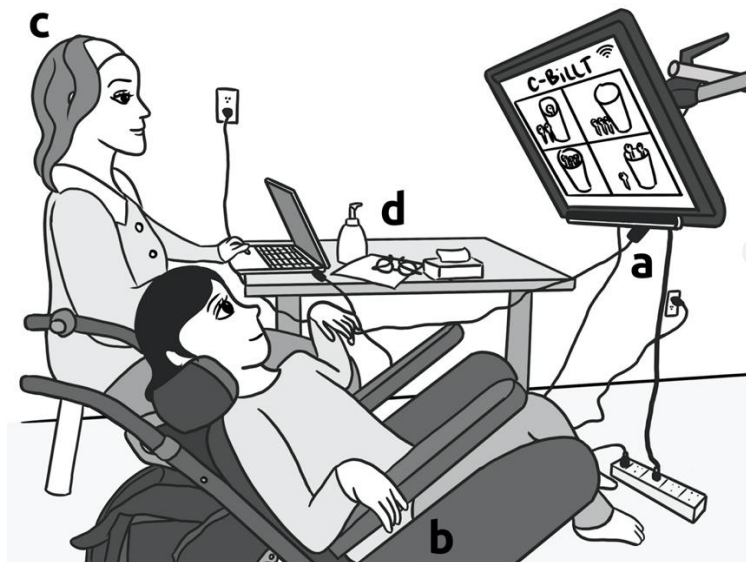
Note. Barriers and facilitators in the image include (a) factors inherent to the C-BiLLT, (b)

child-related factors, (c) clinician-related factors, and (d) factors related to the environment.

Figure by S. Dong

Factors Inherent to the C-BiLLT

Reported barriers related to the C-BiLLT itself were associated with its hardware,

software, and images. Barriers related to hardware included the time needed to set up the

testing situation such as the need to connect different devices (e.g., "a lot of fuss/cables/etc."

[NL_44]). In some cases, clinicians reported that the barriers related to hardware were too big

to overcome (e.g., "too many computer technical conditions to come to testing" [NL_20]). In particular, many barriers related to using the eye-tracking module were reported (e.g., "still can't link the computers with eye-tracking" [NL_85]). Challenges related to the software included format and navigation (e.g., "very rigid and not user friendly" [NL_50]; "navigating within the test is difficult" [NL_49]), and the need for a stable internet connection, particularly if the test was being used at multiple sites (e.g., "connection isn't as strong everywhere" [NL_31]). Finally, clinicians reported feeling some of the photos used in the test were outdated (e.g., photo needs to be updated or removed) and may not be recognized by children (e.g., "pictures are no longer up to date. Like the DVD, television, mailbox (hardly anyone goes there anymore)" [NOR_5]). They noted similar observations from parents.

Facilitators related to the C-BiLLT as a test were its automatic scoring ability (e.g., "scoring is automatic, which means I can pay full attention to the client" [NL_9]), ease of administration, and the lack of distracting test materials (e.g., "no distraction by toys" [NL_85], that "can get lost or broken" [NL_47]).

Factors Related to the Child

Barriers related to the children with whom the C-BiLLT was being used were primarily associated with the complexity of the clinical case and children's visual impairments. It can be challenging to meet the conditions that are needed to properly administer the C-BiLLT with some children with complex needs (e.g., "Right access, right seating, right table" [NL_77]; and "All conditions need to be optimal – physical – alertness – technology – motivation" [NL_52]). Clinicians reported that the C-BiLLT is a visually challenging test, with barriers to assessment for clients with visual impairments. Many suggestions for improving the test for this population were made, such as "better contrast between target and background" [NL_18], "be able to choose different backgrounds"

[NL_77], "possibility to visually rearrange the pictures, e.g., further apart from each other, everything horizontally" [NL_32].

Child-related facilitators included interest and motivation for working with the screen (e.g., "really speaks to children" [NL_22]), and the absence of loose objects or toys for the client to manipulate, which was reported to help children focus. This facilitator was also mentioned in relation to children who may possess the motor skills to participate in more traditional toy-based tests, but "who will lose themselves in all the materials and aren't able to listen or focus anymore" (NL_13).

Factors Related to the Clinician

This theme relates to the clinician's skills, perceptions, resources, goals, and context. Barriers included a perceived lack of technological skills (e.g., "my own clumsiness with IT (+ learned helplessness)" [NL_18]), lack of confidence in C-BiLLT results, and insecurities regarding the interpretation of behaviors exhibited by clients during the assessment (e.g., "the patients that are relevant for me to test with the C-BiLLT usually have extensive difficulties and it is often difficult to decide the validity of the recorded test session because of attention, behavior, communication challenges" [NOR_7]).

Clinician-related facilitators included the perception that the C-BiLLT meets a clinical need, which increased clinicians' motivation to use it. Reportedly, it enabled clinicians to generate important clinical assessment data (e.g., "large need to reliably assess the language comprehension of children with severe motor problems" [NL_6]), and to assess children "who are otherwise untestable" [NL_75].

Factors Related to the Environment

Barriers related to the environment included clinicians' physical work environment, organizational systems, and social factors. For example, some clinicians reported IT policies such as not allowing for the connection of the C-BiLLT's hardware as a barrier (e.g., "we

need to use stand-alone computers if we want to connect devices to it, which is often not possible in our workspace" [NL_48]). Lack of space to set up the C-BiLLT was another reported barrier (e.g., "we have a set up away from practice space because of the size of the screen, this is impractical" [NL_73]), as was lack of familiarity with the C-BiLLT either outside or within organizations (e.g., "lack of familiarity with the C-BiLLT in some agencies, which causes the C-BiLLT results not to be recognized for admissions, for instance for education" [NL_14]).

Facilitators related to the environment included the availability of space, having the assessment set up and ready to go, and a supportive team. The option to have the C-BiLLT set up ready for use (e.g., "own AAC device and computer with eye gaze control and touch screen to use the C-BiLLT" [NL_60], i.e., when "the equipment is in place" [NOR_7]) was reported to make it easier to use the test. Support from colleagues, management, and workplace IT staff was also reported as a facilitator (e.g., "Dedicated team of people who administer the C-BiLLT" [NL_60]).

Discussion

This study investigated implementation of the C-BiLLT in the Netherlands, Dutch-speaking parts of Belgium, and Norway. In all, 90 clinicians shared details about their professional background, caseload, C-BiLLT assessment practices, and perceptions of the instrument. Clinicians rated the instrument highly in terms of appropriateness, acceptability, and feasibility, despite the multiple barriers to its use that they identified. The present study adds to the nascent body of literature examining the implementation of assessment tools into clinical care, which is timely. There has been a rise of new evidence-based assessment tools in pediatric rehabilitation, yet usage in clinical practice remains low (O'Connor et al., 2016). Reasons for why uptake is slow are largely unknown, because studies about the implementation of evidence-based assessment tools are scarce (Colquhoun et al., 2017).

The first study aim was to understand clinicians' contexts, caseloads, and how they used the C-BiLLT. Strikingly, many clinicians reported using the test with children who had diagnoses other than cerebral palsy and with children who had the motor skills to participate in more traditional language testing (i.e., the ability to point, speak, and manipulate small objects). This finding suggests the C-BiLLT was viewed as more than a "last resort" option for children who could not be assessed with any other test. The use of tests for unintended purposes or populations is not uncommon in pediatric rehabilitation (Hanna et al., 2007) and suggests an unmet need in the field. More research regarding use of the C-BiLLT with other populations or in adapted ways is needed to test validity in these new situations (de Vet et al., 2011).

The second aim was to understand clinicians' perceptions about the C-BiLLT's appropriateness, acceptability, and feasibility. Average ratings for all constructs were above four on the five-point scales, suggesting highly positive perceptions amongst those who had used the C-BiLLT in practice. This result was consistent across clinicians from different countries, professions, and phases of implementation. In interpreting this result, two considerations are important. First, it is possible that high ratings were due to perceptions of the clinical potential of C-BiLLT results (e.g., the assessment information it can yield) rather than actual ease of implementation (e.g., ease of use in everyday clinical contexts). However, the AIM, IAM, and FIM were developed to specifically explore implementation outcomes and not service or client outcomes (Weiner et al., 2017). This means that the high ratings were unlikely to be the result of the patient-centeredness of a C-BiLLT assessment (a service outcome) or client satisfaction (a client outcome). Second, respondents were likely a highly trained, specialized, and motivated group of professionals. The majority (81%, n=73) had over 10 years of work experience and 94% (n=85) reported having completed the C-BiLLT training. Furthermore, for some clinicians C-BiLLT use was encouraged, for instance through

the Dutch best practice guidelines for pediatric rehabilitation professionals. Therefore, the respondents may have had better capability, more opportunity, and/or a stronger motivation to use the C-BiLLT, which could explain the high ratings. Future research by this research group will explore how capability, opportunity and motivation impacts clinicians' C-BiLLT use to further contextualize survey findings and identify concrete and tailored suggestions to improve implementation where needed.

This study's final aim was to describe clinicians' perceived barriers and facilitators to C-BiLLT use. Clinicians described the C-BiLLT as meeting a critical professional need, but identified barriers that could hamper its implementation potential for some clinicians or in some clinical contexts. Identified barriers, such as those related to children with complex needs that include visual impairments and available access methods should be reviewed and addressed in future work.

Clinicians highlighted that the C-BiLLT requires advanced clinical skills and experience working with children who have complex communication needs. In half of the non-completion cases, the clinician questioned the validity of the child's responses, particularly in complex cases where the child's vision was also impacted. The visual aspects of the test are particularly important for children with cerebral palsy as approximately two-thirds show visual defects indicative of cerebral visual impairment (Schenk-Rootlieb et al., 1994), and lower visual field impairments are common (Philip & Dutton, 2014). Participants offered many suggestions for improving the C-BiLLT's suitability for children with visual impairments, such as the option to present pictures against a black background, removing the relatively large black buttons on the screen to make the first 30 items more eye-gaze friendly, and presenting the four images per screen in the second half of the test horizontally at the top of the screen rather than in block format. In addition to the above-mentioned suggested modifications to support children with visual impairments, participants also indicated a need

to update some of the images used in the C-BiLLT - both the content of some images (e.g., the DVD and the mailbox), as well as the appearance of others (e.g., the telephone and the television). In current adaptations of the test (i.e., the Norwegian and Canadian-English versions) some images have already been replaced.

Another way to bypass the visual aspect of the test altogether could be the use of a brain-computer interface based on evoked potentials, such as the brain wave P300 (Orlandi et al., 2021). Brain-computer interfaces, where brain responses to stimuli are picked up and interpreted, typically rely on visual stimuli. However, research in adults shows good results with auditory evoked potentials as well (Orlandi et al., 2021). Evidence is emerging for the feasibility of such paradigms in children who have vision impairments but intact hearing (Zang et al., 2019), and this could be a future access method for the C-BiLLT.

Regarding the access methods that were used to complete the C-BiLLT, computerized eye-tracking was the least used direct access method. This may be in part because the C-BiLLT was often used with children who could complete the test in other ways. In general, the popularity of computerized eye tracking as an access method for AAC is rising, likely because of its non-invasiveness and high accuracy (Bates et al., 2005). However, participants identified some challenges with using eye tracking to access the C-BiLLT. For instance, they reported difficulty interpreting their clients' behavior (eye gaze) in response to test items, which led to doubts about the reliability of test results. Computerized eye-tracking may have been difficult for clinicians because it uses the same channel for observation and control, which makes it difficult to distinguish a user command (e.g., selecting a response deliberately) from other user activity (e.g., scanning the response options) (Jacob, 1991). The literature on eye tracking also reports user fatigue (Bates et al, 2005; Higginbotham et al., 2007), which may be why multiple access methods were often used to complete the C-BiLLT.

Other possible explanations for the use of multiple access methods include postural instability (Donker et al., 2008), pain (Mckinnon et al., 2019), and motor fatigue (Berrin et al., 2007).

An additional barrier associated with eye-tracking devices was the high cost. Nine percent of respondents reported that they used low-tech eye gaze (i.e., the clinician's interpretation of where the child looked on the screen) as an access method, suggesting the cost of eye-tracking devices was prohibitive. This corresponds with the literature that reports high costs as a common barrier to the adoption of innovations in rehabilitation care (Duncan & Murray, 2012). Future research could investigate the reliability of the low-tech eye access method for the C-BiLLT to support accessibility for both clinicians and children.

Implications for Practice

While not all suggestions may be readily adoptable, the common barriers faced by clinicians will need to be considered in future implementation interventions. For example, C-BiLLT trainings may be improved by incorporating strategies for observing children during testing and tips for identifying signs of lack of attention or fatigue. Updating C-BiLLT content will be an ongoing process, and additional training materials on the use of technology will be considered.

There is a continuing need for more advanced access methods for children with complex communication needs, who are restricted in expressing their needs, wants, and ideas. There are encouraging developments in access technology, including electroencephalography and infrared sensing (Tai et al., 2008; Higginbotham, 2007), which may be useful in practice in the future. Findings from the current study suggest it will be critical to support clinicians in implementing such technologies in practice, and knowledge translation efforts should directly target identified barriers such as lack of knowledge or technical expertise to support clinicians in using the access method that best meets their client's needs.

Responses to this survey indicated clinicians' willingness and professional enthusiasm for participating in research. The study also highlighted the unique benefit of incorporating clinicians' expertise in research. Future research will capitalize on this resource by actively collaborating with clinicians. By including clinicians' experiences and expertise, implementation efforts are more likely to be relevant and successful (Kothari & Wathen, 2017), and may avoid the traditional education approaches that have been shown to have a limited impact on practice (Paley, 2007).

Finally, it was surprising that not many clinicians mentioned family involvement in the assessment process. For children who communicate non-verbally, parents' or caregivers' knowledge about the child and how they express themselves could help the clinician interpret behaviors during the assessment (Lancioni et al., 2007; Noyek et al., 2020). Future research by this team will explore family engagement in assessment practices for this group of children.

Limitations and Future Directions

The current study has some limitations that must be acknowledged and considered when interpreting results. We achieved a high response rate, however because participation was voluntary and anonymous, we cannot claim that results are representative of all clinicians who have been trained to use the C-BiLLT. Selection bias is also possible, and there may be have been an overrepresentation of clinicians who wanted to drive change or those who were content and had no concerns about the C-BiLLT. Therefore, it is possible that the experiences of clinicians for whom implementation barriers were too large to overcome were not captured. Additionally, the survey lacked follow-up questions, which could have been informative. For example, we do not know whether clinicians who indicated there were occasions when they could not complete the C-BiLLT, were able to finish the assessment in a follow-up session.

Finally, barriers and facilitators were assessed only informally. However, by asking clinicians open-ended questions, this study casted a wide net that was appropriate for this stage of the assessment. Further research is needed to understand clinicians' practices in different contexts and to propose implementation interventions with theoretical and empirical reasoning.

Conclusion

Study participants rated the C-BiLLT as an acceptable, appropriate, and feasible instrument for children with cerebral palsy. Despite the identified barriers, the test is used in clinical practice, and with a wider audience than it was originally developed for in terms of children's motor impairments and diagnoses. An important facilitator for implementation was clinicians' high motivation. The identification of technological, clinical, and resource-related barriers calls for a more detailed exploration of how C-BiLLT users can be better supported.

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Appendix 1

C-BiLLT survey - English

Title of Study: Exploring clinicians' experiences using the C-BiLLT to support implementation in the Canadian practice context: An international survey and interview study

Principal Investigator: Barbara Jane Cunningham, PhD, SLP(C), Reg. CASLPO, Western University

Phone: 519-661-2111 x88179, **email:** bj.cunningham@uwo.ca

Study Funding: CanChild Centre for Childhood Disability Research, Internal Grant

Location: Netherlands, Norway, Belgium

1. Invitation to Participate

You are invited to participate in this research study because you may have received training to use the Computer-Based instrument for Low Motor Language Testing (C-BiLLT) or you may be using the C-BiLLT in your practice in the Netherlands, Belgium, or Norway. Your participation in this study is voluntary, so it is your choice whether to participate.

2. Purpose of the Study

Right now, you are being invited to complete a 10-15-minute online survey about your experiences with the C-BiLLT. The purpose of the survey is to understand clinicians' experiences and their perceptions of the barriers to using the C-BiLLT in clinical practice. Findings from this work will inform future work related to the C-BiLLT and efforts to implement the C-BiLLT into the Canadian clinical context.

3. Inclusion/Exclusion Criteria

Clinicians will be included in this study if they have received training to administer the C-BiLLT, or are using/have used the C-BiLLT in their practice. Clinicians who have been trained to administer the C-BiLLT but are not using it in their practice are also invited to participate. Over 300 clinicians are being invited to complete this survey.

4. Activities of Participants

If you volunteer to complete the survey, you will be asked a series of demographic questions about your training and background and whether you have used the C-BiLLT in your practice. Those who have not used the C-BiLLT will be asked to describe the challenges associated with using it in practice. Those who have used the C-BiLLT will be asked additional questions about the populations they use it with and the benefits and challenges of using it in practice. You will not be required to answer any of these demographic or perceptual questions, and and skip any questions you are not comfortable answering. Those who have used the C-BiLLT will also be asked to make ratings for 12 statements about its acceptability, appropriateness, and feasibility. Participants will not be able to skip these ratings, as complete data are needed to score acceptability, appropriateness, and feasibility. The survey will take approximately 10-15 minutes to complete. Surveys will be conducted using REDCap, an online data collection software housed at Western University. All survey responses will be anonymous. Please note that once you have clicked 'submit', your survey data cannot be withdrawn because the survey is anonymous.

If you agree to participate, you can give your implied consent by clicking on the 'yes' button when asked whether you are willing to complete the survey. At the end of the survey, we will ask whether you would also be willing to be contacted to participate in a 1-hour online interview. If you agree, you will be asked to enter your first and last name, email address, and preferred language into a new REDCap survey that is separate from the survey data. Participating in an interview is also voluntary. Please note that your full name and email address will be captured in this second REDCap survey. If you enter your name and email address to be contacted for an interview, this identifying information will be stored in a secure location that is separate from all study data for 7 years as per Western University's policy on data retention. If you are in Norway, your interview will be conducted at the University of Norway under the supervision of Kristine Stadskleiv. Interview data will be transcribed and translated at the University of Norway, and then shared with Western University through an inter-institutional data sharing agreement.

5. Possible Risks and Harms/Possible Benefits

i. Possible Risks and Harms

We do not foresee any risks or discomforts for this study. When completing the online survey, you may not be comfortable answering some questions. Please know that you can refuse to answer any or all questions. It is also possible that at some point your privacy will be breached, although every effort will be made to protect your privacy by (1) having an interview participant file that is separate from survey data, and (2) describing survey results as an aggregate summary of participants' experiences. There are no other anticipated risks to participating in this study.

ii. Possible Benefits

There are no anticipated benefits to study participants.

6. Compensation

You will not be compensated for completing the survey.

7. Voluntary Participation

There is no expectation or requirement for you to participate. Participation is purely voluntary. If you decide to participate, you may refuse to answer any questions or withdraw from the study at any time. You are not required to volunteer to be interviewed or to enter your contact information following the survey.

8. Confidentiality and Publication

The data collected in this survey will be used for scientific purposes. If you agree to be contacted for an interview, we will collect the following pieces of identifying information: your full name, phone number, your preferred email address. Anonymized survey data may be included in scientific reports and/or publications, but your name will not appear in any publications or presentations. We will protect your confidentiality by storing the names of those who agree to be contacted for an interview separately from the survey data. All data collected during this survey will be stored on a network drive specific to Dr. Cunningham's lab at Western University that can only be accessed by authorized research personnel. Western University Health Sciences Research Ethics Board may also require access to

participants' study records to monitor the conduct of this study. Anonymized data will be retained indefinitely in case data are required for future research. Identifiable data collected for the purposes of scheduling interviews will be destroyed as soon as the interviews have been completed. You do not waive any legal rights by signing the consent form.

If you wish to obtain additional information regarding this project, please contact Dr. Barbara Jane Cunningham at 519-661-2111 x88179 or by email at bj.cunningham@uwo.ca. If you have any questions about the conduct of this study or your rights as a research participant, you may contact the Office of Research Ethics at (519) 661-3036 or by email at ethics@uwo.ca.

Sincerely,

Barbara Jane Cunningham, PhD, SLP(C) (Principal Investigator)

Assistant Professor, School of Communication Sciences and Disorders, Western University
Scientist, CanChild Centre for Childhood Disability Research
519.661.2111 x88179
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Please answer the consent question below to start the survey. If you click "yes", you will be linked to the survey. If you click "no" you will not complete the survey.

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate in the survey. All questions have been answered to my satisfaction.

◯ Yes - I agree to complete the survey
◯ No - I do not wish to complete the survey

In this first section you will be asked to share some basic demographic information.	
1	Please indicate your professional background.	○ Speech-language pathologist ○ Psychologist ○ Educator ○ Other
1a	Please tell us your professional background.	_____
2	How long have you been practicing in this role?	○ Less than two years ○ Between 2 and 5 years ○ Between 5 and 10 years ○ More than 10 years
3	Please indicate your practice context.	☐ Private practice ☐ Treatment centre ☐ School ☐ Hospital ☐ Other: (Check all that apply.)
3a	Please tell us your practice context.	_____
4	Where is your practice located?	☐ Large urban city (population over 100 000) ☐ Medium-sized city (population from 30 000 to 99 999) ☐ Small city (population between 1,000 and 29,999) ☐ Rural community (population less than 1 000) (Check all that apply.)
5	What is your sex?	○ Male ○ Female ○ Other ○ Prefer not to answer
6	Please tell us when you received your C-BiLLT training.	○ 2014 ○ 2015 ○ 2016 ○ 2017 ○ 2018 ○ 2019 ○ 2020 ○ 2021 ○ I don't remember ○ I didn't participate in the official training ○ Other
6a	Please explain:	_____
6b	Why did you sign up for C-BILLT training?	_____
7	Since your training, have you ever used the C-BiLLT in your practice?	○ Yes ○ No

7a   Please explain why not.

_____

7b   What would need to change in order for you to use the
C-BiLLT in your practice?

_____

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	In this section you will be asked some questions about your use of the C-BiLLT in clinical practice.

7c	Approximately how many clients have you used the C-BiLLT with?	○ Less than 3 ○ Between 3 and 10 ○ Between 10 and 20 ○ More than 20
7d	I use C-BiLLT with clients that are:	☐ 18 months-5 years ☐ 6-12 ☐ 13-17 ☐ 18+ ☐ Other (Check all that apply.)
7e	How often do you use the C-BiLLT?	○ Daily ○ Weekly ○ Monthly ○ Every 3 months ○ Every 6 months ○ Once a year or less
7f	What is/are the diagnosis(es) of the clients with whom you use the C-BiLLT?	☐ Cerebral Palsy ☐ Down Syndrome ☐ Rett Syndrome ☐ Angelmann Syndrome ☐ Developmental Language Disorder ☐ Unknown/Undetermined ☐ Other (Check all that apply.)
7f, i	Please list the other diagnoses of clients with whom you use C-BiLLT with.	_____
7g	What are the most common Gross Motor Function Classification System (GMFCS) levels of the clients you use the C-BiLLT with?	☐ Level I (Walks alone) ☐ Level II (Walks with limitations) ☐ Level III (Walks using a hand-held mobility device) ☐ Level IV (Self-Mobility with Limitations; May Use Powered Mobility) ☐ Level V (Transported in a Manual Wheelchair) ☐ I don't know (Check all that apply.)
7h	What are the most common Communication Function Classification System (CFCS) levels of the clients you use the C-BiLLT with?	☐ Level I (Independent sender and receiver with unfamiliar and familiar partners) ☐ Level II (Independent, but slower-paced sender and receiver with unfamiliar and familiar partners) ☐ Level III (effective sender and receiver with familiar partners) ☐ Level IV (Inconsistent Sender and/or Receiver with familiar partners) ☐ Level V (Seldom Effective Sender and Receiver even with familiar partners) ☐ I don't know (Check all that apply.)

7i	Which access methods are used by clients to complete the C-BiLLT?	☐ Touch screen ☐ iPad ☐ Pointing with a finger or body part ☐ Eye gaze using an eye tracker ☐ Eye gaze without using an eye tracker ☐ Client's own technology (e.g. speech generating device) ☐ Switches ☐ Alternate mouse access ☐ Partner assisted scanning ☐ Other
7i, i	Please explain	_____
7j	Do clients ever use more than one access method to complete the C-BiLLT?	○ Always or usually ○ Sometimes ○ Never
7k	Which access methods would you like to see added to the C-BiLLT?	_____
8	Are there ever times where you cannot complete an assessment using the C-BiLLT?	○ Yes ○ No
8a	Please indicate why	☐ I couldn't find the right access method ☐ Client's vision was not adequate ☐ Client's hearing was not adequate ☐ Client's attention ☐ Client's behaviour/compliance ☐ Client's task orientation was insufficient ☐ Doubts about the reliability of the client's answers ☐ Technical issues ☐ Other (Check all that apply.)
8b	Please explain	_____
9	In your practice, how much time do C-BiLLT assessments take? Please fill in the range.	_____
10	What is easy about using the C-BiLLT in your practice?	_____
11	What is difficult about using the C-BiLLT in your practice?	_____
12	If you could change up to three things about the C-BiLLT, what would those things be?	_____

In this final section you will be asked to rate the acceptability, appropriateness, and feasibility of the C-BiLLT

Ratings will be completed using the AIM, IAM, and FIM measures developed by:

Weiner, B.J., Lewis, C.C., Stanick, C. et al. Psychometric assessment of three newly developed implementation outcome measures. Implementation Sci 12, 108 (2017). https://doi.org/10.1186/s13012-017-0635-3

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Acceptability of Intervention Measure (AIM)					
	Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
1 The C-BiLLT meets my approval	○	○	○	○	○
2 The C-BiLLT is appealing to me	○	○	○	○	○
3 I like the C-BiLLT	○	○	○	○	○
4 I welcome the C-BiLLT	○	○	○	○	○

	Intervention Appropriateness Measure (IAM)					
		Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
1	The C-BiLLT seems fitting for my clients	○	○	○	○	○
2	The C-BiLLT seems suitable for my clients	○	○	○	○	○
3	The C-BiLLT seems applicable to my clients	○	○	○	○	○
4	The C-BiLLT seems like a good match for my clients	○	○	○	○	○

Feasibility of Intervention Measure (FIM)

		Completely disagree	Disagree	Neither agree nor disagree	Agree	Completely agree
1	The C-BiLLT seems implementable	○	○	○	○	○
2	The C-BiLLT seems possible	○	○	○	○	○
3	The C-BiLLT seems doable	○	○	○	○	○
4	The C-BiLLT seems easy to use	○	○	○	○	○

Chapter 6: Factors influencing C-BiLLT implementation

6.1 Introduction

Chapter 6 addresses the second objective of this thesis: to develop a contextualized understanding of C-BiLLT clinicians' implementation behaviour. The body of this chapter is an interview study that was conducted with 15 Dutch and Norwegian clinicians. Prior to the manuscript of the study, a brief introduction on the topic of implementation science in Speech-Language Pathology is provided.

6.2 Implementation science in Speech-Language Pathology

Evidence-based practice (EPB) in medicine has been around for decades and has found its way into Speech-Language Pathology (SLP) more recently (Reilly, 2004). Even before it was labelled as such, healthcare professionals were aware of the need to base clinical decisions on more than just reasons of tradition or personal and professional experience (Sackett, 1997b).

An important part of EBP is the translation of scientific evidence, knowledge, and products to practice (Douglas et al., 2015). Knowledge translation can be thought of as the bridge between scientific research and clinical practice. The Canadian Institutes of Health Research define knowledge translation as 'the synthesis, exchange, synthesis and ethically-sound application of knowledge (...) within a complex system of interactions between researchers and knowledge users' (Canadian Institutes of Health Research, n.d.).

How to build that bridge successfully is studied in implementation science, which is defined as 'the study of factors that influence the full and effective use of innovations in practice' (Fixsen et al., 2019, p. 4). Knowledge translation and implementation science are largely overlapping if not exchangeable terms (Khalil, 2016; Wensing & Grol, 2019).

The need for better implementation strategies is evident: while there is a huge increase in scientific evidence in SLP over the last 20 years, the clinical uptake of the evidence is low (Douglas et al., 2015; O'Connor et al., 2016; O'Connor & Pettigrew, 2009; Reilly, 2004). The potential effects of unsuccessful implementation of scientific evidence include underuse of services, i.e. a failure to deliver the service to those who would benefit. Overuse is also a potential effect: providing services to those who will not benefit from them, wasting resources and potentially doing harm (Davis et al., 2003; Madon et al., 2007; McGlynn et al., 2003). Unsuccessful implementation leads to unfavourable outcomes for individual patients, clinicians, healthcare systems, and ultimately communities as a whole (Brownson et al., 2021; Dopp et al., 2021; Hoomans & Severens, 2014).

A scoping review by Douglas et al. (2022) showed that the vast majority of implementation science publications in SLP is published from 2014 onwards. Before that time, however, research already tried to answer the question of how to promote the adoption of evidence-based practice in routine care. Below is a brief overview of the emergence of knowledge translation and implementation science in SLP in the past 15 years, and some of the developments that took place within that timeframe.

The emergence of EBP in SLP started with the realization of the value of scientifically obtained evidence and how scientific foundations for clinical practice are often lacking. Interestingly, much of the focus of early papers on the topic is on the roles and responsibilities of individual clinicians in finding evidence and bringing it into practice (Dodd, 2007; O'Connor & Pettigrew, 2009; Reilly, 2004). Consequently, these papers present the individual clinician and their lack of skills and/or willingness to implement EPB as an important or even a key barrier to the progression of SLP as an evidence-based profession. For instance, O'Connor & Pettigrew (2009) identified "a culture of using traditional methods" in the SLP profession (*i.e.,* decision-making is based on clinical expertise only, and/or relies

on opinions of colleagues). In such a culture, they say, the most prominent barriers to the adoption of EBP in SLP include clinicians' resistance to change and a lack of skills. Reilly (2004) described a 5-step path to "becoming an evidence-based practitioner" (Sackett, 1997a). In the same vein, Dodd (2007) recommended training for SLP professionals to develop the necessary skills to search and critically evaluate evidence.

More recent studies acknowledge the concept, value, and role of knowledge translation. Knowledge translation is described as a complex process for which the individual clinician cannot carry the sole responsibility. In fact, current literature suggests that the success of knowledge translation in SLP is rarely determined by the actions of individual clinicians, but by the complex organizational contexts that they work in (Johnson & May, 2015). For instance, Olswang & Prelock (2015) introduce knowledge translation by describing as an active collaboration between researchers and practitioners. In their view, it is problematic and insufficient to rely on clinicians to read, accurately interpret, and effectively apply findings from scientific literature. Campbell & Douglas (2017, page 73) share this view and note that "researchers are becoming increasingly aware that the provision of knowledge on its own, even when synthesized, is not sufficient to change clinical practice".

The aim of this chapter is to contextually understand clinicians' behaviour in the different phases of C-BiLLT implementation. As mentioned in the introduction to Chapter 5, the explicit use of theory and frameworks in implementation science is often lacking (Douglas et al., 2022; O'Connor, 2020). To gain a theoretically grounded understanding of clinician behaviour in C-BiLLT implementation, chapter 6 was informed by the COM-B model of behaviour change (Michie et al., 2014). The use of the COM-B model allowed us to analyse behaviour as part of a system of the different interacting components of capability, opportunity, and motivation.

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6.4 Implementing the language comprehension test C-BiLLT: a qualitative description study using the COM-B model of behaviour change

Bootsma, J.N., Phoenix, M., Geytenbeek, J.J.M., Stadskleiv, K., Gorter, J.W., Fiske S., Cunningham, B.J. (2022)

Implementing the language comprehension test C-BiLLT: a qualitative description study using the COM-B model of behaviour change

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Abstract

Background

It is challenging to reliably assess the language comprehension of children with severe motor and speech impairments using traditional assessment tools. The Computer Based instrument for Low motor Language Testing (C-BiLLT) aims to reduce barriers to evidence-based assessment for this population by allowing a variety of access methods. The purpose of this study is to develop a contextualized understanding of the factors that influenced clinicians' implementation of the C-BILLT in practice in the Netherlands and Norway.

Materials and methods

A qualitative approach including semi-structured individual interviews with 15 clinicians was used. Data analysis was conducted in two rounds. First, a deductive approach including a codebook was used to code data within the COM-B components describing clinicians' capability, opportunity, and motivation for behaviour change. Then, an abductive approach applying thematic analysis was used to identify meaningful patterns within the COM-B components.

Results

Several meaningful barriers and facilitators were identified across the data. Clinicians used the C-BiLLT with two distinct groups of clients: (1) the population it was originally developed for, and (2) clients that could have also been assessed using a traditional language test. Clinicians working with the first group experienced more, and more complex barriers across all COM-B components, to successful C-BiLLT use than the latter.

Conclusion

This study provides timely insights into the capability, opportunity, and motivation factors important for creating and sustaining assessment behaviour change in clinicians who used or attempted to use the C-BiLLT. Use of the COM-B model allowed for the description of

interactions between clinicians and their contexts. Potential tailored intervention strategies are discussed.

Background

Many children with cerebral palsy (CP) face barriers to communication (Mei et al., 2016; Pennington, 2016; Voorman et al., 2009). Estimates vary, but it is thought that across all levels of motor functioning, 20% - 30% will have some difficulty expressing themselves verbally (Andersen et al., 2010; Nordberg et al., 2013; Sigurdardottir & Vik, 2011). Of those with extensive motor impairments, it is estimated that 15% - 30% cannot use speech to communicate at all (Andersen et al., 2010; Nordberg et al., 2013; Sigurdardottir & Vik, 2011). To alleviate the harmful impact of communication impairments on these children's social, educational, and emotional well-being and development, Augmentative and Alternative Communication (AAC) interventions such as the introduction of graphic symbols, manual gestures, and speech generating devices are recommended (Clarke et al., 2011, 2012; Raghavendra et al., 2012).

Impairments in speech and expressive language production do not necessarily imply an impairment in comprehension (Stadskleiv, 2020), as a child's understanding of spoken language can develop independently of their abilities to produce it (Geytenbeek et al., 2015). This means children's comprehension skills cannot be inferred based on their production skills. Each area of language must be independently assessed so AAC interventions can be developed and tailored to each child's individual needs (Andersen et al., 2010; Fiske et al., 2020; von Tetzchner & Stadskleiv, 2016). However, there are challenges associated with obtaining a reliable assessment of language comprehension in children with CP, because most tests require the participant to manipulate small objects, finger point, and/or speak

(Geytenbeek et al., 2010). As such, children with CP and limited motor or speech function are often excluded from standardized language assessments in both clinical practice and research studies (Smits et al., 2011; Stadskleiv, 2020; Stadskleiv et al., 2018), which may result in inequities in essential care, education, and opportunities to meaningfully participate.

The *Computer-Based instrument for Low motor Language Testing* (C-BiLLT) was developed to address the clinical and research gap regarding testing language comprehension in the CP population (Geytenbeek et al., 2014) (please see www.c-billt.com for more information). It facilitates an evidence-based (i.e., standardized, reliable and valid) assessment of spoken language comprehension for children who were previously often excluded from such testing. The test allows for a variety of response modes besides speaking, pointing, and object manipulation, and reliably assesses language comprehension in children with significant speech and motor impairments (for detailed descriptions of the psychometric properties of the C-BiLLT and its administration procedures, please see (Bootsma et al., 2022a; Fiske et al., 2020; Geytenbeek et al., 2014)). The C-BiLLT was first introduced in the Netherlands in 2014 and is included in the guidelines for the management of spastic CP (*Richtlijn Spastische Cerebrale Parese Bij Kinderen*, 2015). In Europe to date, over 300 clinicians in the Netherlands, Norway, and Belgium have been trained to use the test. A recent study to assess implementation of the C-BiLLT in the European context surveyed clinicians working in various settings in the Netherlands and Norway. Clinicians rated the C-BiLLT highly on measures of acceptability, appropriateness, and feasibility, but they also identified several barriers associated with implementing it in practice (Bootsma et al., 2022b).

The identification of barriers to implementation was not surprising as the uptake of new tools in practice is generally slow and use is low (Légaré et al., 2006; O'Connor et al., 2016; O'Connor et al., 2019; O'Connor & Pettigrew, 2009). This is true despite knowledge that the use of evidence-based standardized assessment tools is considered integral to

evidence-based, family-centred, and collaborative clinical decision making (Brewer et al., 2014; Wright & Majnemer, 2014). Commonly-reported barriers to the use of new evidence-based assessment tools reported by clinicians include a lack of time, knowledge, and confidence in test selection and interpretation (Law et al., 1999); practical issues such as cost and ease-of-use; and a perceived lack of value in using tests (King et al., 2011; Law et al., 1999). In addition to clinicians' skills, perceptions, and beliefs, contextual factors such as work place setting and culture, managerial and organizational supports, and the wider health context can influence test adoption and use (Colquhoun et al., 2017; Duncan & Murray, 2012; Grol & Wensing, 2004). Barriers reported in the literature are similar to results reported in the aforementioned C-BiLLT implementation study, in which barriers were grouped into categories representing four factors: 1) inherent to the test, 2) related to the child, 3) related to the clinician, and 4) related to the environment (Bootsma et al., 2022b). While this initial implementation survey study was useful for identifying barriers and facilitators, a theoretically grounded approach is needed to fully understand clinicians' behaviours. The removal of barriers alone may not be enough to predictably change clinician behaviour in the desired direction (Nilsen & Bernhardsson, 2013), presumably due to the many organizational and individual factors that interact to influence whether new tools are well implemented (Cane et al., 2012; Nilsen & Bernhardsson, 2013).

The Capability, Opportunity and Motivation Behaviour Model (COM-B) (Michie et al., 2011) offers a framework for understanding behaviour in the context in which it occurs. The premise of the model is that for any behaviour to occur, there must be the capability to do it, the opportunity for it to occur, and a sufficiently strong motivation to carry it out. Capability, opportunity, and motivation are each divided into two types. Psychological capability describes a person's knowledge or psychological skills, and the strength or stamina to engage in the necessary mental processes to change behaviours. Physical capability refers

to a person's physical strength, skills, and stamina. Opportunity can be physical, referring to the opportunities afforded by the environment (*e.g.,* time, resources, physical barriers), or social, referring to opportunities afforded by interpersonal influences, social cues and cultural norms. Motivation covers the thought processes that direct behaviour. This can refer to reflective thought processes, involving plans and evaluations, or to automatic processes involving emotional reactions, desires, impulses, inhibitions, drive states and reflex responses. Components of the COM-B model are dynamic and interact over time, and a change in one component may lead to an increase or decrease in other components (Figure 1). For instance, increased motivation can lead people to do things that will increase their capability (*e.g.,* taking a course) or opportunity (*e.g.,* freeing up time). Similarly, increased opportunity or capability can increase motivation (*e.g.,* you are more likely to do something if you know how and have the time to do it). Therefore, the COM-B model can be used to analyse and understand the clinical context and what needs to shift or be modified to achieve desired behaviours. This type of theoretical approach to implementation prevents an overreliance on educational approaches to overcome implementation barriers, which are known to have limited success (Ketelaar et al., 2008; Novak & McIntyre, 2010).

The European C-BiLLT implementation survey provided initial information about the complexities associated with implementing the C-BiLLT into practice. The aim of this qualitative interview study was to better understand the factors that influenced clinicians' implementation of the C-BILLT in practice by using the COM-B model. The new knowledge could be used as the foundation for further implementation efforts. The research question that guided the study was: How do capability, opportunity, and motivation influence clinicians' use of the C-BiLLT?
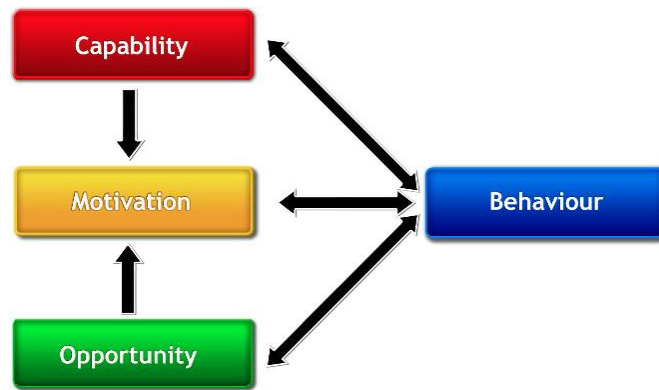
Figure 1. The COM-B model – a framework for understanding behaviour (reproduced from Michie et al., 2011).

Methods

This study employed a qualitative descriptive design as presented by Sandelowski (Sandelowski, 2000, 2010). In qualitative description, analysis remains close to the data when participants' experiences are being interpreted so experiences can be comprehensively summarized using plain language.

Ethical approval for this study was obtained from the Office of Human Research Ethics at Western University. In the Netherlands, the study was classified as not subject to the *Medical Research Involving Human Subjects Act* (WMO), thus no additional ethical approval was required. In Norway, the Norwegian Centre for Research Data evaluated the ethical aspects of the study and gave permission for data collection (2020/# 967236).

Sampling and recruitment

The study was carried out in the Netherlands and Norway, the clinical contexts in which the C-BiLLT was introduced in 2014 and 2019 (Geytenbeek et al., 2014; Fiske et al., 2020), respectively. Participants were recruited from the sample of respondents to our original survey (Bootsma et al., 2022b). After completing the original survey, clinicians were asked if

they agreed to be contacted for a follow up interview, to which 33 clinicians agreed. As more clinicians agreed to follow up than were needed for the study, Dutch clinicians were purposefully sampled based on their experience administering the C-BiLLT (none, low 1 – 9 times, medium 10 – 20 times, high >20 times). Fourteen Dutch clinicians were approached through email, with a maximum of two emails. Three Dutch clinicians did not respond, and two declined participation because of either a lack of time or a change of job (*n*=9 were included). All Norwegian clinicians who volunteered to be interviewed (*n*=6) were included. Because of the relatively small number of C-BiLLT trained clinicians in Norway, workplace details have been left out of the quotes for Norwegian participants to ensure their anonymity.

Procedures and materials

Semi-structured interviews were conducted to understand clinicians' experiences administering the C-BiLLT within their practice setting. The interview guide included introductory questions about clinicians' professional background and current work setting, and four open-ended questions about the introduction, initial adoption, early implementation, and continued use of the C-BiLLT in their practice (Fleuren et al., 2004). Interviews were conducted by two researchers who were also clinicians with experience using the C-BiLLT (JB and SF) in each participant's preferred language (Dutch or Norwegian) and recorded using Zoom videoconferencing software. No further contact was made with the participants after their interview.

Data analysis

Data collection and analysis took place concurrently. Interview recordings were transcribed verbatim in either Dutch or Norwegian and then translated to English by team members who were fluent in both languages (JB, SF). Transcriptions and field notes on the interviews were

imported into Dedoose (*Dedoose Version 8.3.45, Web Application for Managing, Analyzing, and Presenting Qualitative and Mixed Method Research Data*, 2018). After familiarization with the data by rereading transcripts and fieldnotes, analysis was conducted in two rounds. In the first round, a deductive approach to analysis was conducted in which JB and SF first developed a codebook that included the six COM-B components and their definitions (i.e., psychological capability, physical capability, physical opportunity, social opportunity, reflective motivation, and automatic motivation). The codebook was piloted on the first seven interviews by JB and a trained graduate student research assistant. The codebook was subsequently updated with some clarifications about how the COM-B components manifested in relation to C-BiLLT use. The remaining interview transcripts were coded according to the revised codebook. The extracted data in each COM-B component was identified as either a barrier or a facilitator to C-BiLLT use. In round two of data analysis, codes were grouped using an abductive approach (Kennedy, 2018) and analysed using thematic analysis (Braun & Clarke, 2006). In an abductive approach, the researcher moves back and forth between data and theory, and makes comparisons and interpretations while searching for patterns. This allows the researcher to use pre-existing theories (e.g., the COM-B), while also remaining open and sensitive to the data and the possibility of new concepts, ideas and explanations (Tavory & Timmermans, 2014). The research team met monthly to discuss ongoing analyses and to clarify any issues. Visualizations of the codes and relationships between them were used to support discussions, and memos were used to record relevant discussions and coding notes. Throughout the analysis process, these frequent discussions helped to develop a nuanced and rich understanding of the data.

Results

Fifteen clinicians were interviewed between May and October 2021, and interviews lasted

between 20 – 90 minutes. Characteristics of participants are described in Table 1.

Table 1. Characteristics of participating clinicians

	Netherlands (N=9)	Norway (N=6)
Sex		
Male	-	1
Female	9	5
Profession		
Speech-language pathologist	9	-
(Neuro-)Psychologist	-	3
Teacher	-	1
Pedagogical psychological counsellor	-	1
Vision specialist	-	1
Practice setting		
School	-	2
Day care (children & youth) (neurodevelopmental disorders or acquired brain injury)	3	-
Early intervention setting for developmental language disorder	1	-
Congregate care facility	2	-
Pediatric rehabilitation	3	1

Adult rehabilitation	-	1
National competence centre	-	2
Experience with the C-BiLLT		
None (0)	-	2
Low (1-9)	1	2
Medium (10-20)	3	2
High (>20)	5	

Note C-BiLLT; Computer Based instrument for Low Motor Language Testing

All six COM-B components were identified in the data and the identified barriers and facilitators within each COM-B component are listed in Table 2. A feature of the data was the difference in the type of clients that clinicians used the C-BiLLT with. There were clinicians who used the test with the population it was originally developed for (i.e., children with severe motor and speech impairments), but others reported using it with clients that could have also been assessed using a traditional language test but preferred the C-BiLLT's touch screen. Identified differences between these two groups are discussed within the descriptions of the barriers and facilitators in each COM-B component as described below.

Table 2. Using the C-BiLLT in practice, barriers (-) and facilitators (+) experienced by all users, by clinicians using the C-BiLLT with the intended population, and by clinicians using the C-BiLLT in lieu of traditional language tests

	Capability		Opportunity		Motivation	
Factors Experienced by	**Physical**	**Psychological**	**Physical**	**Social**	**Reflective**	**Automatic**

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All C-BiLLT users regardless of population or mode of assessment	+ General assessment skills	+ Professional skill set (e.g., clinical reasoning, communication)	- Incompatibility of C-BiLLT software with organisation's IT environment/policies	- Low status	+ Evidence-based	+ Agency
	- Insufficient practice				+ A smooth assessment	
Clinicians using C-BiLLT with intended population	- Lack of skills to accommodate for vision impairments during assessment	- Lack of knowledge re: vision impairments	- Equipment issues: lack of budget, lack of space, and/or lack of equipment		+ Makes it possible to "uncover what's within"	- Technology related frustrations
	- Lack of skills to use eye tracking equipment	- Difficulty interpreting clients' behaviour			+ Beliefs about positive consequences for clients	
Clinicians using C-BiLLT in lieu of traditional language tests			+ Easy to organize the assessment			

Capability

Within the COM-B model, psychological capability refers to a clinician's knowledge, and cognitive and interpersonal skills associated with test administration. Physical capability

refers to the skills needed to successfully operate the technology required to use the C-BiLLT. Clinicians identified both facilitators and barriers associated with their capability to implement the C-BiLLT in practice.

Facilitators. All clinicians described themselves as having a strong professional skill set (psychological and physical capability), including clinical reasoning, general assessment, and communication skills to support their use of the C-BiLLT. One participant was the exception: she worked as a teacher and had a strong interest in AAC but no clinical background. She described how she felt *"not completely confident"* administering the test, and had consequently never administered it after participating in the training (NOR_06, C-BiLLT experience level: none).

Professional capabilities were described as sufficient for clinicians using the C-BiLLT with clients who had the manual abilities to participate in traditional language testing. In these cases, the C-BiLLT was often used with children who liked being able to only point or touch to give a response (versus manipulate small objects), and for those that struggled to await verbal instructions and/or to inhibit the urge to manipulate test materials. In these cases, clinicians administered the test on an iPad or a touch screen laptop, so they did not need additional skills beyond the general technological skills needed to operate a computer or a tablet.

Barriers. Clinicians reported that the test became *"technically more difficult"* to perform if they had limited opportunities for practice (physical capability) (NOR_01, psychologist, C-BiLLT experience level: none). Reported reasons for lack of practice included an absence of eligible clients, a lack of necessary equipment, and measures associated with COVID-19 that restricted in-person assessments. In some cases, these barriers led to abandonment of the test.

Capability barriers were more complex for clinicians who administered the test with the population it was developed for (i.e., clients with severe motor and speech impairments). These clinicians used, or attempted to use several different access methods, which meant they needed skills in technology. Two main barriers were identified for clinicians using the C-BiLLT with its intended population: a) using the test with children who had visual impairments, and b) challenges associated with various technologies.

Clinicians reported a lack of sufficient knowledge about their clients' visual impairments. For example, clinicians were aware of clients' visual impairments, but were unsure about the nature of the visual impairments and whether or how they could impact C-BiLLT assessment results (psychological capability). Clinicians also reported being unsure how to accommodate for the visual impairments during testing (physical capability).

CP children obviously have a very big risk or, a lot of CVI occurs. And so directing your gaze and being able to hold it for a while is sometimes very difficult. And processing the visual information… how does that work? And is that for your first item still the same as for item 12 when you get that far? Have you already deleted all the photos you've seen, or is it just piling up? I don't know much about that. (NLD_06, SLP working in pediatric rehabilitation service, C-BiLLT experience level: medium)

Visual impairment was also reported to cause uncertainty when interpreting a client's behaviour during the assessment and thus made some clinicians doubt the validity of test results. It was hard for clinicians to judge *"whether children gave the wrong answer because they didn't see it or because they just really gave the wrong answer"* (NLD_05, SLP working in a facility for adults with neurodevelopmental disorders or acquired brain injury, C-BiLLT experience level: medium).

Technology barriers experienced by this group of clinicians centred around eye-tracking equipment. They mentioned a lack of knowledge and skills needed to connect and operate eye tracking hardware and software: *"I noticed that I had a lack of knowledge to, for example, make the mouse cursor disappear or make it invisible"* (NLD_05).

Opportunity

Opportunity refers to the physical and or social opportunities that help or hinder a clinician to perform a certain behaviour. Opportunities afforded or denied by a clinician's work environment (e.g., their organization, larger practice context, or colleagues) impacted the success of C-BiLLT implementation.

Facilitators. Clinicians that used the C-BiLLT with children who could have completed a traditional test, reported how easy it was to organize the assessment (physical opportunity). They liked not needing to coordinate the use of testing materials with colleagues, especially when the clinician could use their own tablet to administer the test. Administration via iPad or touch screen laptop eliminated the need for a sizeable assessment space that would be needed to spread out materials for traditional language tests. Clinicians described ease of administration using a tablet regardless of the testing environment. Finally, for these clinicians the C-BiLLT was freely accessible after completing the training course, because there was no requirement to purchase additional equipment or materials to administer the test (physical opportunity).

Barriers. A commonly reported physical opportunity barrier was incompatibility between the C-BiLLT requirements and clinicians' organizational IT systems or policies. For instance, the C-BiLLT works best using Chrome or Firefox, but some clinicians' work computers or tablets were only set up for Safari and they were unable to change this setting themselves.

A social opportunity barrier mentioned by many clinicians was the lack of other professionals' awareness or familiarity with the C-BiLLT. This meant the C-BiLLT had 'low status' among other professionals (*e.g.,* in education), which presented barriers to implementation in several ways. In the Netherlands, in order to access schools with specific supports for those with speech and language impairments, children needed a certain criterion score on a standardized test. Clinicians who wanted to use C-BiLLT test results to support a client's admission reported the test was not (yet) approved by the COTAN Review System of Evaluating Test Quality (a Dutch agency that oversees the quality of diagnostic tests). In these cases, C-BiLLT test results were not considered valid for determining whether children met criteria for school admission: *"they just won't accept it by definition"* (NLD_02, SLP working in a day care for children and youth with neurodevelopmental disorders or acquired brain injury, C-BiLLT experience level: high).

A second social opportunity barrier was encountered by some clinicians that worked in settings that had prescribed sets of tests to be administered for all clients that did not include the C-BILLT. In these contexts, clinicians wanting to administer the C-BiLLT were required to meet with the responsible care coordinator, which prevented some from using the test.

Interviewer: What I'm still thinking about huh… Well, you say you're pretty positive about the C-BiLLT […] what makes it that you usually still go for the Schlichting or for another test?

Yes, because that's in that format here in healthcare programming. It [the C-BiLLT] *is really something new.[…] So I am really limited by the organization then.* (NLD_07, SLP who recently switched from working in pediatric rehabilitation services to an early intervention day care for toddlers with suspected DLD, C-BiLLT experience level: high)

Even in work settings where there were no restrictions regarding test use, clinicians reported the C-BiLLT may not be familiar to other professionals, which was sometimes given as a reason for choosing another test.

Clinicians who used or attempted to use a variety of access methods, experienced several physical opportunity barriers. Common barriers included a lack of money to purchase equipment and a lack of space in which to use the equipment. For example, some clinicians reported having to share space or equipment with colleagues, and some worked at multiple locations, which meant having to move equipment and identify multiple assessment spaces. Some clinicians reported having access to the equipment they needed, but that the equipment was sub-standard (e.g., an available but poorly functioning eye-tracker). Physical opportunity barriers were often reported to have a cascading effect. Consider the following illustrative interview excerpt in which a clinician described not having access to an eye tracking device or a separate monitor for the client due to lack of funding:

Interviewer: Then you both work on the touch screen.

Yes. Then I make sure that I only put the mouse [away], so that the child really can't reach that. And that's how we, how we, how it usually goes.

Interviewer: Right. And how do you like that, or how, how is that going?

Well that works. Only if children are really more limited, then it is more difficult. Because then I just sit next to the child. And then I can actually not see eye gaze 100%

beautifully. (NLD_06, SLP working in pediatric rehabilitation service, C-BiLLT experience level: medium)

This excerpt illustrates how an initial opportunity barrier (lack of money), led to another opportunity barrier (lack of appropriate equipment), which in turn led to physical capability (lack of agility), and psychological capability (inability to reliably observe a client's response) barriers. To address barriers associated with equipment, clinicians reported solutions they perceived as suboptimal. For example, one clinician partnered with a colleague for every assessment, so the client's eye gaze could be observed from two viewpoints rather than purchasing eye gaze technology. Others had clients touch a non-touch computer screen while the clinician used the mouse to select the client's response. Partner-assisted scanning was also mentioned by several clinicians as a work around to purchasing eye-gaze technology. Partner-assisted scanning is an assessment administration method where the clinician points to the different pictures on the screen in a systematic manner and asks the client to indicate when the clinician points to the correct response. This was not a preferred method, but one that clinicians reported resorting to at times.

Motivation

Motivation can refer to clinicians' reflective thought processes, plans and evaluations, or automatic processes such as emotional reactions.

Facilitators. None of the clinicians were obliged (e.g., by management) to adopt the C-BiLLT in their practice. Instead, they all chose to do so themselves and expressed independence and agency (automatic motivation) in choosing to use the C-BiLLT.

Clinicians expressed motivation to use the C-BiLLT because they viewed it as a scientifically sound test, and felt that it facilitated a smooth assessment process (reflective

motivation). The test was viewed as facilitating assessment because a) there were not too many subtests or objects to keep track of, b) the scoring was automatic which allowed clinicians to pay more attention to the client, c) there were fewer distractions for clients relative to traditional language tests, and d) all clients were familiar with and excited by working on a tablet or a computer. Additionally, Norwegian clinicians described the C-BILLT as filling a practice gap and unmet need for a standardized language comprehension test with (recent) Norwegian language norms.

> *The first time I used it on adults I was a bit sceptical and thought like [...] Will it be too childish? But they did not react to that at all. So it worked!* (NOR_05, psychologist, C-BiLLT experience level: medium)

Clinicians who administered the test with clients who could have completed another traditional language assessment felt the C-BiLLT saved them time, hassle, and money, while providing an evidence-based assessment of their clients' language comprehension skills.

Clinicians who used the C-BiLLT with clients who had severe motor and speech impairments appreciated that the test allowed them to "uncover what's within" their clients with more certainty compared to clinical observation alone (reflective motivation).

> *Yes, I think there are a lot of kids who are locked-in. And um, um I can say that so many times, but if you see it in black and white as a caretaker or as a manager or remedial educator or whoever, that's just a piece of evidence, of hey, look, it just is. Period.* (NLD_02, SLP working in a day care for children and youth with neurodevelopmental disorders or acquired brain injury, C-BiLLT experience level: high)

Clinicians using the C-BiLLT with its intended population described the test as something that they had been waiting for, a way to address an urgent clinical need and *"a big leap forward"* (NOR_04, psychologist, C-BiLLT experience level: low). Clinicians also noted that the C-BiLLT made it possible to access their clients' language comprehension, and they believed an accurate understanding of language abilities would have positive consequences for their clients. More specifically, clinicians reported that the results from assessment with the C-BiLLT led to feelings of happiness and doing right by the client.

> *I had a client who was severely disabled, eh, and where in fact everything was always handed to her, over which she had little control. But what we found out through this assessment is that she can choose between two things. So that she can choose, for example, what she wants on her bread, or that she can choose like, I want to wear my red sweater or my green sweater today. Hey, those are small steps, but perhaps important for a client, for the feeling that they belong and that they can also make their own decisions. So, yes, we like that.* (NLD_04, SLP working in a day care for children and youth with neurodevelopmental disorders or acquired brain injury, C-BiLLT experience level: medium)

Barriers. Technical (physical opportunity or physical capability) barriers encountered by the group of clinicians using the C-BiLLT with its intended population prompted feelings of frustration, annoyance or uncertainty (automatic motivation), which could negatively impact their C-BiLLT use.

Interviewer: Right, I'm just thinking about if you go to that room and the touch screen,

or the pc eye, is not there or the touch screen is not working, how do you proceed?

Yeah then I'm really annoyed [laughs] <Interviewer: [laughs] I get that>. (NLD_08,

SLP working in pediatric rehabilitation services, C-BiLLT experience level: high).

Discussion

This study aimed to develop a comprehensive understanding of the behaviour of clinicians

who implemented or attempted to implement the C-BiLLT into their practice. The COM-B

model was used as a theoretical framework, and fifteen clinicians were interviewed about

their experiences using the C-BiLLT in practice. The COM-B model consists of components

that are dynamic and can interact over time. These interactions were identified in the sample

of clinicians who participated in this study and could help to explain their reported use or

non-use of the C-BiLLT.

Several meaningful barriers and facilitators were identified across the data. Clinicians

appreciated the C-BiLLT for its scientific rigor and because it helped them to achieve a more

streamlined assessment process compared to traditional tests. This finding was consistent with

the high ratings of acceptability (e.g., 'I welcome the C-BiLLT', and 'The C-BiLLT is

appealing to me') reported in the initial survey study (Bootsma et al., 2022b). These positive

motivational factors are reasons for the clinician to *want to* use the C-BiLLT and are likely to

support the uptake of the instrument (Duncan & Murray, 2012; Michie et al., 2011). However,

performing a certain behaviour not only depends on motivation, but also on whether or not

one *can* do it (i.e., if one has the required capability and opportunity). The commonly reported

barriers (i.e., insufficient practice, incompatibility between the C-BiLLT and organizational

IT, and a low status among other professionals) likely impacted the *can*-do aspect of C-BiLLT use. In our sample, the influence of these three barriers ranged from an inconvenience that could be dealt with (e.g., making time to call the IT department for assistance to install another web browser) to a reason to choose another test (e.g., equipment issues).

The type of clients a clinician used or wanted to use the C-BiLLT with (i.e., with the intended population or with any client) was an important distinction in our data because these groups had different experiences implementing the C-BiLLT.

For the group of clinicians that used the C-BiLLT with clients whom they could have assessed with another test, the benefits of using the C-BiLLT were clear. Once trained, these clinicians did not need additional skills (capability) or equipment (opportunity) because they could administer the test on a tablet, laptop, or computer they already possessed. For this group, the C-BiLLT removed a number of practical inconveniences they experienced with other tests. This pragmatic motivation came on top of the generally shared motivational factors about the test, which may have created a positive feedback loop where the clinician was highly motivated to use the C-BiLLT (i.e., *wants to* use it) and also had the capability and the opportunity to do so (i.e., *can* use it). Use of the C-BiLLT with populations other than the ones it was originally developed for is supported by findings from the survey study and highlights clinicians' preferences for easy-to-use assessment tools (De Veer et al., 2011).

The implementation experience was quite different for the group of clinicians using the C-BiLLT with its intended population. This group wanted to use the range of access methods compatible with the C-BiLLT (e.g., computerized eye tracking, input switches) to accommodate for their clients' needs. Clinicians in this group described a more ideological motivation for wanting to use the C-BiLLT: the assumption that the test would help them to reveal the language comprehension abilities of their clients, which would then have positive consequences in their clients' everyday lives. At the same time, these clinicians faced more

capability and opportunity barriers to successful test use. The fact that many kept trying to address barriers and use the test illustrates the strength of their motivation.

The potential benefits of being able to assess this group of children with an evidence-based assessment tool are great. In research, the C-BiLLT could allow for more representative and inclusive samples in studies of language and cognition in children with CP, thus expanding the knowledge base for this population (Stadskleiv, 2020). In practice, individual children, their families, educators and treatment teams could benefit from a trustworthy assessment as a starting point to initiate, plan, monitor, and evaluate communication interventions. Together with the initial survey study (Bootsma et al., 2022b), the results presented here demonstrate that despite these important benefits, barriers to C-BiLLT use remain and must be addressed in order to secure access to evidence-based language assessment for children with neurodevelopmental differences. Implementation interventions and future research should address the barriers experienced by clinicians, particularly those using the C-BiLLT with its intended population.

The COM-B model is at the hub of the Behaviour change wheel (Michie et al., 2014), which is a framework that can be useful for supporting the design of implementation interventions. More specifically, a COM-B analysis of current behaviours can be used to identify intervention strategies that are likely facilitate implementation. This theoretical approach can also help avoid less effective implementation strategies such as passive education-based strategies (Campbell & Douglas, 2017; Paley, 2007; Powell et al., 2014), or strategies that focus solely on the individual clinician (O'Connor, Kerr, Shields, & Imms, 2019), or the innovation (De Veer et al., 2011) without considering the clinical context.

Insufficient opportunities for practice delay and jeopardize the innovation process, regardless of the reason(s) or cause(s) for the lack of practice. For example, in one survey study 685 nurses reported on their experiences with recently introduced technologies, and the

right time frame between the training and availability of technology in daily practice was identified as an important factor for success (De Veer et al., 2011). This barrier requires a multi-factorial solution to ensure clinicians can maintain their knowledge and skills. In the current study, some clinicians reported a lengthy delay between when they received their C-BiLLT training, and when they were able to start using the test. If the lag is caused by organizational barriers (e.g., not providing funding for the equipment soon enough or an inability to quickly resolve incompatibility issues), clinicians should be supported to prepare for C-BiLLT use even before they participate in the training. In the Netherlands, this is currently done by providing information about the technology requirements to everyone who enrols in the training course. If the lack of practice opportunities stems from a lack of eligible clients or unforeseen challenges such as COVID-19 restrictions to in-person care, there should be opportunities for trained clinicians to practice their skills in the absence of 'real' test use. Opportunities could be offered virtually to accommodate clinicians' schedules and to circumvent potential restrictions on in-person gatherings, and may include training videos to support general skills for C-BiLLT administration, as well as videos to support specific technical skills such as how to set up access methods like eye tracking equipment. In Norway, the lack of practice barrier was recently addressed by refresher webinar (November 2021), that from now on will be offered annually.

Education would be a meaningful strategy to address the knowledge barriers regarding vision impairments and their potential impact on C-BiLLT assessment, a barrier that was reported in the survey study as well (Bootsma et al., 2022b). Clinicians could be given additional information during the training course, or information could be available in the manual, or on the instrument's website. Prompts or cues could be added to the C-BiLLT's materials to direct clinicians reasoning about vision impairments before and during the assessment process, and when interpreting the results. For instance, users could be prompted

to use the novel Eye-pointing Classification Scale (Clarke et al., 2020), that was developed to describe looking behaviours in relation to eye-pointing in children with CP affecting their whole body using a five-point scale. This may help clinicians to reach a more precise description of a client's behaviours during the C-BiLLT testing and to interpret the C-BiLLT scores with more confidence.

To address the impact of the C-BiLLT's low status among other professionals and fields of practice, different actions could be taken. One is to engage in knowledge mobilization efforts to raise awareness about the C-BiLLT and its strong psychometric properties. For example, publishing about the C-BiLLT outside of academic journals and in media could raise awareness for professionals who are not familiar with the tool (e.g., professionals working in healthcare fields outside rehabilitation). Another one is to include the C-BiLLT as a measure in research. For example, the C-BiLLT was recently used in the Netherlands in a longitudinal study of language comprehension in children with CP (*Cerebral Palsy - Communication and Language Learning*, n.d.), which has increased the C-BiLLT's profile among participants and clinicians. Additionally, forthcoming results can be used as evidence for the C-BiLLT meeting the COTAN requirements for test quality, which would permit use of C-BiLLT test scores to support children's admission to special schools. This research may also increase awareness about the test in the scientific and clinical communities over time. A final potentially impactful strategy for improving the C-BiLLT's profile is to direct implementation efforts towards families in addition to providers, as such 'patient-mediated' knowledge translation interventions show promise in other healthcare domains (Gagliardi et al., 2016).

In an attempt to resolve technology related barriers including feelings of frustration, easily accessible practical support could be offered. This could be achieved by a frequently asked questions section on the website, or by providing easy ways to contact developers and experts

who can offer practical support. Lastly, to support clinicians who need to advocate for C-BiLLT resources (e.g., budget, space, equipment), documents could be prepared and distributed at or before training sessions. For instance, factsheets or infographics about the C-BiLLT may help individual clinicians to communicate the message that their client population requires an accessible language assessment instrument. Some of these types of practical supports have already been implemented in the Netherlands, in response to the feedback from training participants.

Strengths and limitations

A key strength of this study is that it presents a contextualized understanding of clinicians' behaviour in assessment practices, an area of the literature with limited evidence to date (O'Connor et al., 2016; O'Connor et al., 2019). Paired with the quantitative data from the initial survey study, results have been used to identify meaningful barriers and facilitators to assessment instrument uptake in the real-word context (Nilsen & Bernhardsson, 2013).

One limitation of this study is the risk of social desirability bias, where respondents felt like they had to report positive aspects because they knew that members of the C-BiLLT team were involved in this project. This type of bias may also have influenced who agreed to enroll in the study. Judging from the results, however, participants appeared to feel comfortable sharing a variety of barriers. Still, it cannot be ruled out that this type of bias may have influenced who agreed to enroll in the current study, and who did not.

Another possible limitation is the imbalance in participants' professional backgrounds as professional background, experience, and work setting may have impact on how they use the C-BiLLT and how they experience the assessment process. All of the Dutch clinicians were SLPs, while none of the Norwegian clinicians were SLPs. This difference was also present in the survey study, where all but one Dutch respondents were SLPs, and only one

Norwegian respondent was an SLP. The C-BiLLT training is open to professionals who are trained to administer evidence-based psychodiagnostic assessment tools, regardless of their profession.

While we viewed as a strength, the use of the COM-B model for data analysis bears a possible limitation as well. Using a pre-existing theory to support qualitative data analysis could lead to overlooking aspects of the data that do not fit the theory, but that may be meaningful to the research question. This approach could also lead to overinterpretation of the data, if the data are forced onto the predefined theoretical concepts. These risks were mitigated (but cannot be fully excluded) by the second, abductive round of data analysis.

Conclusion

This study provided timely insights into factors important for creating and sustaining assessment behaviour change in clinicians who used or attempted to use the C-BiLLT. The novel use of the COM-B model identified complex interactions between the individual clinicians and their contexts. Future research should capitalize on this knowledge when designing implementation interventions. Future research will also explore the validation of the C-BiLLT as an assessment tool for other populations, such as children with other developmental conditions (e.g., Rett syndrome, Angelman syndrome), or adults with intellectual disabilities.

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Chapter 7: Parents' perspectives on the C-BiLLT assessment

7.1 Introduction

This chapter addresses the final aim of this thesis: to design a study to understand parents'
experiences of language assessment for their child growing up with cerebral palsy and
complex communication needs. The body of this chapter comprises the protocol for a
qualitative study for which, at the time of writing, ethical approval has been granted by the
appropriate ethics body.

7.2 Parents' perspectives on the C-BiLLT assessment of spoken language comprehension for their child with cerebral palsy and severe motor and speech impairments: Protocol for a qualitative study

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Parents' perspectives on the C-BiLLT assessment of spoken language comprehension for their child with cerebral palsy and severe motor and speech impairments: Protocol for a qualitative study

Abstract

Background: Family-centred care is an important approach to rehabilitation services for children with cerebral palsy (CP) and their families. However, principles of family-centred care, such as prioritizing the family's needs and values, are currently often overlooked in the assessment stages of the therapeutic process. To optimize testing of language comprehension in children with CP and complex communication needs, it is necessary to obtain insight into the experiences of families with the assessment process.

Purpose: To understand parents' experiences of the assessment of spoken language comprehension with the C-BiLLT, for their child with CP and severe motor and speech impairments.

Methods: This is a qualitative interpretive description study. Parents of children with CP (aged 3-13 years) and severe motor and speech impairments will be invited to participate in an online focus group. A semi-structured topic guide will be used, and data will be analysed inductively. A family research partner with lived experience was involved in all stages of the research process.

Ethics and dissemination: This study received ethical approval from the Amsterdam University Medical Centres Research Ethics Committee (#2017-255). Anticipated outcomes of this study are recommendations to improve the assessment process that reflect the views and experiences from parents. Findings will be disseminated among all stakeholders: families, C-BiLLT clinicians, and clinicians and researchers in the field of childhood disability.

Introduction

Many children with cerebral palsy (CP) experience problems in communication. Their ability to communicate may be limited by difficulty speaking, or by cognitive and/or sensory impairments (Novak et al., 2012; Pennington, 2008). Of children who are able to move around by themselves (i.e. Gross Motor Function Classification System [GMFCS] level I-III), at least 20% experience communication difficulties (Himmelmann et al., 2013). In children who are non-ambulatory and in need of powered mobility or physical assistance (GMFCS level IV-V), communication difficulties are a reality for almost all (Himmelmann et al., 2013; Voorman et al., 2009). The combination of severe motor and speech problems causes children to have much lower rates of participation at home, at school, and in the community (Clarke et al., 2011, 2012; Raghavendra et al., 2012), when compared to children with CP and motor impairments only. The life of families of children with CP and severe motor and speech impairment may differ substantially from the life families with typically developing children, or children with either motor or speech impairments only. Time demands of the basic, recurring activities such as toileting and dressing or disability-activities such as therapy appointments or medication form barriers to spending time on leisure and education (Barabas et al., 1992; Edebol-Tysk, 1989). Children with CP and severe motor and speech impairments and their families will receive many health care services and have frequent appointments they have to attend (Markowitz et al., 2014; Young et al., 2007). Parenting a child with CP and severe motor and speech impairments is physically and psychologically demanding and may cause stress and decreased wellbeing (Parkes et al., 2009; Raina et al., 2005; Sawyer et al., 2011; Unsal-Delialioglu et al., 2009).

Augmentative and Alternative Communication (AAC) intervention strives to provide children with the opportunity to live a life where they are able to participate fully in education, family, and community life, and have the chance to develop friendships and

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intimate relationships (McNaughton & Kennedy, 2010). AAC methods (e.g., speech generating devices, communication boards, or mobile technology with AAC apps) have proven to be effective in alleviating the developmental and participatory risks of these children by providing access to functional speech (Branson & Demchak, 2009; Romski et al., 2015). Speech-Language Pathologists (SLPs) working with children with CP and severe motor and speech impairments often provide AAC assessment and intervention. In AAC care for children with CP, timely and frequent language assessment using psychometrically robust tools provides essential information to guide therapists and families with planning interventions, predict resource needs, and provide objective evaluation of interventions (Hustad et al., 2014; Mei et al., 2016). There are two issues that hamper the availability and applicability of evidence-based language assessments in children with CP and severe motor and speech impairments that we will discuss in more detail.

First, assessment with traditional language assessment tools is challenging or even impossible for children with severe motor and speech impairments because these tools require a spoken or other motor response (Geytenbeek et al., 2010; Stadskleiv, 2020). This means that these children are least likely to receive formal standardized assessment of unobservable aspects of their functioning, such as cognition and language comprehension (Andersen et al., 2008). This issue is addressed by the Computer-Based instrument for Low motor Language Testing (C-BiLLT), which is globally the first accessible assessment tool to reliably evaluate spoken language comprehension in children with severe motor and speech problems. It requires minimal of fine motor skills and no verbal responses for the child to complete testing (Geytenbeek et al., 2014). The test has been in use in the Netherlands since 2015, is part of the Dutch best practice guidelines for pediatric rehabilitation for CP (Richtlijn Spastische Cerebrale Parese Bij Kinderen, 2015), and is implemented in all pediatric rehabilitation facilities in the country. The C-BiLLT provides information on the child's ability to

understand spoken language by means of responding to items presented orally by the test administrator and visually on the screen of a computer or tablet. Children can respond using a method that suits their abilities, *e.g.,* a touch screen (operated by any body part e.g., hand, foot, nose), input switch(es) that can be adjusted to any body part, independent eye gaze computer control with an infrared camera or with an eye control module. The variety in access methods allows even the most impaired children to reliably and autonomously respond to the presented tasks of the test. Besides the original Dutch C-BiLLT, there currently is a C-BiLLT version validated for use in Norway (Fiske et al., 2020), and a Canadian English version is expected to become available in 2022 (Bootsma et al., 2022a).

The second issue in traditional language assessment relates to the delivery of the assessment. Pediatric rehabilitation care in general, and AAC services in particular, are most beneficial when it is offered in a family-centred way (King & Chiarello, 2014; McCoy et al., 2020) in which the family and therapist form a collaborative partnership. Literature on the benefits of family-centred care has shown an increase in participation in family/recreational activities (McCoy et al., 2020), decrease of parental stress (Dunst & Trivette, 2009), and an increase of family satisfaction with the services (Järvikoski et al., 2015; Law et al., 2003). Two complimentary components characterize family-clinician collaboration: 1) relational practice (e.g., active listening, showing respect, honesty, and trust), and 2) participatory practice (e.g., engaging families in the therapeutic process, incorporating their needs and priorities) (Blue-Banning et al., 2004; Dunst & Trivette, 2009). While many clinicians are aware of the need to emphasize the partnership with and the engagement of parents, they struggle with how to implement the participatory practice of family-centred care in their services (An et al., 2019). This knowledge-to-practice gap is especially prominent in pediatric rehabilitation *assessment* practices (Gibson et al., 2018). Assessment in pediatric rehabilitation in general, and for AAC interventions in particular, needs to be considered

within the context of family-centred practices (King & Chiarello, 2014). Assessment forms a big part of services and it is often the start of the relationship between the child, their family, and the clinician (Simeonsson et al., 1995). Therefore, it is an important opportunity to get this relationship off to a good start for everyone involved (O'Connor, 2020). However, as is true for the vast majority of assessment instruments (Gibson et al., 2018), the C-BiLLT's user manual and training focus on standardisation, to ensure a good reproducibility and validity of the test administration. Currently, the manual and training do not explicitly cover family engagement in the assessment process, or approaches how to discuss and interpret results collaboratively.

There is a lack of clinician knowledge about parents' perspectives on routine assessments, their purpose, and the results they yield (Chilosi et al., 2013; Gibson et al., 2018; Kerr et al., 2016; Öhrvall & Eliasson, 2010; Rich et al., 2014; Scime et al., 2017). Therapists reported feeling insecure about communicating the assessment process and results with families out of fear that it will negatively impact the parent-professional relationship (King et al., 2011; O'Connor et al., 2016; O'Connor et al., 2019). Additional insight into the complex realities of families of children with severe motor and speech impairments in relation to language assessment practices is needed to advance disciplinary knowledge in family-centred care (Coburn et al., 2021).

To address this knowledge gap, the aim of this study is to understand parents' experiences of the assessment of spoken language comprehension with the C-BiLLT for their child with CP and severe motor and speech impairments, including the delivery and discussion of the assessment's results. This will inform clinical practice by advancing disciplinary knowledge on the use of the C-BiLLT.

Research questions

1. What are the needs, experiences and perspectives of the families on the assessment process with the C-BiLLT?

2. What are the needs, experiences and perspectives of the families on the delivery and discussion of the C-BiLLT assessment results?

Methods and analysis

Study design

This is a qualitative study using the approach of interpretive description (Thorne, 2016), a research methodology that aligns with a constructivist perspective on inquiry. Interpretive description studies strive to yield knowledge products that are suited to answer the pragmatic clinical problems of health care practice. The complexity of clinical care poses challenges that are not well captured using more traditional, theoretically driven qualitative research methods (Thorne et al., 1997). By applying interpretive description to this project, we aim to reach "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).

This research project will use focus groups to ask families to discuss their experiences, needs, and perspectives on the assessment process using the C-BiLLT. Data collected through discussions in online focus groups will be inductively analysed.

Co-production

The research team that developed and will conduct this project includes a family research partner by experience (MB), two research SLPs (JG, JB), a senior researcher (MK), and a pediatric physiatrist (JWG). The family research partner will be involved in all aspects of the research, including design, facilitating focus groups, analysis, write-up and dissemination.

The type and intensity of involvement of the family research partner will be discussed throughout the project using the Involvement Matrix (Smits et al., 2020), a tool to support research teams in these decisions and discussions. The family research partner was recruited through the Dutch initiative OuderInzicht (www.ouderinzicht.nl), a foundation that advocates for the involvement of family research partners in studies about childhood disability. The family research partner will receive monetary compensation for their work.

Data collection

Data will be collected through focus groups. Focus groups are an appropriate method of data collection because this study seeks to explore the experiences and perspectives of services users (the families) as fully as possible. Opinions, attitudes and beliefs are more likely to be revealed in a reflective process facilitated by the social interaction that a focus group entails (Smithson, 2000; Wilkinson, 1998). Additionally, focus groups foster interaction which is expected to lead to richer information (Smithson, 2000). The analysis will aim to define key themes based on participants' perspectives and their own choice of words (Guest et al., 2017). Data collection for this study is planned to begin in the Spring of 2022 and analyses are planned to be completed by December 2022.

A focus group guide (Appendix 1) will be used to encourage discussion of all relevant aspects of the C-BiLLT assessment process. This includes participants' overarching views, thoughts, and feelings, and specific reflections on aspects of the process including the practicalities of the assessment and communication about the results. The focus groups will be led by two trained members of the research team (MB, JB). Each focus group will last 60-90 minutes.

Recruitment

Participants will be recruited from the database of families enrolled in the Cerebral Palsy - Communication and Language Learning study (CP-CaLL; Vaillant et al., 2022), a Dutch longitudinal study examining the development of spoken language comprehension in children with CP across all levels of functioning. Potential participants will receive a recruitment letter that provides the information sheet for this study, which outlines the purpose and nature of the study, and the ethical details about data protection and privacy. There will also be contact information in case they have any additional questions or concerns they would like to discuss. If the family would like to take part in the study, they can return the attached consent form and a member of the research team will contact them to schedule the online focus group.

Sample size

The aim is to conduct at least 4 focus groups, containing two to four parents each. The number of focus groups will be guided by the concept of meaning saturation. Hennink et al. (2017) describe the difference between code saturation and meaning saturation as the difference between "heard it all" and "understand it all". There is some evidence that most themes are identified in the first two or three focus groups (Guest et al., 2017). For this study it is anticipated that a total of approximately 3-6 focus groups is needed to reach this point.

Inclusion criteria

Parents (i.e., mothers, fathers, caregivers) of children with CP will be invited to participate if a) they have previously agreed to be contacted for further research projects; b) their child's gross motor functioning is classified as GMFCS IV or V (i.e., physical assistance and/or powered mobility is needed for the child to move) (Palisano et al., 1997); and c) their child's speech production and intelligibility are classified VSS III or IV (i.e., speech usually not understandable to unfamiliar listeners out of context, or no understandable speech at all)

(Pennington et al., 2013). Parents can participate regardless of whether they attended the assessment. The total number of eligible families in the database is 65.

Analysis

Focus group data will be analysed inductively using a reflective thematic analysis approach (Braun & Clarke, 2006, 2013, 2020). The focus groups will be audio and video recorded and transcribed verbatim. First step of the analysis process includes familiarization with the data, including transcripts and the fieldnotes (Appendix 2) that will be completed by JB and MB after each focus group. The transcripts will be coded inductively by the lead researcher (JB), using the same language as the participants where possible. As a validity check, two transcripts will be coded by another researcher, and codes will be discussed until consensus is reached. Then, initial coding of textual data into broad thematic patterns and iterative testing and questioning of the labels and linkages between and across data elements will take place. Thematic interpretations will be developed by one researcher (JB) and reviewed and discussed in meetings with the other research team members (MB, JG, MK, JWG). An audit trail of decisions during the data analysis and a reflective journal will be kept by the primary author. Finally, study participants will be asked to reflect on the interpretation that was produced, its authenticity and the degree to which it captures their experiences.

Data protection

All confidential data will be kept for 15 years on password protected servers only accessible to members of the research team affiliated with the Amsterdam University Medical Centres (JG, JB). During transcription, the audio-recordings will be anonymized, with all identifying information removed prior to using the software analysis tool. All video and audio recordings will be destroyed after transcription.

Ethics and dissemination

Ethical considerations

Written informed consent to participate and be audio recorded will be obtained from all participants. Participants will be requested to keep their video on during the focus group but are allowed to join with only audio. Data management and storage will be subject to the General Data Protection Regulation, the European Union's data privacy and security law. Ethical approval for the current study was obtained from the Medisch Ethische Toetsings Commissie (Medical Ethics Research Committee) of the Amsterdam University Medical Centres, the Netherlands (#2017-255).

Output and dissemination

This research has been designed to obtain insight into the experiences of families in order to make recommendations for the C-BiLLT assessment process. The findings will be disseminated via peer-reviewed publications, conferences, the international network of C-BiLLT researchers and clinicians, and lay reports and C-BiLLT training materials. Care will be taken to develop dissemination materials that are accessible to families, i.e., in lay language and available free of charge, through social media outlets and the C-BiLLT website (www.c-billt.com).

Discussion

Family values and preferences are a component of evidence-based practice and family-centred care, yet research into those values and preferences during the assessment process

scarce. To address this critical gap in knowledge, we will collect information on the needs, experiences and preferences of families about the C-BiLLT assessment for their child with CP and severe motor and speech impairments.

Limitations

This study is designed to collect experiences with and feedback on the C-BiLLT assessment process from the perspectives of the families whose children have been assessed. Data will be collected in focus groups, facilitating interaction between parents. It is acknowledged that parents' experiences and perspectives may differ across time and context, which means that the findings of this study may not reflect or predict the experiences of all parents. To maximize transferability of the findings to other contexts and settings, the following actions will be taken: triangulation of investigators (i.e., the team that will analyse the data consists of clinician-researchers, researchers, and a family research partner) and method (i.e., data will be collected from focus groups and the primary researcher's field notes). Because of the concurrent nature of data collection and data analysis, it could also be possible to purposefully sample participants for the last focus group(s). For example, participants whose experiences are counter to the trend could be invited to check the viability of the emerging findings. Finally, the analytic logic followed in this study will be explicated through an audit trail in which the core elements of the study and its interpretive findings are presented in an accessible manner.

Conclusion

The current study will engage with parents of children with CP and severe motor and speech impairments to understand their experiences of the C-BiLLT assessment process. The goals are to inform clinical practice by advancing disciplinary knowledge in clinicians on the use of the C-BiLLT. The anticipated output will be recommendations for improvement of the assessment process with the C-BiLLT for children with CP and severe motor and speech impairments and their families. Lessons learned from this study will also inform recommendations to improve the family-centredness of pediatric rehabilitation assessments in general.

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Appendix 1 Focus group guide: parents' experiences with the C-BiLLT

Jael: Welcoming and introducing.

This focus group is about the C-BiLLT language test that was administered to your child. We have asked you to join this conversation because we are curious about your experiences and opinions about the C-BiLLT. We are very happy that you are here today. You know your child best. We will conduct *#x number* of these types of focus group discussions. With the results of all these conversations we want to improve the C-BiLLT administration for children and parents. The conversation will be recorded so we can type it out later.

In today's conversation we will discuss two main themes. We will start with a conversation about the actual administration of the C-BiLLT. The second half of the conversation will be about the results of C-BiLLT. We would like to discuss these two themes on the basis of questions and statements, but you are also very welcome to contribute your own ideas.

Second, I want to emphasize that there are no right or wrong answers. You have experienced it as you have experienced it, and we are curious about that.

You can choose how much you want to share about your personal situation. I would also like to ask you not to share the stories told in this hour and a half with others.

To ensure that the conversation goes well, I would like to ask you not to talk at the same time.

Explanation mute / unmute buttons. To speak: unmute and start or use the raise hand button.

The focus group lasts a maximum of one and a half hours, so until [time]. At the end there will be time for questions again, but for now: does anyone have a question or comment before we really start? […]

I now turn it over to my fellow researcher Mariska.

Mariska:

Introduce yourself, with this information about Lara (example of succinct introduction).

First of all, please to introduce yourself and tell us what your child's name is, how old they is, and which school they attend. Is there anything important for the others in this group to know about you?

Duration (approx.)	Topic	Prompts (if needed)	Related themes (O'Connor)
10 minutes	First of all, would you like to introduce yourself and tell us how old your child is and where they go to school? Is there anything important for		N/A

| | the others in this group to know about you? | | |

Duration (approx.)	Topics we want to hear about	Prompts (if needed)	Related themes (O'Connor)
25 minutes			
Topic: Administration of the test	Who would like to share what the C-BiLLT administration of his/her child looked like? What comes to mind when you think about the C-BiLLT administration with your child? Presence and role of the parents (Important? Why/why not?) How did you feel during the test? Factors that influence the test administration, such as e.g.: Stress Travel time Physical condition What does it cost…	*How was that with you?* *Whether and which positive thoughts or feelings it evokes / evoked* *Whether and which negative thoughts or feelings it evokes/evoked* *Were you invited to it? Would you have liked to be there?* *How could it be better? / Which would have been better and why?* ---Short summary (check if there are additions) and then introduce the next topic.---	Involvement Trust Protection
25 minutes			
Topic: Results of the test	and what does it yield? Focus on possibilities or on limitations? Recognition of child in results? To what extent? Positive thoughts/feelings, or	*Have the results been discussed with you? In what way?* *What insights did the administration(s) and/or the C-BiLLT results yield?*	Finding worth Positively framed

	negative thoughts/feelings	*How could it be better? / Which would have been better and why?* *How did you/did you proceed with those insights?* E.g.: -impact on child -impact on family life -impact on communication -impact at school If no important information: *What was this about, do you think?* *Could this have been done differently, and if so, how?*		

Jael: Thank you so much for all your stories, opinions and insights. Today, I learned that [summary of what has been discussed]. Is there something I have misunderstood or does anyone have an addition or comment? […] Are there other things about the C-BiLLT that you think are important to bring up, but that have not yet been discussed? […]

As soon as we have completed and analyzed all conversations, I will send you a Dutch summary of the results by email. In the meantime, if you have any questions or comments, you can always contact one of us by email (addresses on PowerPoint slide).

Again, thank you all very much for participating.

General prompts for the group conversation:
- *Is this recognizable?*
- *Anyone want to say anything more about this?*
- *Has anyone experienced this differently?*
- *Is there anyone who thinks otherwise?*

Table 1: Themes and subthemes from O'Connor et al. (2019)

Theme	Protection	Positively framed	Bridging the gap	involvement	Finding Worth	Trust
Subthemes	Protecting my child's identity Protecting the self	Representation Possibilities Support	Unknowing Complying Resigned Reconciled	Overlooked Spectators Intermediaries	Relevant and helpful making plans Insights	In good hands openness Familiarity

				Mentees mentors instigators	An eye on things Accessibility	Will it work?

Appendix 2 C-BiLLT FAM Focus group report (fieldnotes)

Focus group date and time	
Attendees	
Organizational details (e.g.: people left early, faltering technique, etc.)	

Notes

Atmosphere during the conversation:

What did it feel like to facilitate this group and why:

Reflections on the collaboration between Jael and Mariska:

Striking statements, behaviors and interactions:

Insights for the purpose of the analysis and/or the following focus groups:

Chapter 8 Overall discussion and conclusions

8.1 Discussion overview

In this dissertation I have tried to make a meaningful contribution to the work that clinicians do to assess and support the communication of children with cerebral palsy (CP) and severe motor and speech impairments, by researching the Computer-Based instrument for Low motor Language Testing (C-BiLLT) from different angles.

As a speech-language pathologist trained in evidence-based practice, I thought I was aware of the importance of quality assessment when starting my PhD. However, over the past four years my understanding of what "quality assessment" actually entails grew considerably with every step along the way. In a sense, I started at a more 'traditional' standpoint of what an assessment tool should do and be: to truly measure what it says it measures (i.e., a test's validity) and to do so with little unwanted variance, or error, in the scores (i.e., a test's reliability) (De Vet et al., 2011). From my clinical experience, I knew that for me to truly like and adopt a test into my daily practice (i.e., a test's implementation), it also needed to be easy to administer (aspects of a test's feasibility), to add value to a client's life, and not be too taxing for clients and their families (aspects of a test's clinical utility). Back then, I did not realize the extent to which these last three facets of assessment are worthy of scientific attention. However, I now know that a psychometrically robust assessment tool such as the C-BiLLT is worth little if its implementation into practice fails, if it causes stress or harm to participants, or if its results are not meaningful to the patient, their family, and their clinicians. I consider this as a key lesson learned.

In this final section of my thesis I will present how this body of work made important contributions to the literature on different aspects of evidence-based assessment. I would be thrilled if this dissertation would help to further people's thinking about what a good

assessment tool is, just like it did for me. First, however, I will reflect on the dramatic effect

that the Covid-19 pandemic had on the data collection for the psychometrics study of the

Canadian English version of the C-BiLLT (C-BiLLT CAN).

Data collection for the study described in Chapter 3 was about half-way when the

Covid-19 pandemic shook the world in 2020. Like most regions in the world, the Canadian

province of Ontario took drastic measures to reduce the risk of the spread of the virus,

including closure of schools and restrictions on all in-person meetings. These measures

impacted our data collection process immediately. We were in the middle of the data

collection in which we administered several different cognitive tests to typically developing

children, and children with CP and severe motor and speech impairments. Prior to the

pandemic, some of the study visits with typically developing participants (age 1.5-8.5 years)

took place at McMaster university, but more often the child would participate in the study at

their own school. In such cases, a student research assistant would travel to schools and assess

the child in a quiet room. Since both the university and all primary schools were closed, these

visits were discontinued. Study visits for the children with CP always took place at the Ron

Joyce Children's Health Centre in Hamilton, and these also had to be discontinued to comply

with the rules. As described in the section that preludes Chapter 3, our team was able to

successfully pivot to online study visits to complete data collection for the typically

developing children, but not for the children with CP. Their study visits would often include a

trial of different access methods to participate in the C-BiLLT (e.g., access via head mouse,

eye tracking, or non-computerized eye gaze). Such trials were impossible to implement in

their homes in the time frame of our study. This meant that we were not able to find a way to

continue the study visits with these children and their families.

To me, this was a harsh reminder of the complexities of assessment for these children.

It also felt ironic. The C-BiLLT was developed specifically to *reduce* barriers to assessment

and all of a sudden, we could no longer include interested children and families in our study, many of whom had eagerly awaited their turn. It was frustrating because it meant that we had to base our findings and recommendations about the C-BiLLT's feasibility for Canadian children with CP on a limited sample ($n = 9$). For a dissertation about improving services specifically for children with CP and severe motor and speech impairments, this has felt like a disappointing number at times.

Thankfully however, the multidisciplinary group of experts, including several international alliances, that was formed during the different projects of this PhD proved to be strong and prolific. The specific needs of these children and families will be assessed and addressed thoroughly in an encouraging next step that builds on this dissertation: a four-year research project about the implementation of the C-BiLLT CAN in the Canadian healthcare context. This future project is described in more detail below in section 7.3. Both professionally as well as personally, it is exciting and comforting to know that through this new project more children and families will be reached. This will hopefully result in the possibility for robust evaluation of spoken language comprehension skills for all children in Canada.

8.2 Summary of findings

Across four chapters, this thesis examined the C-BiLLT from different angles. The following aims and knowledge gaps were addressed: a) to develop the English language version of the C-BiLLT for use in Canada; b) to explore feasibility of the C-BiLLT in the Canadian healthcare context; c) to assess the implementation process of the C-BiLLT to date, (d) to understand C-BiLLT related clinician behaviour; and e) to understand families' experiences with their child's C-BiLLT assessment. Each study was implicitly or explicitly informed by a

number of frameworks: the International Classification of Functioning, Disability, and Health (ICF, WHO, 2001), the framework of evidence-based practice, and family-centred care. The paper on the psychometric properties of the C-BiLLT CAN (Chapter 3) provided evidence of acceptable levels of convergent validity, internal consistency, test-retest reliability, and measurement error of the C-BiLLT CAN, when used with typically developing children. The cross-sectional study also revealed some feasibility issues when the C-BiLLT was piloted in a Canadian healthcare setting with children with CP and severe motor and speech impairments. For instance, some participants had to travel for hours to the clinic, which sometimes caused fatigue that would interfere with the completion of the C-BiLLT. The second study (Chapter 4), reporting on a survey among 90 clinicians, provided evidence for the use of the C-BiLLT in clinical practice in the Netherlands, Belgium, and Norway, and described its implementation status. It demonstrated how clinicians use the C-BiLLT with children with CP and also with children with a variety of other disorders. In the third qualitative description study (Chapter 6), I explored clinician behaviours with regards to using the C-BiLLT in more detail. The COM-B model of behaviour change (Michie et al., 2014) was used to understand how capability, opportunity and motivation play a role in the adoption, implementation, and continued use of the test in clinical practice. The study identified a need for implementation support for clinicians who use the test with the intended population, i.e. children with severe motor and speech impairments. Proposed strategies include instructional videos that clinicians can watch in lieu of real practice, and additional information about the interpretation of looking behaviours in the participants. The final study (Chapter 7) is a protocol paper that describes a qualitative study about collecting families' experiences with their child's C-BiLLT assessment process. The approach to qualitative data analysis is interpretive description (Thorne, 2016), which strives to yield knowledge products that are suited to answer the pragmatic clinical problems of healthcare practice.

Overall, this dissertation makes important contributions to the literature and has meaningful implications for practice. The ways in which this work can contribute to research and practice in language comprehension assessment for children with CP and severe motor and speech impairments are presented next.

8.2.1 Development of the first English language C-BiLLT

Through the development of the C-BiLLT CAN (Chapters 2 and 3) I have made a new and important contribution to evidence-based assessment tools for language comprehension. During the past decades, the number of assessment tools for children with CP has risen considerably (Schiariti et al., 2018; Wu et al., 2015). Despite this increase overall, children with severe motor and speech impairments can still often not participate in formal assessments. This is especially true for tests that aim to measure constructs that are not readily observable, but that need to be implied from behaviours on a test, such as language comprehension and cognitive abilities. The exclusion of children with severe impairments from participation in formal assessments leads to a paucity of evidence about their functioning and development (Smits et al., 2011; Stadskleiv, 2020). In turn, this lack of knowledge can fuel well-intentioned but faulty assessment practices and poor-quality interventions (Beukelman & Mirenda, 2013a; Hanna et al., 2007) The implications of missing out on quality assessment and intervention are disheartening: children with CP and severe motor and speech impairments may never live up to their full communicative potential and thus will miss many opportunities for activities and experiences that make a fulfilling life (Smits et al., 2019; Voorman et al., 2009).

My doctoral work on the development of the C-BiLLT CAN addressed the gap in evidence-based accessible language tests. The C-BiLLT CAN can serve as the foundation for accessible evidence-based assessment of language comprehension for Canadian children

whose primary language is English. The cross-cultural adaptation of the C-BiLLT described in Chapter 2 is a testament to the comprehensive process that was used, as recommended by the International Test Commission (2017). This process was elaborate and thus took time. However, the process thorough process brought concerns (e.g., about the conceptual equivalence of some items) to the surface early, so that they could be dealt with before moving on with the evaluation of the psychometric properties.

The psychometric properties of the Canadian version reported in Chapter 3 demonstrate the robustness of the resulting instrument, akin to the original Dutch C-BiLLT. In practice, the C-BiLLT CAN can help clinicians to gather information about a child's comprehension of spoken language, accommodating different access needs. This information will hopefully be used to ensure that the child receives developmentally appropriate education and tailored communication supports.

8.2.2 Focus on implementation from the start

Another unique contribution of this work is the extent to which the actual implementation of the C-BiLLT has been addressed: from a small-scale exploration of the feasibility of the C-BiLLT CAN in Chapter 3 to an in-depth study of the implementation status of the original C-BiLLT in the Netherlands and the C-BiLLT NOR in Norway in Chapters 5 and 6. The use of evidence-based assessment tools is not self-evident, even if guidelines, knowledge, resources, and motivation are present (Proctor et al., 2011; Straus et al., 2013). The healthcare field is increasingly aware of this knowledge to practice gap, and research about implementation theories and strategies is on the rise (Menon et al., 2009). Individual clinician traits are a particularly poorly understood determinant of implementation (Menon et al., 2009). In Chapter 6 I applied a theoretically driven analysis to clinician interview data about their C-BiLLT related behaviours. This study identified a distinction

between clinicians who use the C-BiLLT with children with severe motor and speech impairments (the test's target population) and clinicians who use it with any client, in lieu of another language test. This study highlighted the strong motivation of the first group of clinicians, but also the complex barriers they faced trying to use the tool. Barriers included for instance insufficient opportunities for practice and knowledge and resource barriers related to the group of children with CP and vision impairments. These barriers to C-BiLLT use must be addressed in order to secure access to evidence-based language assessment for all children with CP and severe motor and speech impairments in the future. It is known from the implementation science literature that relying on passive educational strategies is often not enough. Our study gave tailored suggestions to reduce or remove the barriers that clinicians experienced using other strategies (e.g., offering technical support, and virtual training opportunities), which increases the chances of success.

8.2.3 Involving patient and family partners in research

Disability rights activists coined the term "nothing about us without us" to underline that no policy should be reached without full participation of representatives of all stakeholders (Charlton, 1988; Wikipedia., n.d.). Patient communities soon adopted the motto in their venture to get a seat at the table in the healthcare system. The involvement of patient and family partners in research is increasingly valued (Elf et al., 2017; Richards et al., 2015). Patients and families can make important contributions in all aspects of the research cycle: from study inception and priority setting, the execution of the study, to the dissemination of the results (Curran et al., 2018; Domecq et al., 2014; Shippee et al., 2015).

I have learned a lot about why it is important, how it can be done, and how challenges can be overcome. In the final year of my PhD, I had the opportunity to solidify this knowledge by participating in the Family Engagement in Research course, offered by Kids

Brain Health Network and CanChild. To graduate from this ten-week course, together with fellow students I created a resource for trainees who want to involve families in their research. We developed a guide based on our own experiences and evidence from the literature to help trainees prepare for authentic and successful family involvement in their research project(s). This guide (please see https://kidsbrainhealth.ca/index.php/2022/02/03/building-blocks-of-partnerships/) is one example of a non-traditional yet meaningful outcome of my PhD.

Another endeavor to advance family engagement in research was my participation in a paper about compensation for family research partners. This paper is the product of a collaboration between several CanChild students, family research partners, and scientists. It describes the challenges in compensating family research partners for their time and work, and offers suggestions for how to handle these challenges (Novak-Pavlic et al., 2022).

Last but not least, the qualitative study described in Chapter 7 included a family research partner on the team. The family research partner was and will be involved in all aspects of the research, including design, facilitating focus groups, analysis, write-up, and dissemination. The family research partner was recruited through the Dutch initiative OuderInzicht (www.ouderinzicht.nl), a foundation that advocates for the involvement of family research partners in studies about childhood disability. To be able to financially compensate this partner for their involvement in this project and underline the value of their involvement, I secured funding through the CHILD BRIGHT Graduate Student Fellowship in Patient-Oriented Research. The existence of such funding opportunities is an encouraging and necessary step towards the recognition of the value of patient and family partners in research.

8.3 Future directions

8.3.1 C-BiLLT CAN

While this thesis provided evidence of the validity and reliability of the C-BiLLT CAN, we also have identified some knowledge gaps. For example, discriminant validity was lower than hypothesized, for which several possible causes were considered in Chapter 3. Validity of an assessment tool should be re-estimated if the tool is applied in a new situation or for another purpose (de Vet et al., 2011). Here, the new situation was the new language and culture version of the C-BiLLT. To test if this new version measures what it purports to measure, the C-BiLLT CAN was validated on a sample of 80 typically developing English speaking Canadian children. In the adaptation process, care was taken to select items and images that are present in the world of Canadian children with severe motor and speech impairments, to ensure that the items can be actually known by them. Because we did not assess validity in a sample of children with such impairments, it is not yet clear if we were successful in reaching this goal.

To explain why we did not assess validity of the C-BiLLT CAN with a larger sample of the test's target population, we need to go back to this study's inception. In the Netherlands, the psychometric properties of the test were assessed in a larger sample of children with CP and complex communication needs (N = 87), and while their mean C-BiLLT scores varied widely across the different age groups, the validity and reliability parameters were excellent (Geytenbeek et al., 2014). Our Canadian team decided to focus this research on investigating the validity of what has changed in this new version: the translation and adaptation of the test's content from Dutch to English. This was done under the assumption that the Canadian children with CP and severe motor and speech would perform similar to their Dutch peers, given that the test would be psychometrically sound.

The same reasoning was followed regarding the assessment of the C-BiLLT CAN's reliability. Reliability of an instrument depends highly on the distribution of the characteristic (i.e., language comprehension) in the population (i.e., children with CP). It is possible that language comprehension abilities are distributed differently in a population of typically developing children, and that therefore the reported reliability of the C-BiLLT CAN in this thesis may be different when estimated in a sample of children with CP. Future research can address this by estimating validity and reliability of the C-BiLLT CAN in a sample that reflects the test's target population.

8.3.2 C-BiLLT Implementation

This dissertation identified several facilitators and barriers to C-BiLLT implementation. This prompted the development of a grant application led by principle investigators Drs Chau and Cunningham, and myself as a co-investigator among others, entitled *"Innovative language assessment for children with low motor and speech function: Engaging stakeholders to understand the necessary conditions for implementing the C-BiLLT in Canada"*. This grant proposal was submitted to the Canadian Institute for Health Research and was approved for funding. In four years (2022-2026), the team will address the feasibility barriers and develop and implement user trainings for clinicians, in line with the knowledge and practice gaps identified in this thesis. The project's three aims are to: 1) understand Canadian clinicians' and families' perceived barriers and facilitators to using the C-BiLLT, and how they would use results to inform service delivery and education plans; 2) modify and test the C-BiLLT's accessibility (access methods) with Canadian children to ensure all children have access to a reliable assessment of their language comprehension; and 3) develop and pilot training materials, and methods to support implementation in Canada. The project involves a collaboration between researchers, clinicians, and family research partners affiliated with

Western University in Londen, Ontario, CanChild, McMaster University in Hamilton, Bloorview Research Institute in Toronto, and Glenrose Rehabilitation Hospital, in Edmonton, Alberta. This new research project will address and improve the four elements of quality decision making as defined by Sackett et al. (1996) as follows: the project will provide clinical research evidence about existing and new access methods for the C-BiLLT CAN, it will support clinician expertise by providing training materials, it will consider patients' and families' values and practices regarding the assessment process, and finally, it will ensure the C-BiLLT's fit with locally available resources. Outcomes of this new research project will hopefully bring evidence-based language assessment closer for *all* children in Canada. This project may also yield valuable information for C-BiLLT assessment worldwide. Because of Canada's geographical size, virtual training, implementation, and potentially even administration of the test will sometimes be more feasible than in-person alternatives. This will provide information and materials that may be used in other countries as well, for instance when in-person meetings are restricted in future pandemics or because families and clinicians appreciate the opportunity.

8.3.3 Family-centred Assessment

The approach of family-centred care is evolving from being focused mainly on interventions to including the assessment process as well (O'Connor, 2020), an exciting development in pediatric rehabilitation therapy. It means that measurement research will focus not only on an assessment tool's content and establishing its psychometric properties, but will also seek to understand and improve the experience of testing, and families' perspectives on the test's purpose and their interpretation of its results (Gibson et al., 2018). To this end, the findings from the study described in the protocol paper in Chapter 6 of this thesis could inform the development of materials to support family centred assessment with the C-BiLLT. It will

likely advance the disciplinary knowledge of clinicians working with children with severe motor and speech impairments in a more general way.

Because the study itself is beyond the scope of this thesis and therefore there are no study results from this project yet, the suggestions hereafter are based on the existing literature and on the knowledge and experience I have built in the last four years. Collaboration between clinicians and families should be based on the fundamentals of family-centred care, i.e., the relational practice component and the participatory practice component. It is important to note that family centred-care should not be understood to mean that families always take the lead in decision making regarding their child (Wiart et al., 2010). Families abilities and preferences should be acknowledged and respected. To promote an assessment process in which families can participate to the extent that they are willing and able, several actions can be considered in future research.

Families and children need to be provided the opportunities to learn what will happen during assessment with the C-BiLLT before they participate. Currently, if and how this is done is up to the individual clinician. In future research, materials can be developed to prepare children and families for C-BiLLT assessment (e.g., videos that show what will happen) to ease test anxiety and stress during the assessment.

Even with the C-BiLLT, assessment is often still complex for many children with severe motor and speech impairments. There are many more factors outside accessibility that can weigh into the child's well-being and behaviour in a testing situation, including but not limited to personality, fatigue, pain, and epilepsy. A closer and well-prepared collaboration with the child's family could provide the clinician with insight into how such factors influence the child's behaviour. This knowledge can then support their clinical reasoning. To support such clinician-family collaboration, some great suggestions have come from clinical practice. These ideas and tools are presented on websites such as www.praacticalaac.org, and

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on social media such as YouTube (e.g., teachmetotalk). After all, the C-BiLLT's official result is just one number, the entire assessment process as it is reportedly already yields much more information (Bootsma et al., 2022b), and it could yield even more.

8.3.4 Important considerations

I would like to end this section on future directions with two more general considerations that I think should be kept in mind in future C-BiLLT research endeavors. The first suggestion is to anchor a multilingual lens to all C-BiLLT related studies and developments. Given the fact that globally, most children are raised in multilingual environments (Valdés, n.d.), a multilingual approach would enhance the C-BiLLT's validity by being a truer representation of real-world language comprehension. Equally important is that it would contest the marginalizing and discriminative practices that a monolingual standard may provoke (Schissel et al., 2019). Two ways how such a multilingual perspective could be operationalized are to: a) purposefully recruit multilingual children for future samples; and b) consider how multilingualism impacts the construct of spoken language comprehension and to apply this knowledge to the content of the C-BiLLT. This suggestion is based on the realization that both Speech-Language Pathology and Augmentative and Alternative Communication (AAC) practice are not value-free (Beukelman & Mirenda, 2013a; Hetzroni, 2002; Parette & Brotherson, 2004; Wickenden, 2013). Standardized assessment tools in these fields reflect societal and cultural norms and ideas (e.g., about what or who can be considered normal, important, and/or valuable), and thus have the ability to define and shape the identity of the person who is being assessed (Stobart, 2008). Moreover, evidence-based assessments can hold power over the opportunities a person gets in life. Assessment is often used to determine who deserves access to supports, and who does not. For the children that this thesis is about, access to appropriate supports can make a huge

impact on their development and wellbeing. This brings me to the second consideration about using the C-BiLLT in clinical care.

The second suggestion is about assumptions when introducing AAC interventions. There is a history of setting prerequisites for getting started with AAC, or for the selection of certain types of AAC (Zangari et al., 1994), also known as candidacy models (Beukelman & Mirenda, 2013a). These models would prescribe the isolated training of non-functional skills (e.g., learning about object permanence by finding toys hidden under a towel) in order for the child to 'become ready' for the introduction of AAC. At large, the C-BiLLT's purpose is to further a child's communication by gaining insight in their current skills in understanding spoken language, and this could easily be thought of as a prerequisite skill.

However, current evidence suggests that these prerequisites, be it specific to the client's age, cognitive, linguistic, or motor skills, are not meaningful or predictive of future performance (American Speech-Language-Hearing-Association, n.d.). Therefore, the field currently holds the stance of *presuming* competence, a concept first introduced in 1984 (Cress & Marvin, 2003; Donnellan, 1984). It implies that a child does not have to show that they for instance have good language comprehension or sufficient communicative intent before they are provided access to a robust AAC system.

This is of huge importance to children growing up with severe motor and speech impairments, who may not have been provided with the means to develop these skills in the first place, and for whom assessment of these skills is often flawed. In his book on the uses and abuses of assessment (2008), Stobart describes this relationship between a person's (IQ) assessment scores and their environment and experiences. The logic in this relationship should be that "a diminished environment will generate lower IQ scores, and higher scores will have benefitted from richer ones" (Stobart, 2008, p. 48), and not the other way around, i.e., that a person is prospering *because* of their high intelligence. There are several causes

why the environment of children growing up with CP and severe motor and speech impairments is likely diminished by definition. To name a few, these children cannot explore their environment in ways that typically developing children do, restricting their experiences with people, objects, and events in the world around them (Anderson et al., 2013; Houwen et al., 2016, Light, 1997). Accompanying sensory impairments would limit their capacity to explore and interact with the world around them as well (Moeller, 2007; Tadić et al., 2010). This lack of self-initiated, independent exploration together with the inability to produce speech and to communicate easily in conventional ways, means that they elicit less language input (Pennington, 2008). Lastly, the daily personal and medical care for these children take up so much time, that this happens at the expense of engaging in leisure and education (Barabas et al., 1992; Edebol-Tysk, 1989).

Therefore, care must be taken not to defeat the C-BiLLT's overarching purpose by allowing C-BiLLT assessment results to not work in favor of the child, but against them. C-BiLLT scores should not be understood in isolation nor to base cut-off scores on that determines if and what kind of AAC a child should receive. C-BiLLT assessment results should be interpreted in the context of a broader assessment that considers many different aspects of the functioning and participation of the child, including environmental factors. A helpful framework for carrying out AAC assessments and how to integrate the C-BiLLT in the process, could be Beukelman and Mirenda's Participation Model (1988). This model evaluates communication in the context of an individual's life, with the goal of optimizing their functional participation in communication (Beukelman & Mirenda, 2013b). Assessment according to this model considers the interactions of the individual who uses AAC, the activity to be completed, and the context in which the activity is performed. It includes the assessment of several possible opportunity and access barriers to participation. Opportunity barriers pertain to societal or support system limitations (e.g., policies, practices, or the skills

of the child's communication partners). Access barriers pertain to the capabilities and personal factors of the individual who communicates using AAC. The degree to which a child currently understands spoken language (i.e., results from the C-BiLLT assessment) would inform if and how this ability affects the child's current participation, among all other interactions.

8.4 Conclusion

The lectures, meetings, conferences and the more informal interactions during the past four years of my PhD program have expanded my thinking about assessment, rehabilitation, healthcare and research methodologies considerably. I have deepened knowledge and skills that I already had, but more excitingly, I gained knowledge and skills that I previously did not even know existed. This is thanks to the many excellent people that I met along the way. The obvious ones in the form of my wonderful supervisory committee members and lecturers. I have also learned so much from unanticipated contacts with for instance the participating children and families, the many students who assisted in my projects, and experts in fields that I coincidentally came across. I am so grateful for everything I have learned.

It has been a tremendous privilege to be able to spend so much time immersed in research. It has awakened my interest for qualitative research methodologies, something I would have never been able to predict at the start of my PhD in 2018. I have learned that the research questions that are best answered by a qualitative investigation fascinate me most. In several studies of this thesis, I was able to explore some the whys and the hows of qualitative research for clinical questions. Yet, it feels as if I have only done so at a relative surface level, due to the time constraints of a PhD. However, what I do know now is how rewarding this

type of research is to me and I look forward to practicing and expanding my knowledge and

skills in future positions.

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