Measurement of the functional impact of adaptive seating technology in children with cerebral palsy

De invloed van zitaanpassingen op het functioneren van kinderen met een cerebrale parese

door

Stephen E. Ryan

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(met een samenvatting in het Nederlands)

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Contents

List of Abbreviations

AACPDM	American Academy for Cerebral Palsy and Developmental Medicine
ANOVA	analysis of variance
AT	assistive technology
ASD	adaptive seating device
API	activity performance issue
COPM	Canadian Occupational Performance Measure
CP	cerebral palsy
CTT	classical test theory
FIATS	Family Impact of Assistive Technology Scale
GMFCS	Gross Motor Function Classification System
HAL	Home Activity Log
ICC	intraclass correlation coefficient
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health – Children and Youth Version
IFS	Impact on Family Scale
IQ	Intelligence Quotient
IRT	item response theory
MACS	Manual Ability Classification System
MHA	Minnesota Handwriting Assessment
OT	occupational therapy
OQAQ	Overview Quality Assessment Questionnaire
PEO	Person-Environment-Occupation Model
RCT	randomized controlled trial
UN	United Nations
WHO	World Health Organization

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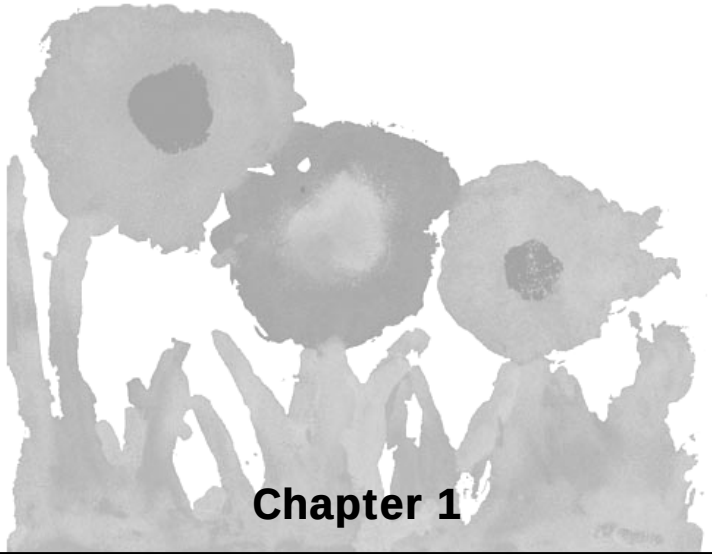

Chapter 1

Introduction

Stephen E. Ryan

Human rights are the basic liberties to which all people are entitled. Economic, social, and cultural human rights are internationally accepted as immutable and inherent in people of all ages. Children are vulnerable and need protection and care to guarantee that their human rights are fulfilled and secured. As a sign of our global obligation and commitment to ensure the rights of children to develop to the fullest and participate fully in family, cultural, and social life, the United Nations created the *Convention on the Rights of the Child* [1] in 1989. The Netherlands and Canada are among 190 countries that have ratified this agreement and, by doing so, agree to be bound by and held accountable to its articles under international law.

Through this convention, and the related *Convention on the Rights of Persons with Disabilities* [2] which entered in force in 2008, the international community acknowledges special entitlements of children with disabilities. In particular, ratifying countries agree to take the necessary steps to "ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children", [2 (Art.7, Para. 1)] and "enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community." [1 (Art.23, Para. 1)] Further, children with disabilities have the right to receive access to quality health care, rehabilitation, education, and other services so as to achieve the fullest possible individual development and social integration.[1,2]

MEASUREMENT OF CHILD-ENVIRONMENT INTERACTION AND CHILD FUNCTIONING

The World Health Organization (WHO) International Classification of Functioning, Disability and Health - Children and Youth Version (ICF-CY)[3] published in 2007 provides a universal, interactive way to think about and measure the health of all children. Based on the original ICF classification system and model for adults,[4] the ICF-CY includes a biopsychosocial framework to describe health conditions and identify factors that may affect the health-related state of children. The framework is constructed to describe the relationship and interaction between a child's health condition and contextual factors (figure 1.1).

Health condition is the overarching term for the underlying acute and chronic disorders that may influence the emotional, physical, and/or social status of the child. Whereas, *contextual factors* include both environmental and personal factors. Environmental (external) factors include natural or human-made products in the child's immediate surroundings; elements of the natural or physical environment; physical and emotional support provided by family and other people at home, at school and in the community; the attitudes of friends, family members, and other people that may influence the child's life; and societal

systems, processes and policies. Personal (internal) factors include the child's gender, educational level, behaviour, preferences, and cultural background.

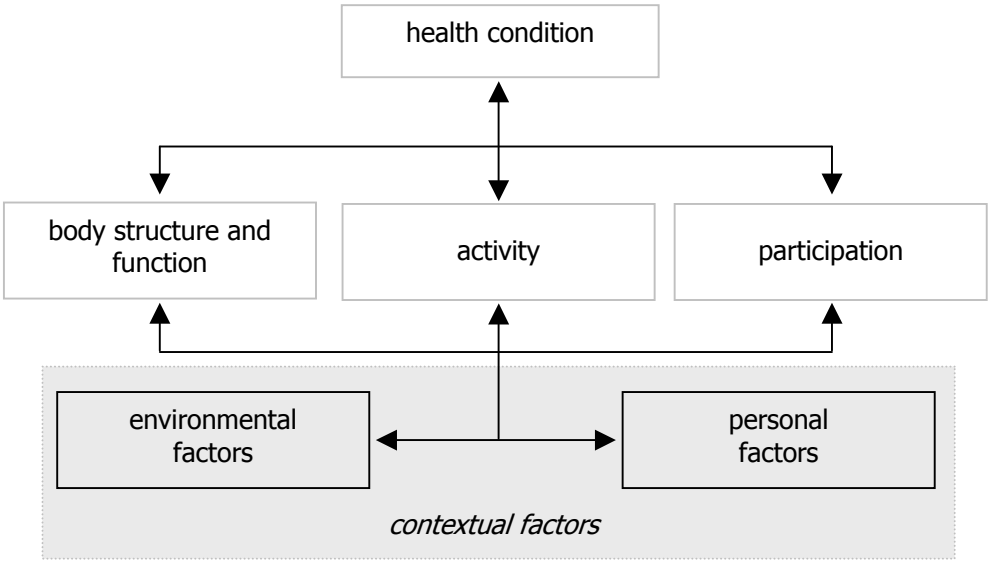

Figure 1.1: ICF-CY Framework

These contextual factors influence and modify one another, the biological aspects of a child's condition (body structure and function), the everyday tasks that the child undertakes (activities), and the child's involvement in life events (participation). It is the interaction of these factors that affect and are affected by the child's health condition. Within the ICF-CY model, contextual elements may act as facilitators and/or barriers to change in the child's levels of functioning, health, and disability.

Models of Child Functioning The interaction between heath condition and contextual factors resonates with contemporary models of functioning in paediatric rehabilitation. Helders and colleagues[5] promote the adapted Nagi framework[6] encouraging health care providers, decision makers, and other stakeholders to conceptualize outcomes of paediatric rehabilitation to be a combination of individual (the child's condition and reaction to a condition), extra-individual (the influence of others such as parents and family members), and risk factors (the consequences of environmental facilitators and barriers). These co-factors reflect the same environmental and personal factors described within the ICF-CY model.

Other complementary interaction frameworks in children's rehabilitation include the person-environment-occupation (PEO) model[7] that describes transactions among the child, the physical, social, and cultural environments, and the fulfillment of the child's self-directed tasks; determinants of motor change[8] model that contends the motor development of a child with physical disabilities influences and is influenced by child characteristics and personality, family ecology, and the availability and accessibility of health care services; and the family-centred care[9] model that promotes rehabilitation research and services that acknowledge and integrate the needs of the child and family within home, school and community settings. An overview of these emerging models is described in more detail elsewhere.[10] Despite their different conceptual foci, these models are consistent with the ICF-CY construction through consideration of the influential effect of both environmental and personal factors when describing the functional outcomes of children with disabilities.

Interactionist Model In the interactionist model for rehabilitation practice and research, Bartlett and colleagues[11] expand the clinical utility of the ICF model by positing that environmental and personal factors relate by both interaction and association, and that interactions exist between the functional dimensions of body functioning/structure and activity, and activity and participation rather than exclusively through direct interaction with these dimensions. Through the adoption of the interactionist approach, practitioners are urged to work with children and their families to set realistic goals to target modifiable environmental and personal factors. With respect to rehabilitation research, this approach is promoted to frame research questions, plan appropriate methodological designs, and assist in the consolidation and interpretation of empirical evidence.

What makes the adoption of this view of the ICF-CY framework particularly appealing to interventionists and researchers is that it 'provides many more points of entry…to enhance the activity and participation of children whose functional well-being is at risk.' [12, p.7] Darrah[13] builds upon this thinking in paediatric rehabilitation by encouraging practitioners to consider interventions directed at one dimension in the context of affecting changes both within a targeted ICF dimension and among other dimensions. For instance, clinical strategies aimed at improving upper extremity control of a child with cerebral palsy (CP) can be viewed to influence and modify a child's ability to play (activity) and interact with other children or family members (participation) at home, in school, and in community settings (including different physical, temporal, and social environments). Should the intervention at the impairment level lead to increased child autonomy, one may find improvements in the child's confidence, peer interaction, and family relationships. Such outcomes could precipitate positive attitudinal and motivational changes that promote further autonomous child behaviours in other settings and situations.

Within this interactive structure of child functioning, evaluation of the impact of interventions may be qualified by what the child can do at his or her best under ideal conditions (capacity) and what the child actually does in real world settings (performance). Evaluation of capacity is conducted in a standard environment without personal assistance or assistive devices. Whereas, the measurement of performance outcomes is done in relevant contexts such as the child's home, school, and community.[13] The description of child functioning using these qualifiers helps clinicians and researchers to isolate the source and elucidate the magnitudes of change due to interventions and other contextual factors.

Child-Environment Interaction Model Simeonsson and colleagues[14] recommend that clinicians and researchers consider the child's developmental stage when assessing the consequences of environmental factors on function, because a child's world changes dramatically across infancy, early childhood, middle childhood, and adolescence (figure 1.2). The developing child is seen to include the levels of physical and mental functioning in domains such as the gross motor, fine motor, cognitive, and sensory abilities, and personal factors such as beliefs and preferences.

Levels of functioning within each of these dimensions exist along a continuum from intact to impaired. Recognition of the developmental stage of the child is required to understand the varied impact of environmental factors. For example, the influence of family factors and home settings will likely have an important influence on the functioning of toddlers and young preschoolers; whereas, the interaction of school settings and peer interactions will very likely have greater a contributory effect on the functional performance of older children and adolescents.

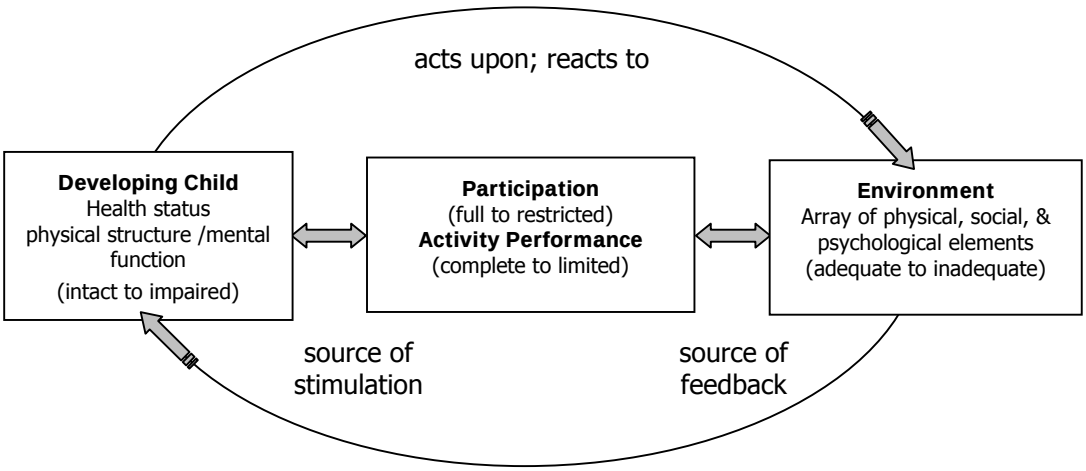

Figure 1.2: Child-environment interaction (from Simeonsson et al.[14])

This child-environment interaction model is consistent with the ICF-CY paradigm. The model developers posit that the child's actions and reactions to the psychosocial and physical elements of the environment stimulate the acquisition and development of complex skills for everyday living. The development of these skills is advanced and reflected in the child's levels of participation and activity performance. Restrictions in participation and limitations in activity performance may be heightened or mitigated by the child-environment interaction. Isolating and understanding the influence of specific environmental resources will assist targeting interventions that may have beneficial effects on the health of the developing child.

ASSISTIVE TECHNOLOGY DEVICES AS ENVIRONMENTAL RESOURCES FOR CHILDREN WITH DISABILITIES

Assistive technology (AT) devices are common environmental resources defined as 'any product, instrument, equipment, or technology adapted or specially designed for improving the functioning of a disabled [child].'[3, Ch. e1] AT devices are considered extrinsic enablers[15] because they are peripheral products intended to optimize abilities and thereby influence the level and nature of a child's activities and participation in everyday settings and situations.

Despite general acceptance of the important role that AT devices play, little is known about their impact on the lives of children and their families. In part, this lack of understanding may be attributed to acceptance of the 'obvious' benefits of AT devices.[16,17] However, clear and consistent evidence of AT device abandonment, dissatisfaction, and non-use leads one to question the magnitude and directionality of AT device impact in children with disabilities.[18-20]

Children with functional impairments often use many types of AT devices depending upon their activity performance needs. AT devices may include adaptive seating devices (such as custom wheelchair seating, special school chairs, floor sitting devices, toileting systems, and shower chairs), special postural control devices for standing or lying (such as standers and bed positioning devices), mobility devices (such as walkers and manual wheelchairs), communication devices (such as integrated augmentative and alternative communication systems and word prediction computer programs), and orthotic products (such as ankle foot orthoses and spinal jackets).

In surveys of AT device use, parents report that children used devices for everyday positioning, mobility, bathing, toileting, and eating activities at home,[21,22] and used different AT devices to assist in execution of the same tasks[23] and in different settings.[24] Cross-sectional studies such as these are helpful in understanding the association of AT use and impact on child and family functioning. However, since

both outcomes and AT use are measured simultaneously, causal relationships and the contributory influence of other contextual factors cannot be determined.[25]

To understand what is known about the impact of AT device use on child functioning, it is essential to review and analyze primary research evidence. A systematic review is "a review of the evidence on a clearly formulated question that uses systematic and explicit methods to identify, select and critically appraise relevant primary research, and to extract and analyze data from the studies that are included in the review."[26, pg.4]

Henderson and colleagues[27] conducted a systematic review of AT outcome studies published between 1996 and 2006 to estimate the effect of AT devices on child, caregiver, and family functioning. The authors described the outcome foci and evaluated the strength of articles that studied only AT devices used by children with chronic impairments. The levels of evidence guidelines adopted by the American Academy for Cerebral Palsy and Developmental Medicine[28] (figure 1.3) were used to evaluate the articles included in the review. More rigorous research designs, such as randomized controlled trials and prospective cohort studies, provide the means to control for systematic biases due to confounding factors (associated with both the AT exposure and the outcome), moderating influences (the strength and directionality of the outcome), and mediating effects (in the causal path between the AT exposure and outcome). Consequently, these methodological designs are rated more highly than case series, case-control, and case studies because it becomes more difficult to disentangle these factors from causal ones.

Level I
Systematic review of randomized controlled trials (RCTs)
Large RCT (with narrow CIs; *n*>100)
Level II
Smaller RCTs (with wider CIs; *N*<100)
Systematic reviews of cohort studies
'Outcomes research' (very large ecologic studies)
Level III
Cohort studies (with control group)
Systematic reviews of case–control studies
Level IV
Case series
Cohort study without concurrent control group
Case–control study
Level V
Expert opinion
Case study or report
Bench research
Expert opinion based on theory or physiological research
Common sense/anecdotes

Figure 1.3: AACPDM Levels of Evidence

Among the 54 articles that met the inclusion criteria, the reviewers[27] found all but three articles focused on child-related outcomes relating to dimensions of activity, participation, and personal factors. However, less than 30% of the articles included caregiver outcomes, and none considered the effect on family functioning.

Although AT use was reported to have a positive influence on child functioning in most articles, the levels of evidence were low (i.e., levels IV and V studies, primarily, and no level I or II quantitative studies).

Consistent with Lenker and colleagues earlier findings,[17] almost all studies in the review used measurement scales with unreported levels of reliability and validity. The lack of rigorous research designs and sound outcome measures made it impossible to use meta analyses to pool study outcomes. This review confirmed that the overall reported effect of AT device impact on children was positive. However, the reviewers identified the need for more well-designed studies to advance understanding of the effect of specific types of AT devices on children with functional impairments and on their caregivers and families.

MEASUREMENT OF ADAPTIVE SEATING DEVICE OUTCOMES

AT device outcome measurement experts assert that a device-specific research agenda is an appropriate way to build outcome evidence by helping to guide the selection of research study designs, measurement constructs, and data analysis strategies.[29] In this sense, AT outcomes research in paediatric rehabilitation may be described as systematic investigations of functional changes in the lives of children, their caregivers and families due to the introduction and use of specific AT devices.

Fuhrer and colleagues[29] recommend that AT device outcomes be measured as part of a time-dependent process that includes initial acquisition of the AT device, its introductory and longer-term use, and the interaction of an array of functional and contextual factors. The discontinuance of AT device use may be viewed as being due to user-perceived changes in product effectiveness, efficiency, and satisfaction. During this process, the child (or family member) may replace one device with another or use other environmental resources (e.g., personal support worker) to improve or augment a child's functioning. This time-dependent AT outcomes framework is useful because it helps to formulate measurement models and research studies to detect the functional consequences of specific AT devices on the everyday functioning of children with physical disabilities.

This framework can be described by considering AT device outcomes for children with CP who have motor impairments that affect how they sit and move. CP is "a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain." [30, p.9] It is estimated that the incidence of CP in Western countries is 2 to 3 per 1000 live births,[31] with a current prevalence of about 7,500 and 13,500 children under 15 years of age in the Netherlands and Canada, respectively.[32,33] CP is usually identified when children are 12 to 18 months of age. Usually, they fail to reach the motor milestones of

children with typical development by showing measurable clinical differences in gross motor development and muscle tone.[34]

Since the location and extent of the non-progressive brain disturbances vary among children with CP, the severity and distribution of impairments affect the functional abilities of children to varying degrees. The typical sitting performance of children with CP may be described using the Gross Motor Function Classification System (GMFCS)[35,36] (table 1). The GMFCS is a 5-level ordinal scale that has been shown to have high inter-rater and test-retest reliabilitites.[37]

Children with CP rely on adaptive seating devices (ASDs) to improve their seated postural control, activity performance, and participation in everyday activities. Those who can walk without hand-held devices (GMFCS Levels I and II) usually need little additional sitting support for everyday functioning at home and in school. Whereas, children who lack voluntary control of movement and the ability to control their head and trunk (GMFCS Level V) need full support for the pelvic, trunk, head, lower extremities and feet in order to sit and interact with others in these settings.

Level I	Gets into and out of, and sits in, a chair without the need for hand support.
Level II	Sits in a chair with both hands free to manipulate objects. Moves from chair sitting to standing, but often requires a stable surface to push or pull up on with arms.
Level III	Sits on a regular chair but may require pelvic or trunk support to maximize hand function. Moves in and out of chair sitting using a stable surface to push on or pull up with arms.
Level IV	Sits on a chair, but needs ASDs for trunk control and to maximize hand function. Moves in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms.
Level V	Limited in ability to maintain head and trunk postures and control arm and leg movements. AT devices improve head alignment and seated posture, but limitations are not fully compensated by equipment.

Table 1.1: Sitting performance within the GMFCS levels

Although many children with CP have unique positioning requirements, all children use a variety of seating devices for common sedentary activities. Young children sit on a booster seat or kitchen chair at mealtimes, a toilet seat in the bathroom, a safety seat when travelling in the family car, and a school chair when at nursery school or in the classroom. However, the functional effects of these seating devices in children are rarely considered.

Ergonomists and human factors researchers contend that associations exist between ill-fitting chairs and negative functional outcomes including poor seated postures,[38] back and neck pain,[39,40] heightened muscle tension,[41] compromised fine motor skills,[42] and reduced academic performance[43] in children with typical development. In classroom environments, researchers raise concerns about the association between poorly-designed school furniture for children and the high prevalence of chronic musculosketal pain in adolescents.[44,45]

With preliminary evidence of the deleterious consequences of seating devices on the health of children in the general population, it is reasonable to question the strength and directionality of the functional impact of seating devices on children with CP who have motor coordination problems and diminished seated postural stability and control. ASDs are often recommended by therapists for young children with CP and other developmental disabilities who have motor impairments that affect their ability to sit.[46] In particular, children with CP use seating devices for postural stability to optimize volitional arm and hand function, and avoid spastic postures.[47] Without stabilization for the pelvis, trunk, and lower extremities, children with CP may have limited ability to shift their weight, maintain an optimal body position for the task demand, and return to a neutral, resting position.

EVIDENCE OF THE IMPACT OF ADAPTIVE SEATING DEVICES ON FUNCTIONING OF CHILDREN WITH CEREBRAL PALSY

With the regular influx of new commercial AT products and related clinical interventions for children with CP and other disabilities, third party payers are demanding evidence of the effectiveness of AT devices, including adaptive seating products and their associated clinical services.[48,49] Motivated by this and the promotion of evidence-based practice in health care settings, clinical research teams have published seven literature and systematic review articles to estimate the effect of ASDs for children with CP on postural control and management,[50-52] sitting posture,[52] upper extremity function,[53,54] occupational therapy outcomes,[55] and overall clinical efficacy and effectiveness.[56]

A summary of the purpose of each review, the search strategy and method for assessing the quality of articles selected, and authors' findings and recommendations is provided in table 1.2 (pages 21-23). Further, the Overview Quality Assessment Questionnaire (OQAQ)[57] was used as a guide to assess the

scientific quality of each ASD review article. The OQAQ has adequate levels of reliability and validity when used to assess the quality of literature overviews in medicine.[57] This index includes ten questions regarding whether the search for original articles was adequate and comprehensive, inclusion criteria were stated, selection bias was avoided, valid criteria for assessing article validity was reported, the methods used to pool results were appropriate, and the reviewers' conclusions were supported by the data. Limitations of the reviews using the OQAO are noted in the final column.

As was concluded in the research synthesis of the impact of AT devices on children with functional impairments,[27] none of the reviews found sound evidence of the impact of ASDs on child activity and performance aspects of the ICF-CY, or on interaction of these environmental resources on the lives of caregivers or family members. The authors noted that data from the original research studies could not be combined to make recommendations for clinical practice due to the heterogeneity and lack of clarity in population characteristics, intervention types, and outcome measurement scales.[50-56]

With few exceptions, the review article authors used comprehensive search strategies of electronic health and allied medical databases to identify articles relating to the general impact of ASDs on various aspects of child functioning. Further, six of the seven reviews used valid criteria[28,58-62] to identify and assess the methodological quality of the articles. Despite the varied approaches and levels of rigour used to conduct their reviews, the authors consistently reported positive outcomes from studies of the association of adaptive seating technologies on seated postural, postural stability, trunk extension, upper limb functioning, and cognition in children with CP in general. However, all reviewers reported broad inclusion criteria for age and functional status.

Since the type and need for ASDs vary across children with CP, an aggregate analysis of all original studies may mask the influence of specific ASD interventions by important child demographics. Future systematic reviews and original research articles must incorporate greater specificity in their inclusion criteria for child developmental level, functional status, and ASD intervention.

SUMMARY AND RATIONALE

The overall putative impact of ASDs is that they help children with CP to participate optimally in everyday activities at home, at school, and in the community.[15, 21-24, 27, 46, 47, 50-56, 63] However, reviews of the multidimensional outcomes of adaptive seating interventions on the functioning of children with CP, their caregivers, and their families provide little compelling evidence to support this. While high quality randomized controlled trials provide the highest levels of causal evidence,[64] adoption of this 'gold standard' design may only be appropriate to answer some

important rehabilitation research questions about the effectiveness of these products. The measurement of their efficacy and effectiveness must be embedded in the ICF-CY biopsychosocial paradigm so clinicians, researchers and other stakeholders may gain a greater understanding of the role that these AT devices play in the lives of children with CP.

McDonald and colleagues promote the ICF – and by extension the ICF-CY – as an ideal model for ASD assessment and provision for children with CP.[65] They reason that the ICF framework provides a powerful, universal way to view child functioning and communicate the basis of clinical decision making with children, families, health care administrators and policy makers. While this holistic approach to adaptive seating assessment and provision is laudable, evidence-based clinical practice requires 'integrating individual clinical expertise with the best available external clinical evidence from systematic research.'[66]

Indeed, if one agrees that it is the inalienable human right of every child to live 'in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community,'[1] then it is essential to initiate rigorous programs of research to explore, measure, and understand the multidimensional role that adaptive seating and other environmental resources play in the reduction of disability and optimization of functioning and health of children with cerebral palsy.

Review	Purpose of Review	Search Strategies/ Quality Criteria for Studies	Findings/Recommendations	Limitations of Review †
Roxborough, 1995[56]	• effectiveness and efficacy of ASDs on children (birth–19 y) with GMFCS Levels I-V CP	• searched 3 allied and medical health electronic databases + hand searched 2 relevant seating conference proceedings and reference lists + citations of seating researchers between 1982 and 1994 • quality criteria: Sackett 1986 criteria[59]	• 8 relevant studies: heterogeneous interventions + designs • weak evidence of effect of ASDs on sitting posture, vocalization, and eating skills + no evidence of effect on visual tracking, self-feeding, drinking skills • recommendation: more high quality ASD impact studies needed	• publication bias in selection of English published studies, only • inclusion criteria too broad • unable to combine heterogeneous studies to make inferences re the effect of ASDs on child function • possible reviewer bias due to single reviewer
Farley et al, 2003[51]	• effectiveness of postural management strategies on children and adults with CP and other disorders	• searched 3+ allied and medical health electronic databases, unknown publication period • quality criteria: Sackett 1986 criteria[59]	• 18 relevant articles for the ASD effect on children and adults with CP • reported that most methods were weaker methodologies including retrospective qualitative or descriptive designs • recommendations: "clearly demonstrated" seating interventions enhanced cognitive function, upper extremity function, and communication"	• unclear, non-reproducible, search strategy • publication bias in selection of English studies, only • inclusion criteria too broad • unable to combine heterogeneous studies to make inferences re the consequences of ASDs on child function • recommendations are not supported by rigorous scientific evidence

† Following the guidelines of the Quality of Overview Assessment Questionnaire (QOAQ)[58]

Review	Purpose of Review	Search Strategies/ Quality Criteria for Studies	Findings/Recommendations	Limitations of Review †
Steultjens et al, 2004[55]	• effects of occupational therapy interventions (incl. ASDs) on performance outcomes for children with GMFCS Levels I-V CP	• searched 9 allied and medical health electronic databases for controlled and uncontrolled designs, published 1966 – 2003 • quality criteria: modified Tulder et al criteria[59]	• 2/17 relevant AT-related studies: uncontrolled design with non-significant results for functional abilities • problem with responsiveness of measures used • recommendation: more high quality ASD impact studies needed	• search terms too broad to identify all articles relevant to ASDs • publication bias in selection of English/Dutch studies, only, with no relevant hand search of journals • inclusion criteria too broad • unable to combine heterogeneous studies to make inferences re the effect of ASDs on child function
Harris et al, 2005[50]	• effectiveness and efficacy of postural control interventions (including ASDs) for children (birth to 19 years) with GMFCS Levels I-V CP	• searched 10 allied and medical health electronic databases + hand searched 3 relevant journals, published between 1990 – 2004 • quality criteria: Sackett et al (2000) criteria[58]	• 12 relevant studies: 10 group + 2 single subject designs • mostly lower levels of evidence • recommendation: more high quality ASD impact studies needed	• publication bias in selection of English studies, only • inclusion criteria too broad • unable to combine heterogeneous studies to make inferences re the effect of ASDs on child function
Stavness, 2006[53]	• determine the most appropriate sitting position for children with GMFCS Levels I-V CP to conserve energy and promote optimal functional abilities	• searched 12 allied and medical health electronic databases for primary quantitative studies, published 1986 – 2002 • quality criteria: none stated	• 16 relevant articles: 3 randomized crossover, 4 longitudinal, 2 before-after, 1 survey, 5 prospective case-control, 1 single subject design • contends 0-15º forward seat inclination improves upper extremity function • recommendation: more high quality ASD impact studies needed + classification system	• publication bias in selection of English studies, only • reviewer bias due to single reviewer • inclusion criteria too broad • no valid criteria for assessing study quality • no rigorous scientific evidence to suggest the benefit of anterior tipped seating on upper extremity function

Review	Purpose of Review	Search Strategies/ Quality Criteria for Studies	Findings/Recommendations	Limitations of Review †
McNamara et al, 2007[54]	• effects of seat inclinations on postural control, muscle activity and upper extremity function for children with GMFCS Levels I-V CP	• searched 7 allied and medical health electronic databases for primary quantitative studies, published 1990 – March 2006 • quality criteria: McMaster review criteria form[61]	• 10 relevant articles: 4 single case/case series + 4 between-group + 2 longitudinal studies • neutral to forward inclined seat inclinations can affect child function • recommendation: more high quality ASD impact studies needed	• publication bias in selection of English published studies, only • inclusion criteria too broad • unable to combine heterogeneous studies to make inferences re the effect of ASDs on child function
Chung et al, 2008[52]	• effects of ASDs on sitting posture and postural control + functional abilities on children (birth to 20 y) with non-ambulatory GMFCS Level III-V CP	• searched 12 allied and medical health electronic databases + 3 relevant journals for primary quantitative studies (no surveys), published 1980 - 2007 • quality criteria: AACPDM Quality Assessment Scale[28] for group designs + Horner et al criteria[62] for single subject design	• 14 relevant studies: 11 group designs, 1 single subject research design, 2 case studies • only 1 study used GMFCS for classification • 9 studies include body fcn/structure + 5 incl activity and participation components • limited evidence of functional impact on child • recommendation: more high quality ASD impact studies needed + motor impairment classification system to describe capacity/performance of children	• publication bias in selection of English published studies, only • inclusion criteria for age and (possibly) GMFCS level too broad • unable to combine heterogeneous studies to make inferences re the effect of ASDs on child function

Table 1.2: Summary of systematic and literature reviews of the effect of ASDs on the functioning of children with CP

THESIS OBJECTIVES AND OVERVIEW

In light of what is known about the effect of adaptive seating technologies, this dissertation builds on existing evidence by advancing the measurement and understanding of the functional impact of ASDs in young children with cerebral palsy and their caregivers and families.

The specific objectives of the following chapters are to:

- determine the impact of the introductory use of conventional and specialty school furniture configurations on the printing performance of ambulatory Grade 1 and 2 students with CP
- describe the conceptual development of the Family Impact of Assistive Technology Scale (FIATS) – a multidimensional measure designed to detect the impact of adaptive seating devices on the functioning of children who use these technologies and their families
- describe the item generation and selection for the FIATS, and empirically estimate the reliability of the FIATS and its subscales
- estimate the parent-perceived effect of two special-purpose adaptive seating devices on the functioning of young children with cerebral palsy and their families
- estimate the influence of these adaptive seating devices on the activity performance of children with CP
- identify avenues for future research to explore and understand the multidimensional consequences of adaptive seating and other assistive device use on child and family functioning

Specific objectives are addressed in the follow chapters. **Chapter 2** describes the outcomes of an RCT designed to compare the gains in handwriting legibility of first and second graders with ambulatory CP who used both conventional and ergonomic school furniture. **Chapter 3** details the preliminary development and evaluation of the multidimensional FIATS. In **Chapter 4**, a classical test theory approach is used to estimate the internal consistency and test-retest reliability of the FIATS. **Chapter 5** reports on the parent-perceived impact of using two adaptive seating products over a 12-week long case series study using the FIATS. **Chapter 6** describes the use of the Canadian Occupational Performance Measure (COPM) as a means to detect the influence of these products on the child-specific activity performance issues. Finally, **Chapter 7** synthesizes the original research studies described in the preceding chapters and makes recommendations for future ASD outcomes research.

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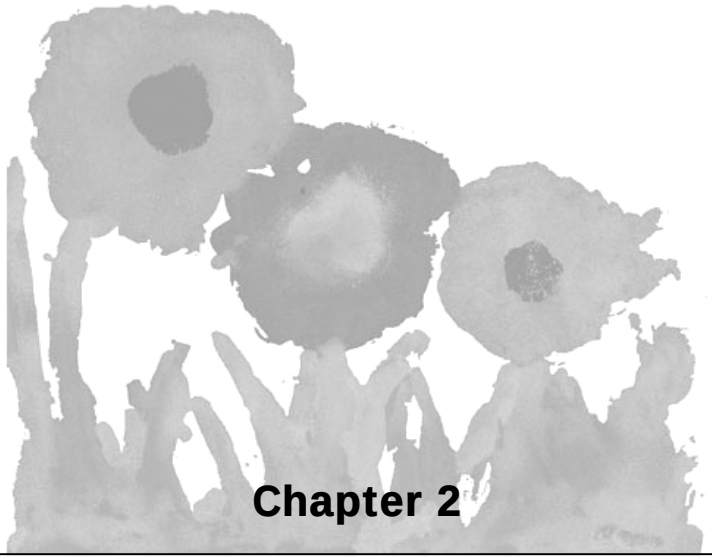

Chapter 2

Effect of school furniture on the printing performance of children with cerebral palsy – a randomized controlled trial

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ABSTRACT

Objective: To estimate the effect of two different school furniture interventions on the manuscript handwriting legibility of Grades 1 and 2 students with Gross Motor Function Classification System (GMFCS) Level I and II cerebral palsy (CP).

Design: Randomized controlled trial, crossover study. Each child provided one printing sample while seated on each of two different school furniture configurations during a single session. The configuration order was randomized using block allocation sequence and concealed until the intervention was assigned. A trained assessor who was unaware of the intervention assignment used an adapted version of the Minnesota Handwriting Assessment (MHA) to score printing performance errors for samples collected during the sessions.

Setting: Seated postural control laboratory at a children's rehabilitation center.

Participants: Thirty children, aged 6 to 8 years, with GMFCS Level I and II CP.

Interventions: Ergonomic school chair and desk (experimental) and conventional school chair and desk (control).

Main Outcome Measure: Minnesota Handwriting Assessment.

Results: Paired t-test detected no significant difference in legibility score means between the two interventions ($t = -.30$, $p = .77$, $df = 29$) and the effect size was small (Cohen's $d = -.03$; 95% CI, -.24 to .18). Secondary analyses of the effect of the interventions on other MHA quality categories suggest no immediate handwriting performance gains in letter formation, spacing, alignment, sizing, and rate.

Conclusions: Compared to the use of conventional school furniture, the use of ergonomic school furniture does not appear to lead to immediate gains in the manuscript handwriting legibility and other handwriting performance areas for young children with CP.

Handwriting is a core language development skill that students learn during their elementary school years, but one that is not mastered by all children. Evidence suggests that handwriting difficulties are present in an estimated 30% of children by the end of Grade 1 and 10-15% of children by the end of Grade 5.[1] Persistent problems with letter and word construction may be due to factors that include impairments in visual motor coordination, motor planning, cognitive abilities, perceptual skills, and kinesthetic awareness.[2]

Elementary school teachers use various instructional techniques to promote mastery of handwriting skills during the early elementary years, because the educational curriculum in later grades focuses on other advanced writing and literacy skills.[3] Although computer-based technologies provide solutions for some children who need support for writing activities, teachers expect that students in later elementary grades will have already acquired basic competency in handwriting for common classroom activities such as completing work sheets, writing tests, and copying blackboard notes.[2,4]

Children with cerebral palsy (CP) have motor disorders and associated disturbances in sensation, cognition, communication and/or perception that make the development of handwriting skills particularly challenging.[5] Early identification of handwriting difficulties and implementation of remedial strategies are important for students with CP and other motor coordination disorders because delays may lead to other academic and interpersonal difficulties at school.[6]

Occupational therapists (OTs) are trained to assess handwriting problems in children with and without disabilities, and recommend or implement remedial strategies to optimize handwriting performance at school. In their survey of 50 experienced Canadian OTs, Feder and colleagues found that therapists used standardized outcome measures to assess a child's motor skills, perceptual skills, quality of movement and motor planning, and evaluate the effectiveness of handwriting interventions.[7] However, decisions regarding which interventions OTs used to address handwriting problems were based upon their training and experiences rather than upon standard clinical practice guidelines. Clinical researchers contend that the development of guidelines for handwriting remediation has been hampered by the paucity of empirical evidence of intervention effectiveness for children with CP and other clinical populations.[8-10]

Handwriting authorities assert that school furniture configurations are common environmental interventions that affect handwriting outcomes in all children.[4] Clinicians believe that appropriately-configured school chairs and desks promote good seated posture, improve proximal control, and support purposeful fine motor activity distally.[11-14] However, evidence of their effect on fine motor performance in children is limited. In two crossover trials, young children without disabilities who

were positioned optimally on school chairs, did better on in-hand manipulation tests[15] and IQ tests[16] than when they were seated on oversized school chairs.

Marschall and colleagues[17] demonstrated the biomechanical benefits of ergonomic school chairs with forward sloping (inclined) seat surfaces that angled 10º-15º downwardly toward the desk, and desk surfaces that sloped downwardly toward the user at 15º. Compared to conventional school furniture with 5º rearward sloping seats and horizontal desk surfaces, ergonomic configurations encouraged more spinal lumbar lordosis, increased spinal extension, and increased seated comfort in young children with typical development.[18] Although other human factors investigators have shown ergonomic furniture to improve performance and productivity in other occupational sectors,[18] further research is needed to study the effect of these environmental resources in academic settings.

Little is also known about the effect of ergonomic seating on the functioning of children with chronic physical disabilities, such as CP. Children with CP have motor impairments that affect how they sit. They rely on adaptive seating devices to improve seated postural control, activity performance, and participation in everyday activities. However, a child's functional level and activity performance goals dictate the type of adaptive seating device and level of sitting support that are most appropriate. For example, children with CP who can walk without hand-held devices usually need little additional sitting support for everyday functioning at home and in school. Whereas, non-ambulatory children with CP who lack voluntary control of movement and seated posture need full adaptive seating support for the pelvis, trunk, head, lower extremities, and feet in order to sit and interact with others in the classroom and other settings.

In two recent independent reviews of the empirical evidence of seating configurations on the seated posture and functional performance of children with CP, Stavness[19] and McNamara and Casey[20] found evidence of the immediate benefits of inclined seat surfaces on the seated posture, postural stability, respiration, and upper extremity functioning of children with CP in general. However, the findings are more controversial if one considers only studies involving ambulatory children with CP and seat inclinations *without* back support. Rehabilitation researchers have reported same-session improvements in seated posture,[21,22] but others[23] have found poorer postural stability and no difference in upper extremity functioning when children with CP used ergonomic, inclined seating surfaces compared to seats with horizontal surfaces.

Further, Shen and colleagues[24] showed that children and youth with CP who sat in their own adaptive seating systems could trace standardized shapes more accurately if they used a desk with a cut-out for trunk support rather than a conventional desk without a cut-out. However, the investigators found no evidence of accuracy gains in the same tasks when participants used a desk surface that

inclined downwardly toward them at 20º compared to a desk surface that was horizontal.

We proposed to advance adaptive seating research by studying whether the use of ergonomic school chairs and desks that promote functional sitting leads to immediate, concomitant gains in the printing performance of ambulatory first and second graders with CP. We chose these grades because of the common belief of educators that remedial strategies for improving printing and other literacy skills are most successful when applied at the primary level.[3] Since increased legibility in handwriting is the most important outcome according to elementary school teachers who refer their students for handwriting remediation,[25] our research question was: "Compared to the use of conventional classroom furniture, does the use of ergonomic school furniture lead to gains in the printing legibility of children in Grades 1 and 2 with Gross Motor Function Classification System (GMFCS) Level I or II CP?"

METHODS

We received ethical clearance for this study from the research ethics board at our institution.

Participants We obtained informed, signed consent from the parents of 30 children who had received services at our rehabilitation centre between 2004 and 2007. Children were eligible to participate if they (a) had a functional status of GMFCS Level I or II CP*; (b) were between the ages of 6 years and 8 years, 11 months and enrolled in either Grade 1 or 2; (c) lived in a geographic area served by our facility; and (d) were reported by their parents to be in good physical health and able to print the alphabet. Exclusion criteria included children who had a genetic disorder, attention-deficit hyperactivity disorder, or pervasive developmental disorder as documented in their health records.

We reviewed the health records at our facility and identified 123 children who met our age and gross motor functional status requirements, and had none of the excluded diagnoses. We assigned random numbers from a uniform distribution. The children were then sorted on the basis of the assigned random numbers and recruitment proceeded from the top of the list down. This ensured that the children were approached in a randomly selected order. A research team member initially phoned parents to describe the project, determine whether they were interested in having their child participate in the study, and screen their child for eligibility. We mailed an information letter about the study to parents who were

* Children with GMFCS Level I CP walk indoors and outdoors, climb stairs, and get into and out of a chair without hand support. Children with GMFCS Level II CP walk without canes or crutches for short distances over level surfaces, climb stairs holding onto a railing, and often need a stable surface to push or pull up on with their arms to stand from a sitting position.[26]

interested and whose children met the eligibility criteria. Eligibility screening calls continued until 30 parents agreed to let their child participate in the study. After providing signed consent, parents and their children attended the research session at our seated postural control laboratory.

Protocol The conventional seating configuration (control) included a Virco Classic Series school chair[a] with a fixed 40.6 cm (16 in.) seat height and a nominal 5° rearward sloping seat, and a height adjustable Virco model 785 school desk with a flat, rectangular, horizontal surface.[a] Although the manufacturer recommended this chair for Grade 2 students, the seat height exceeded the popliteal height of a 50th percentile 8-year-old by 9.4 cm (3.7 in.).[27] The desk height was individually adjusted to be 5.1 to 7.6 cm (2 to 3 in.) higher than the seated elbow height of the participant. This combination simulated the oversized school furniture configurations observed in several measurement surveys in US elementary schools and elsewhere. [28-30]

The ergonomic seating configuration (experimental) included: (a) a QLearn Classic school chair[b] with a nominal 10° inclined seat and a seat height individually adjusted to encourage sitting symmetry with the user's hips extended to 100°, knees extended to 135°, and feet fully supported on the floor; and, (b) a QLearn desk[b] individually adjusted to provide a table surface height of 2.5 cm (1 in.) higher than the child's seated flexed elbow height, and a surface that angled downwardly toward the child at 10° from the horizontal. The chair and desk adjustments were set in accordance with the manufacturer's recommendations and cited research.[17,31,32] As supplied by the manufacturer, the backrest was fixed at the rear portion of the seat and reclined away from the child at an angle of 20° from vertical. The manufacturer supplied the desk with a standard, semi-circular cutout to accommodate the child's trunk.

We chose a randomized, single-blinded, AB/BA crossover design because we did not expect a carry-over effect in our primary outcome (legibility) following the initial intervention. Crossover designs have the advantage of having participants act as their own controls, thereby increasing statistical power by reducing the error variance.[33]

During each session, the research occupational therapist asked the child to provide one near-point printing sample using each intervention. We randomized the order of presentation of the seating configurations to the children in three blocks of 10 sessions using a random number generator. A study investigator prepared the order sequence instructions and sealed the envelopes. At the start of the session, the therapist who administered the Minnesota Handwriting Assessment (MHA) opened a sequentially numbered, sealed envelope to identify the intervention assignment. Each child provided two complete manuscript handwriting samples within a single one-hour session.

The assigned school chair and desk were adjusted to the size of the child as per the research protocol. The research therapist showed a 20.3 cm x 25.4 cm (8 in x 10 in) color photo of a typical child seated optimally using the same furniture (figure 2.1) and asked the participant to assume this seated position before administering the MHA. The children did not use the back supports of either chair during the handwriting test. The seat depth of the conventional chair was too deep to allow the child's back to contact it; whereas, the seat surface inclination of the ergonomic chair encouraged the child to assume an optimal seated posture for deskwork activities without the back support. (The manufacturer intended that students use the back support of the ergonomic seat during listening or resting activities in the classroom.)

Before copying the manuscript handwriting exemplar, the child played with a desktop game or toy for 5 minutes to become accustomed to the furniture. During this time, the therapist observed the child's in-hand manipulation skills and used the Manual Ability Classification System (MACS)[34] to categorize how the child handled objects with his/her hands.[†] Using the standard instructions and lined paper provided with the MHA, the therapist instructed the child to copy the exemplar. The child received no prompting to sit differently once printing commenced.

The child took a 10-minute break following the first test while furniture adjustments were made for the second configuration. Children were given the same time to get accustomed to the new chair and desk, and the therapist administered the MHA again.

Outcome Measure The MHA is a norm-referenced, multidimensional measure designed to identify printing errors of first and second grade students in six categories.[35] These categories include: legibility (letter recognizable out of context, all strokes present, no reversals); form (absence of gaps or overlaps greater than .16 cm (1/16″)); alignment (letters rest within .16 cm (1/16″) of the baseline); size (measure of relationship of all other parts of each letter to midline, upper and lower sizing lines on MHA sheet); spacing (correct letter and word spacing); and speed (number of letters printed in a set time). When used with children with typical development, the MHA categories have acceptable inter-rater reliability (ICC = .73 to .99) and intra-rater reliability (ICC = .93 to .99).[36]

The MHA has evidence of construct validity. In one study of first graders who were academically at-risk, the MHA showed meaningful gains in the handwriting quality due to a remedial intervention.[37] In another study of typical Grade 1 students, the

†The MACS is 5-level, manual ability classification system for children with CP aged 4 to 18 years. The MACS has good validity and excellent inter-rater reliability when completed by therapists (ICC = 0.97, 95% CI 0.96 –0.98).

MHA legibility scores were shown to correlate well with standardized handwriting performance indicators including eye-hand coordination, visual motor integration, and in-hand manipulation.[38]

To administer the MHA, the child copies a standard set of jumbled words that use all 26 letters of the alphabet (i.e., the brown jumped lazy fox quick dogs over). The child is asked to provide his/her best printing to discourage writing quickly and illegibly. After 2.5 minutes, the child circles the last letter completed, and then continues to print until the sample is complete. Scoring is performed for each letter, word and combination of words using the specific quantitative and qualitative criteria identified in the manual.

Fig 2.1: Child with optimal seated postures on the ergonomic (left) and conventional (right) school furniture.

Each letter in a sample may receive only one error score in each category. Since 34 letters are scored, a handwriting sample receives a score from 34 (no errors on any letter) to 0 (all letters have at least one error) for each category. The letter circled after 2.5 minutes provides a rate score. If all letters in the entire sample are completed in this time, then a maximum rate score of 34 is assigned. The MHA manual provides normative performance bands for children in Grades 1 and 2 to assist in identifying handwriting performance that is 'at peer level', 'somewhat below peer level', or 'well below peer level' for each of the five quality categories and rate. The normative data were derived from a sample of more than 2,000 typical first and second graders from 11 different US states.[35]

Before conducting our primary analysis, we used a random sample of 10 handwriting samples from the study to estimate the reliabilities of the MHA categories in our study. A panel of three researchers completed the training module in the MHA manual and independently scored the printing samples from the collected. We estimated MHA inter-rater reliabilities to be below acceptable levels (i.e., ICC< .70) for legibility and two other MHA quality categories.

To reduce measurement error, we developed an addendum to augment and clarify the MHA scoring rules. The main purpose of the addendum was to minimize subjective interpretation by the assessor by adding decision-making rules to the MHA scoring criteria. These rules did not replace the original MHA scoring criteria. Rather, the addendum provided more detailed rules for the assessor to follow to score or not score an error for a specific letter in each handwriting sample.

Since not every error could be anticipated and a rule for scoring applied, we adopted the MHA's original leniency rule of not penalizing questionable letters, words or spacing to avoid elevated error scoring and improve rater agreement. For example, we did not assign errors to upper and lower case letters that look the same when viewed out of context (such as the letters 'c' and 'C'). Using the draft MHA addendum, the researchers independently scored a second set of 10 random handwriting samples.

Paired comparisons of MHA scores yielded inter-rater reliability ICCs estimates that exceeded the ICC=0.7 threshold of acceptability for all five quality subscales of the MHA. Three of the quality subscales had point estimates that exceeded ICC=0.9. The investigators revised and added new rules to clarify the scoring and minimize measurement error on all subscales. The addendum provided eight general scoring notes and categorical rules by letter for each of the five quality subscales (Appendix A). We retained the original MHA procedure for summing errors scored for each quality category and rate.

Using the new MHA addendum, a panel of three research team members collectively reviewed and agreed on the scoring assignment for all 20 handwriting samples. The random sample did not contain identifying information, so panel members were unaware of whether one or more samples came from the same child. The final consensus scoring of these samples was established as the 'gold standard' against which the inter-rater reliability of the assessor would be judged.

A research occupational therapist with 3 years' experience conducting writing assessments for children with cerebral palsy, but with no prior exposure to the MHA, was trained as the handwriting assessor for the study. She completed the training modules in the MHA manual and met with a study investigator to review, discuss, and clarify the adapted scoring criteria for the MHA and addendum. They reviewed rules in the addendum once more after the assessor scored the first set of 10 random samples. The investigator clarified the rules, but did not view any

samples with the assessor at this time. Afterwards, the assessor scored the remaining 70 handwriting samples using the adapted MHA, exclusively.

The assessor was blind to the study protocol, the interventions, and number of children who provided handwriting samples. The order in which the samples were provided for scoring was randomized, and the samples were provided in lots of 20 to provide scoring breaks for the assessor that extended for up to five days. The assessor was unaware that the 20 gold standard samples were randomly distributed among the pool of handwriting samples.

Using a two-way mixed effects model for absolute agreement,[39] we estimated the intra-rater reliability ICC for the assessor and inter-rater reliability ICC for the assessor and a consensus rating by three other research team members for legibility errors to be .98 (95% CI, .91 - .99) and .99 (95% CI, .97 – 1.0), respectively. The intra- and inter-rater reliability ICCs for the other four quality categories and rate exceeded .96 and the lower 95% confidence limit for ICCs exceeded .90 for all subscales.

Data Analysis We employed an intention-to-treat analysis[40] and used a t-test for the paired differences of MHA legibility scores to compare using the ergonomic school configuration to the conventional configuration. If the primary analysis yielded a significant result ($p<.05$ (two-tailed)), then t-tests were planned to compare the difference in means between the configuration orders.

As part of a secondary analysis, we studied the effect of the configurations by conducting paired t-tests for each of the other categories. A Bonferroni correction adjusted the alpha level for the five other categories to .01. Cohen's d and 95% confidence intervals were computed to estimate the effect sizes for all MHA categories.

Baseline descriptive statistics (mean and SD or frequency) were compiled for age, gender, MACS level, handedness, and standing height. Descriptive statistics (means, SD) for the MHA legibility and other categories were computed.

Sample Size Calculations We performed power calculations to assess our ability to detect a difference in legibility errors. The standard deviation of the MHA change scores was taken from a study of the handwriting performance of children who were academically at-risk and either received remedial instruction or no remedial instruction.[37] The standard deviations of the mean legibility change scores for the intervention and control groups in this earlier study were reported to be 4 and 4.7 points, respectively.[37] We selected the higher SD of mean difference scores in our power calculations, because we expected greater variability in motor performance for children with CP compared to children with typical development.[41]

Since an 8-14% change in handwriting legibility scores was reported to yield important effects in two handwriting intervention studies involving elementary grade students,[37,42] we chose a mean change score difference of 3 points on the MHA legibility scale (i.e., a 10% change) as the minimal clinically important difference to be detected in the current study.

Based on the foregoing, a sample size of 22 was needed for a Type I error probability of α=.05 (2-sided) and power of 80%. To accommodate for non-compliance loss and unknown variability in handwriting legibility for children with CP, we increased our sample size to 30 children. No interim analyses were planned.

RESULTS

Recruitment We contacted 77 parents to assess the eligibility of their child with CP (figure 2.2). The principal reasons for not meeting participation criteria related to the child's functional level including the need for assistive technology devices for mobility and/or the inability to print the alphabet. Parents of children who met the inclusion/exclusion criteria, but who declined participation indicated they were too busy, lived too far from our test laboratory, and/or had other personal reasons. Thirty children who met the eligibility criteria provided both handwriting samples during a single research session. Fifteen children sat at the conventional configuration first; whereas, the remaining 15 children used the ergonomic workstation first. There were no deviations from the random allocation.

Participants Children had a mean age of 7y 2 mo (range, 6y 1mo to 8y 5mo; SD, 8mo) at session they attended. All participants had a charted primary diagnosis of CP, with 17 children at a functional status of GMFCS level I and 13 at a GMFCS level II. Twenty girls and ten boys participated. The research therapist categorized the bimanual motor ability status to be MACS level I for 14 children and level II for the remaining 16 children.[‡] Eleven participants printed with their left hand and 19 children printed with their right hand. The mean standing height of participants was 1.20 m (47.4 in.) (range, 1.02 m (40 in.) to 1.32m (52 in); SD, .08 m (3.2 in.)).

Outcomes Our primary outcome of mean difference scores on the MHA legibility scale did not show a significant effect (table 2.1). Since the distribution for the traditional furniture legibility scores on the MHA demonstrated a kurtosis greater than 3, a non-parametric Wilcoxon Signed Rank test (Z=-.36, p=.72) verified our non-significant paired t-test result. There was no need to test

[‡] Children classified as MACS Level I handle objects easily and successfully; whereas children with MACS Level II handle most objects with somewhat reduced quality and speed.

for order effects. Similarly, secondary outcomes of the other four MHA quality categories (form, alignment, size, and spacing) and rate showed no evidence of change in performance scores due to the interventions (table 2.1). Mean MHA scores were below norms for Grade 1 students on legibility and the other four quality indicators for both interventions. Speed score means were within grade level expectations.

DISCUSSION

We did not find evidence to support our alternative hypothesis that the use of an adjustable, ergonomic school chair and desk would lead to immediate gains in the printing legibility of Grades 1 and 2 students with GMFCS Level I or II CP. Our null findings are in opposition to the current collective evidence of the immediate effect of ergonomic seating on the functioning of children with CP.[19,20] In two literature reviews of empirical evidence of the most appropriate sitting configuration to promote optimal functional abilities[20] and the effect of seating inclination on upper extremity functioning[19] for children with CP, the authors independently concluded that inclined (ergonomic) seating may improve functioning. However, both reviews included studies of children with CP who had different levels of sitting ability and included interventions with different levels of sitting support. Further, the reviewers based their recommendations on non-randomized studies that are susceptible to confounding factors.

Only three studies from these reviews involved ambulatory children with CP who sat on inclined seat surfaces similar to our intervention (i.e., no back support, but with foot support). Using non-randomized, between-group factorial designs with typical-developing children as controls, these studies reported that children had significant same-session increases in spinal extension,[21] improvements in postural control,[21,22] and better overall sitting posture in some cases[23] when children used a 5° to 10° inclined seat surface compared to using a horizontal seat surface. However, one of these studies[23] reported that compared to horizontal seats, seats inclined 5° had no effect on the upper extremity functioning in ambulatory children with CP. While the seat inclination in our study was greater, we provided an inclined desk surface for the handwriting tasks. Despite this additional support for the upper extremities, we similarly could not detect meaningful, functional effects on handwriting quality outcomes due to the school furniture interventions.

In this context, our research adds evidentiary weight to this latter study by employing a more rigorous scientific methodology. Our research results have incremental value in the same manner as other studies that found no differences in the handwriting performance of children who had received targeted interventions for factors associated with poor handwriting outcomes. (see Sudsawad and colleagues' RCT that found no support for the efficacy of body

awareness training on better printing outcomes for school-age children with impaired kinesthesia. [43])

MHA Category	Range	Mean ± SD	Mean Difference (95% CI)	SD of Difference	t-test (p value (2-tailed), df)
Legibility					
conventional	19-34	30.7 ± 3.3	-0.1 (-.8 to .6)	1.8	-.30 (0.77, 29)
ergonomic	21-34	30.6 ± 3.3			
Form					
conventional	8-30	21.5 ± 5.8	.8 (-.5 to 2.2)	3.6	1.27 (0.21, 29)
ergonomic	11-30	22.3 ± 5.3			
Alignment					
conventional	2-33	22.5 ± 8.4	-.3 (-1.7 to 1.1)	3.7	-.44 (0.66, 29)
ergonomic	1-33	22.2 ± 8.7			
Size					
conventional	1-33	14.6 ± 10.5	-.3 (-2.0 to 1.4)	4.6	-.32 (0.75, 29)
ergonomic	0-33	14.4 ± 9.8			
Spacing					
conventional	14-33	26.8 ± 5.2	.4 (-.6 to 1.4)	2.7	.89 (0.38, 29)
ergonomic	17-33	27.3 ± 4.8			
Rate					
conventional	12-34	25.8 ± 7.5	-.9 (-2.9 to 1.1)	5.3	-.94 (0.36, 29)
ergonomic	8-34	24.9 ± 7.8			

Table 2.1: Primary and secondary MHA outcomes for conventional and ergonomic seating interventions.

In sum, our study was underpowered to detect a performance effect as large as we proposed. For our sample size calculation, we relied on descriptive statistics from another study[37] that explored the effect of remedial interventions on handwriting legibility. Since the motor performance variability in children with CP is generally greater than the variability in the general population, we conservatively increased our study sample size to account for this. However, we estimated the SD of mean difference scores for legibility in our study to be 60% smaller than the SD of mean difference scores used in our power calculations (i.e., SD of mean differences = 1.8 (our study) versus 4.7 (reference study)).

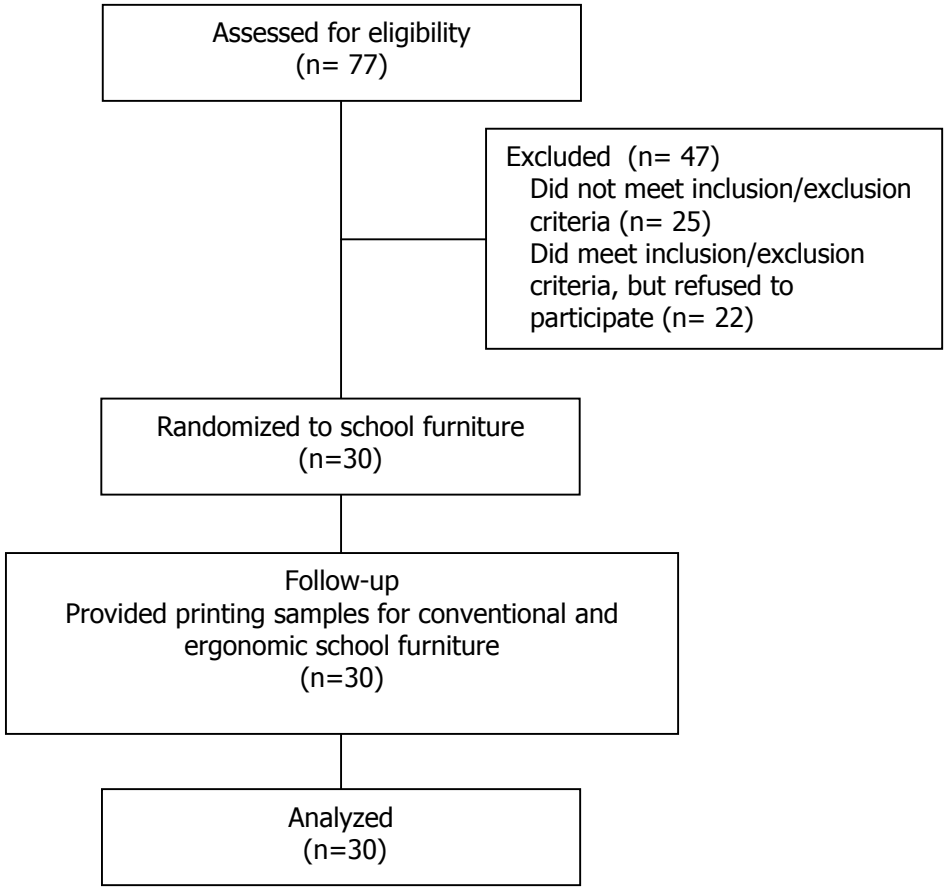

Fig 2.2: Participant flow diagram as per Consolidated Standards of Reporting Trials (CONSORT) guidelines.

Similarly, we could not detect significant differences in means for other handwriting performance indicators including letter formation, alignment, sizing, and rate. Of interest, only two categories had 95% upper confidence limits for effect size that exceeded .3. The upper confidence limits approached a medium effect size for letter form quality (in favor of the ergonomic intervention) and rate (in favor of the conventional intervention) (table 2.2). Although we could not make statistical inferences regarding the effect of the interventions on these indicators, these possible effect sizes are large enough to merit further study. It is reasonable

to expect improvements in letter form if ergonomic seating improved postural control for children with ambulatory CP as reported in other studies.[21,22] However, it is less defensible why we did not detect larger effects in letter/word alignment, spacing, and sizing.

With respect to MHA rate, it may be that the children's familiarity with the horizontal desk surface contributed to a high effect size limit in support of the conventional school furniture. Printing speed was not emphasized to study participants and is generally considered to be of lower clinical importance than the other quality categories at this grade level.[37] However, speed becomes increasingly important as a child progresses through elementary school to meet changing academic demands.[44]

Study Limitations Our trial had several limitations. We did not monitor the seated postural alignment and stability of children. Although children assumed an optimal seated posture on both interventions before printing began, we did not prompt children to reassume this seated posture to avoid confounding both the intervention and printing outcome. Anecdotally, our research therapist reported that almost all children moved from the optimal orientation and readjusted their postures while printing. Consequently, it is unclear the extent to which moving from an optimal to a "preferred" seating posture affected the construction and formation of letters and words.

Prior to training our assessor to score the handwriting samples of children, we developed an addendum for the MHA because we estimated the inter-rater reliability of the legibility subscale to be below an acceptable level. To reduce measurement error while maintaining the MHA scoring intent, we chose rules that reduced error scoring for letters where legibility and other performance errors were questionable. Our rules may have led to fewer errors being scored by the assessor than was intended by the MHA authors. Consequently, the addendum may have changed the measurement sensitivity of the MHA. However, the mean legibility scores in our study (about 30.7 points) were within the range of legibility means (29.8 – 32.4 points) in our reference MHA study of children who were at-risk academically.[37]

Further, 55-70% of participants were below MHA norms for Grade 1 legibility and most were below norms for all other handwriting quality categories. This suggests that the modified MHA was sensitive enough to detect that our sample included a greater proportion of students with poorer quality handwriting than expected in the general population. However, further research is needed to study the validity of the mean levels we measured in the context of the MHA norms for children with typical development.

Our sample was taken from a pool of children with CP who received services at a rehabilitation center located in a large metropolitan area. It may be that children who participated in our study were more alike than other children who were not included in the initial pool. For example, children who participated may have attended schools that had better (or inferior) access to remedial handwriting resources than children with CP living in other regions. Replication of the study outcomes for other samples of children with CP would help to confirm the external validity of our findings.

Finally, since we could not mask the intervention to create a double-blinded, randomized controlled trial, we took other steps to reduce observer and participant bias. Although the research therapist was aware of the study objectives, she was blind to the intervention assignment until after opening the sealed envelope, and followed a standard protocol to adjust the furniture and administer the MHA. Further, children who participated and their parents were unaware of the specific research objectives.

Recommendations for Future Research We provided minimal time for the children in our study to become accustomed to the interventions. In smaller, non-randomized seating research studies,[45,46] children showed significant improvements in handwriting productivity and other important bimanual activities following adaptation periods of 1 to 5 weeks. As posited by Linton and colleagues,[32] children do not automatically know how to sit properly in ergonomic classroom furniture. It may be that we would have detected important differences in print legibility and other quality indicators if children had more time to learn how to optimize their seated postures for handwriting activities. We recommend that future research be directed toward exploring the influence of school furniture design, seated posture training, and adaptation time on printing quality outcomes.

CONCLUSIONS

Little remains known about the effectiveness of environmental interventions intended to improve the handwriting quality of children with CP. Although we did not detect a significant, immediate impact of school furniture configurations on printing performance, other experiments should be conducted to study the effect of these and other environmental resources in classroom settings over longer follow-up periods. Ultimately, these studies will shape clinical practice guidelines by improving our understanding of the effectiveness of strategies employed to optimize the handwriting performance of children with CP and other clinical populations.

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SUPPLIERS

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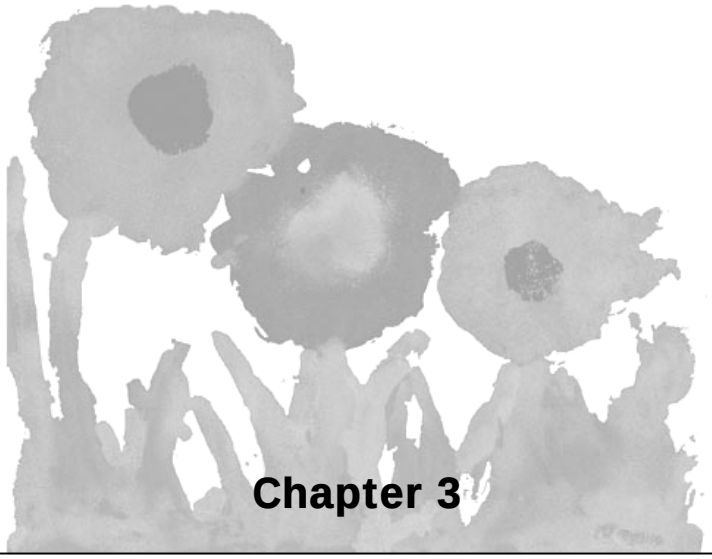

Chapter 3

Development of the new Family Impact of Assistive Technology Scale (FIATS)

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ABSTRACT

Objective: To estimate the content validity and face validity of a new measure of the impact of assistive technology devices on the lives of young children and their families.

Design: Survey of clinicians and parents of children with cerebral palsy for content validity phase. Three-stage review involving two surveys and one focus group with parents of young children with cerebral palsy.

Setting: Children's rehabilitation centre.

Participants: Eight parents of young children with cerebral palsy and six clinical experts in children's rehabilitation.

Interventions: None.

Main Outcome Measure: Family Impact of Assistive Technology Scale (FIATS).

Results: Experts agreed that the FIATS contains the key variables needed to study the effect of assistive technology use on child and family functioning with the addition of one domain that measures parents acceptance of assistive technology devices for their children. Parents concurred that items on the preliminary version were relevant and clear.

Conclusions: The preliminary version of the FIATS appears to provide sufficient content coverage according to both clinical experts and a sample of parents of children with CP who need AT devices for support. The FIATS needs to undergo further psychometric testing to reduce the item construction and demonstrate the acceptability of its internal consistency, test-retest reliability, and construct validity (responsiveness) before being used to measure the impact of AT devices on the lives of children and their families.

While parents of typically developing children expect them to gain functional skills and acquire autonomy throughout the preschool years, parents of children with physical disabilities face a different picture. The amount of care and direct supervision required for children with physical disabilities, such as cerebral palsy (CP), does not decrease as they age, thereby placing an additional burden of care on mothers and other family members.[1,2] This added caregiver burden could lead to serious health problems for parents and other family members.

In their study of 468 primary caregivers of children with CP living in Ontario, Canada, Brehaut and colleagues found that parents had more psychological and physical health problems than parents of children in the general population.[3] The researchers found that parents of children with CP had a higher prevalence of back problems, migraine headaches, stomach ulcers, and many other chronic health problems. One explanation offered was that the poorer health states might be due to the additional stress and burden of caring for children with disabilities. Findings from this study suggest the need for healthcare providers to identify and employ effective interventions to improve the health and well-being of parents and their families.

Assistive technologies, in the form of postural control devices, show promise as interventions that may benefit both children with CP and their parents. It is generally accepted that using postural control devices helps to improve upper extremity function by supporting the trunk, pelvis and lower extremities of children with CP.[4,5] Improving function may enable children with CP to gain greater autonomy, require less assistance from caregivers, and improve face-to-face communication and social interaction with peers and family members.[6,7] Despite the wide use of postural control technologies and other interventions in clinical practice, there is little evidence of their efficacy and effectiveness for children with CP.

Steultjens and colleagues conducted a systematic review to determine whether occupational therapy (OT) interventions improve outcomes for children with CP.[8] The provision of assistive technologies was among the categories of OT interventions investigated. Although the authors included seventeen clinical trials in their review, they could not make conclusions about the efficacy of the OT interventions due to methodological flaws in the original studies. They recommended that future research studies be designed with higher methodological rigour using standardized outcomes that reflect the aims of occupational therapy. There are good, standardized measures such as the Pediatric Evaluation of Disability Inventory[9] to measure child function, however, there is a need for new reliable and valid instruments that can measure important outcomes such as the impact of interventions on social participation and well-being of families.

Fuhrer and others[10] concur that current AT outcome measures tend to focus on understanding the impact of technology on user function. While it is important to understand the effect of AT on users, Fuhrer[11] recommends that AT outcomes research include the perspectives other stakeholders, including parents, to understand more about the important role that assistive technologies play in their lives.

Due to the investment in time and resources needed to develop sound outcome measures, experts agree that it is preferable to use a standardized scale that is close to what is needed rather than develop a new one.[12] By utilizing standardized outcome measures to study the role that these technologies play in the lives of families who have children with physical disabilities, clinicians may better understand the potential application and effect of these interventions.

We reviewed the literature to find standardized measures that we could use to detect the effect of AT on families of children with disabilities. Lenker and others reviewed and evaluated 83 outcome studies that measured assistive technology outcomes published between 1980 and 2001.[13] Of the more than 200 outcome variables reported in the studies retrieved, less than 5% of the studies reported on fundamental psychometric properties such as test-retest reliability and construct validity. Further, less than 3% of the measures reviewed included caregiver variables. None of the variables was specific to measuring the effect of AT on children with disabilities and their caregivers because "the conceptual theory underlying outcomes for children is not yet well developed."[13]

Despite the lack of appropriate AT-specific measures, standardized scales designed to measure family functioning do exist. The McMaster Family Assessment Device,[14] Impact on Family Scale (IFS),[15] and the Family Assessment Measure (FAM III),[16] are being used by clinicians to evaluate important areas of stress such as family functioning, financial burden, social relationships and coping strategies in families who have children with cerebral palsy,[3] spina bifida,[15] and family members with acquired brain injuries.[18] However, these generic scales are not designed to be responsive to changes in family functioning due to enabling AT interventions, such as postural control devices for children with disabilities.

PURPOSE

In this article, we report on the development of Family Impact of Assistive Technology Scale (FIATS) to fill this gap in outcome measurement. The FIATS was developed to detect change in the adaptability of families who have young children who are unable to sit without support. Since the psychometric properties of most AT-related outcome measures are underreported,[13] we describe our process to develop the domains, generate items and study the content validity and face validity of the FIATS. We report on our investigation of other important

psychometric properties of the FIATS including internal reliability, test-retest reliability and construct validity elsewhere.

RESEARCH METHODS AND FINDINGS

We advanced the development of the FIATS by consulting with clinical experts and parents to evaluate the clarity, assess the content, identify new, relevant areas of inquiry and help generate new items for the FIATS. We received ethical clearance from the Research Ethics Board at Bloorview Kids Rehab, a children's rehabilitation hospital in Toronto, Canada.

Examining the Content Validity of the FIATS We reviewed pertinent peer-reviewed journal articles, considered relevant content from other relevant health measurement scales, and used our clinical judgment to identify key dimensions for the preliminary version of the FIATS. We identified and defined eight unique domains over which we could measure the impact of postural control device use on child function and family life (figure 3.1).

Autonomy: Degree to which the child needs help to perform activities.
Disposition: Degree to which the child is content during the day.
Effort: Degree of exertion needed to assist the child.
Function: Degree to which the child has voluntary control over his/her own actions.
Respite: Degree to which parent needs relief from caregiving.
Social and Family Interaction: Degree to which the child interacts with others.
Supervision: Degree to which the child requires attention from family members.
Well-Being/Safety: Degree to which parent is worried about the child's well-being and safety.

Figure 3.1: Preliminary domains and definitions for the FIATS

To test the content validity, Streiner and Norman[13] recommend that "highly experienced" people in the content area be invited to review the coverage and relevance of the proposed domains. We recruited five clinical specialists – including experts in early childhood education, social work, occupational therapy, physiotherapy and community-based nursing – and two parents who have school-

age children with cerebral palsy to help us examine the representativeness of the content areas proposed. The clinical specialists each had more than 10 years service and/or research experience working with children with physical disabilities. Parents had school-aged children with CP who were clients of Bloorview Kids Rehab and recommended to us by their child's primary therapist.

Content experts used a form that we created to record their ratings and opinions about each of the proposed domains (figure 3.2). For each domain, experts considered the definition, reviewed a sample item that related to that area, and assigned ratings on a 6-point Likert scale to reflect the degree to which they felt that the proposed domain was relevant to the scale's intended purpose. Further, we asked participants to suggest and similarly rate other important content areas that we should include in the new scale. Results of relevancy ratings assigned by content experts are summarized in figure 3.3.

Experts mostly agreed that our suggested domains were either "relevant" or "totally relevant" for our new measurement scale. *Autonomy* and *Well-Being/Safety* domains had the least variability in ratings. *Function* and *Supervision* had higher variability compared to the variability of ratings in other domains due to a single "irrelevant" rating provided by one respondent. The expert reasoned that children who are unable to sit on their own cannot use a seat without assistance and the level of supervision would not change with the use of the device.

Content experts offered advice about other possible content areas. Two content experts recommended that *Technology Acceptance* be included as a ninth subscale of the FIATS. The reviewers recommended the inclusion of this subscale because they reasoned that parents who are less accepting of technology would be less affected by their child's use of AT. Other experts suggested domains that relate to specific characteristics of the device, such as weight, appearance and portability, but conceded that these may relate closely to existing domains such as *Effort* and *Well-Being/Safety.*

We generated a pool of 93 items for the FIATS scale to cover domains endorsed by experts, including the one additional domain of *Technology Acceptance*. Each domain had between 7 and 12 items.

Examining the Face Validity of the FIATS To assess the face validity, Streiner and Norman[13] suggest that potential respondents be asked to review the scale to determine whether each item appears and to be clearly measuring what we intended. We asked clinical staff at Bloorview Kids Rehab to recommend parents for a focus group meeting to evaluate the preliminary items on the scale. From the pool of candidates suggested, we invited a convenience sample of seven parents to participate. Each parent had a child with CP who was between 3 and 8 years of age and used assistive devices for postural support.

Autonomy: Degree to which the child needs help to perform activities. Sample item: *My child can play without someone holding her/him.*	Totally Irrelevant	Irrelevant	Somewhat Irrelevant	Somewhat Relevant	Relevant	Totally Relevant
	1	2	3	4	5	6
	Comments:					

Figure 3.2: Sample rating form for content validity study

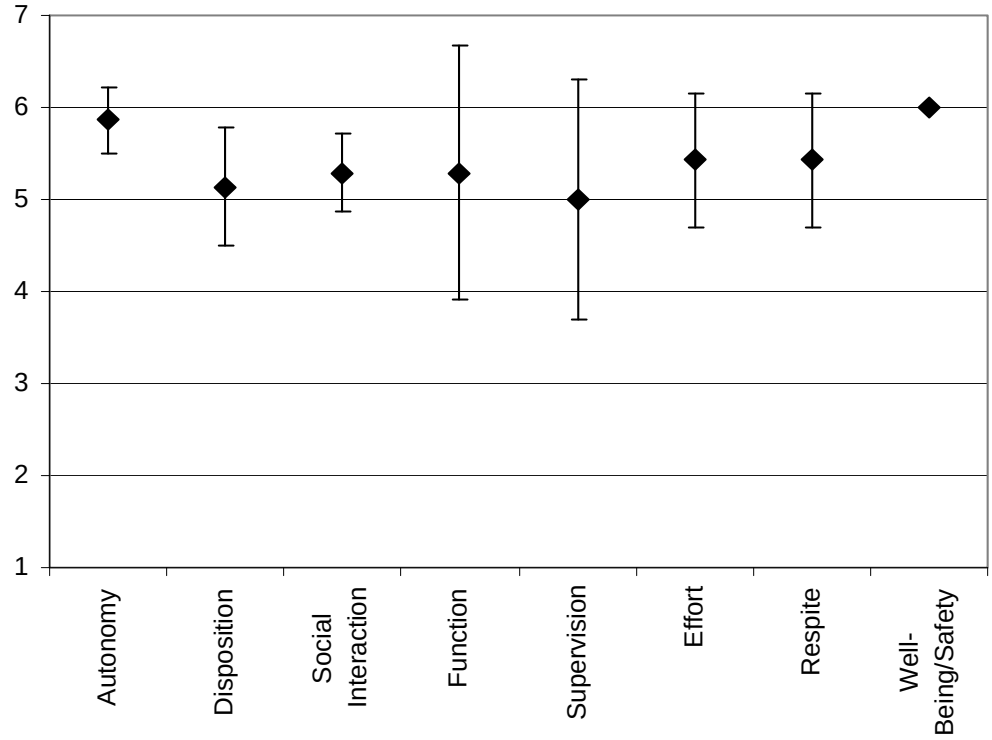

Figure 3.3: Mean ratings with 95% confidence intervals for relevance of FIATS subscales for content validity study

One week before the meeting, we sent parents a draft version of the 93-item FIATS to read and rate. Each parent rated the degree to which they agreed with each item using a 7-point Likert scale that ranged from 7 (strongly agree) to 1 (strongly disagree). For items that were difficult to understand, parents circled a "?" rather than provide a rating. We contacted each parent one day before the focus group to ask him or her to tell us which items were unclear. Of the 93 items reviewed, one or more parents had difficulty understanding the meaning of 24 items.

During the meeting, parents collectively reviewed the 24 unclear items. Where possible by group consensus, parents reworded items to make them clearer. If an item could not be reworded to improve its clarity, the item was retained as originally worded. Once all 24 items were reviewed, reworded or skipped, participants indicated independently and in confidence whether they understood the item, or still felt it was unclear using a scoring form that we created.

We agreed a priori to retain only items rated "clear" by all seven participants. Of the 24 items considered, parents reworded five items and at least one parent reported that four other items were unclear. In particular, parents felt that supervisory statements suggesting children could be left "alone" were objectionable. They recommended that these items be reworded to indicate that the child could sit "independently" with or without assistive devices.

Parents further suggested that a child should be "supported" in a sitting position rather than sit "upright". They agreed that the latter wording suggested an optimal sitting position that would be impossible for their children to achieve. Parents recommended that we include brief written instructions on the first page of the questionnaire to describe how to complete the FIATS.

The revised version of the FIATS had 89 items covering nine unique domains that each tap into the perceived impact of technology use on families. Instructions on how to complete the questionnaire were added to the first page of the scale as recommended by parent participants. We retained the original 7-point Likert scale so parents could record the degree to which they agreed or disagreed with a particular item.

DISCUSSION

The domains suggested for the preliminary version of the FIATS were highly relevant based upon our review of pertinent literature, our consideration of related, standardized outcome measures, and the ratings assigned by content experts. Most experts agreed that these subscales should be retained. Some experts suggested additional domains that were directed more toward the physical properties of devices. Although these may have an indirect effect on child

development and family functioning, we agreed to include only those domains whose scoring could be influenced by the *use* of the technology in the home. Clearly, technology acceptance was an important domain that could be influenced by use, therefore we incorporated this as the ninth subscale in the multi-dimensional version of the FIATS.

Streiner and Norman[13] recommend that people who are the intended users of a scale should evaluate the face validity of the scale. Although participants in the face validity study were not randomly selected from the population, the seven mothers who participated each had a child who used an adaptive seating device for postural support. Thus, we reasoned that each could offer valid opinions about the clarity of the items on the FIATS.

The participants reported that they understood 74% of the original 93 items on the preliminary version of the FIATS. Although 24 items were originally rated as unclear by at least one parent, after discussion and rewording of items, only four of these items were still rated as unclear by at least one parent.

CONCLUSIONS AND RECOMMENDATIONS FOR FURTHER RESEARCH

Postural control devices are assistive technologies that provide children with the stability and support needed to engage voluntarily in important occupations such as independent play and personal care. Little is known about the enabling effect of device use on child development and family functioning. This initial study of the validity of the FIATS provides an important first step in the development of a psychometrically sound measurement scale. Our plan is to conduct further research using the FIATS to estimate its other important measurement properties such as test-retest reliability and construct validity.

Using the FIATS to study the family effect of postural control devices and other assistive technologies may help healthcare professionals, parents, and third party payers to understand how these technologies may be used to support and improve child performance and family life.

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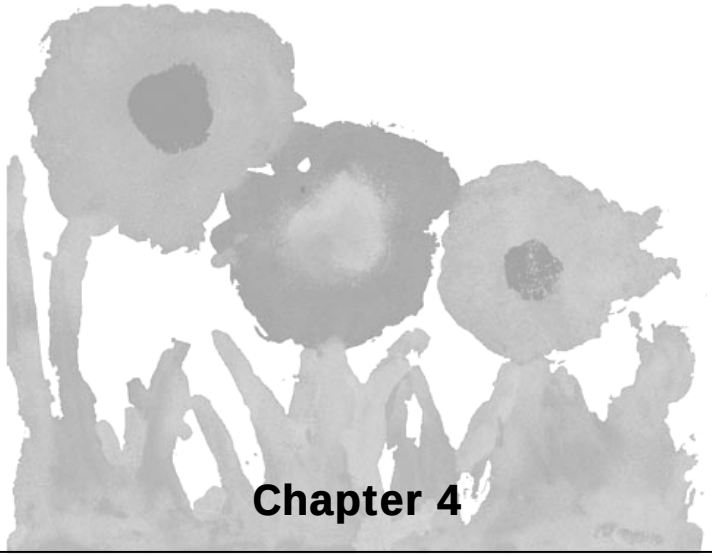

Chapter 4

Reliability of the Family Impact of Assistive Technology Scale

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ABSTRACT

Objective: To examine the internal consistency and test-retest reliability of the Family Impact of Assistive Technology Scale (FIATS) when used to measure the perceptions of parents about important aspects of family life that may be influenced by their children's use of assistive devices.

Design: Repeated measure.

Setting: Homes of 50 participating families.

Participants: Parents of young children with cerebral palsy.

Interventions: Not applicable.

Main Outcome Measure: The FIATS.

Results: Through an a priori item reduction process, we reduced the length of the FIATS from 89 to 64 items. We retained 8 of the 9 original subscales. The 8 subscales included: autonomy, caregiver relief, contentment, doing activities, effort, family and social interaction, caregiver supervision, safety, and technology acceptance. All items for 1 domain (technology acceptance) correlated well with its own subscale total, but did not relate well to the FIATS total score. This construct was retained as a separate, but noncontributing scale within the FIATS. The overall FIATS and its 8 contributing subscales had acceptable internal consistencies and test-retest reliabilities.

Conclusions: The FIATS shows promise as a homogeneous and reproducible multidimensional measure of dimensions of child and family life. We plan further testing to examine the sensitivity and clinical meaningfulness of change scores on the FIATS.

Parents who have young children with complex physical disabilities face challenges that are both physically and emotionally demanding. Parents of children with disabilities spend more time providing child assistance and supervision than other parents because their children are unable to do many everyday activities on their own.[1,2] These added responsibilities, for mothers in particular, translate into less time attending to their own needs, the needs of their other children, and household chores, and most mothers do not have time to work outside the home.[2,3,4]

Investigators have reported significantly higher stress levels in parents of children with developmental disabilities,[5] autism and pervasive developmental disorders,[6] Down's syndrome,[7] and cerebral palsy (CP)[8] when compared with the stress levels experienced by parents of the same-aged children without disabilities. Other researchers suggest that parents of children with disabilities have a higher risk of child maltreatment[5], dysfunctional relationships,[9] and unemployment[10] than parents of children without disabilities.

We hypothesized that assistive devices used by young children with complex positioning problems at home would enhance functional outcomes for children and provide a measurable form of relief for families by reducing caregiver burden. By using outcome measures with high levels of reliability and validity to study the role that these technologies play in the lives of families, we may better understand their facilitating effects. However, measures with good psychometric properties are either unavailable or not sensitive enough to measure the effect that enabling technologies have on family life.

We developed the Family Impact of Assistive Technology Scale (FIATS) – a measure designed to detect the multidimensional effect of assistive device use on families who have young children with disabilities – to fill this measurement need. We initiated the development of the FIATS by reviewing the literature and identifying domains that assistive devices could influence. We conceptualized the impact of the use of assistive devices on family life as a latent variable defined by the measurement of items that related to each of these domains.

We consulted with clinical experts and parents to assess the relevance of the proposed domains, estimate its content validity, and identify new content areas. This process yielded nine dimensions of child and family life that assistive devices could affect. The dimensions included: autonomy, caregiver relief, contentment, doing activities, effort, family and social interaction, caregiver supervision, safety and technology acceptance.

We generated a pool of items that addressed these content areas. Parents of children with CP evaluated the clarity of these items and examined the face validity of the FIATS using a consensus building approach that we developed. We showed

that the FIATS has very good face validity and content validity. Details of this earlier exploration are reported elsewhere.[11]

The preliminary version of the FIATS developed from this earlier study had 89 statements that tapped into one of the nine subscales identified by content experts as being relevant to the scale's intended purpose (Table 4.1). This version of the FIATS was used in the present study.

Domain	Definition	Number of Items
Autonomy	Degree to which the child can perform activities independently.	7
Caregiver Relief	Degree to which parent needs relief from caregiving.	11
Contentment	Degree to which the child is content during the day.	12
Doing Activities	Degree to which the child has control over his/her own actions.	13
Effort	Degree of energy needed to assist the child.	9
Family/Social Interaction	Degree to which the child interacts with others.	9
Safety	Degree to which parent is worried about the child's safety.	10
Supervision	Degree to which the child requires attention from family members.	8
Technology Acceptance	Degree to which the parent accepts assistive devices for the child.	10
	Total Number of Items	**89**

Table 4.1: Subscales of the preliminary version of the FIATS

The FIATS included a 7-point Likert scale to record the degree to which parents agreed or disagreed with each statement as shown in figure 4.1. To reduce the likelihood of rater bias, subscale items were randomly assigned throughout the FIATS and 48% of the statements were reverse scored.

The preliminary version of the FIATS showed very good content and face validity. The objective of the present research study was to (a) improve the homogeneity of the FIATS by adopting an a priori item reduction method; (b) estimate the internal consistency of the revised FIATS and its subscales; and (c) estimate the test-retest reliability of the FIATS.

	Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree	Domain
I have little time to get chores done around the house.*	7	6	5	4	3	2	1	Supervision
I'd like my child to be as independent as possible.	7	6	5	4	3	2	1	Supervision
It is easier to play with my child when someone is holding him/her.*	7	6	5	4	3	2	1	Family/ Social Interaction
My child socializes with others at mealtime.	7	6	5	4	3	2	1	Family/ Social Interaction

Fig 4.1: Sample items from the preliminary version of the FIATS. (* = reverse scored)

METHODS

We received ethical clearance for the study from the Research Ethics Board at Bloorview Kids Rehab, a fully-affiliated teaching hospital of the University of Toronto, located in Toronto, Canada.

Participants We invited parents and their young children who were clients of one of three regional children's rehabilitation centres in southeastern Ontario, Canada to join this study. These centres included our children's centre (Bloorview), Erinoak and Grandview Children's Centre. Eligible parents cared for children who: (a) had a primary diagnosis of CP with a functional status defined by Gross Motor Function Classification System (GMFCS)[12] Level III or IV; (b) were between 2 years, 6 months and 7 years, 6 months; and (c) lived in a geographical area served by one of the three participating rehabilitation facilities. Following a review of electronic medical records for children with this level of disability, we identified 347 children who met the initial inclusion criteria.

We sent a letter to these families to introduce the study. We phoned parents of children who were Bloorview clients one to two weeks later using a uniform randomization approach to provide each family with an equal chance of being invited to participate. We used a different recruitment procedure for the other two participating centres to protect the privacy of their clients and families. Our collaborators from the other two centres mailed letters to families to invite them to contact our study coordinator if they were interested in being involved.

We developed and employed a screening questionnaire to identify parents who: (a) were primary caregivers, defined as providing not less than 10 hours of direct supervision per day; and (b) did not use specialized postural control devices to support their children at home for floor sitting, chair sitting and toileting activities. We included children who did not use postural control devices at home because we invited their parents to participate in a follow-up intervention study to examine the effect of these devices on family life using the FIATS. The outcomes of this intervention study are not considered here.

We explained the project protocol and expectations of participants during the phone call. We mailed an information letter to caregivers who were interested and met our screening criteria. Each participant provided signed consent. Recruitment continued until 50 families were enrolled in the study.

Of the 258 families we contacted, 162 families did not satisfy the screening requirements, 24 families declined due to scheduling conflicts, 16 families met the screening criteria but later declined after receiving more information about the project by mail, 6 children were deemed clinically ineligible by the research occupational therapist during the first home visit, and 50 families agreed to

participate. We recruited 45 families from Bloorview Kids Rehab and the remaining five families from the other two children's centres to reach our target sample of 50 families.

Protocol One of two research occupational therapists conducted interviews in the homes of families. At the first home appointment, the therapist used a questionnaire that we developed to interview a parent to gather basic demographic information including the number of family members, the school schedule of the child and the number of hours the parent worked out of the home. For this reliability study, we asked parents to complete the FIATS twice – once at the first home visit and again 2 to 3 weeks later during the second visit. Although we administered other questionnaires during the home visits, these were not included in the reliability analyses so are not discussed further.

Statistical/Data Analysis We adopted an a priori item reduction strategy based on the recommendations of health measurement scale authorities.[13] Our general plan was to identify and eliminate those items that did not correlate well with the overall FIATS scale or the subscale to which they were assigned. Specifically, we compiled data from the first administration of the FIATS and eliminated items in the following order:

(1) Items with more than 80% of respondents selecting the same rating for a particular item were discarded;
(2) Items that had low corrected item-total FIATS scale correlations, defined as Pearson's | r |< .20, were eliminated;
(3) Items with low corrected item-total subscale correlations (| r |<.20) were correlated with other subscales. If the item-other subscale correlation was equal to or greater than .20, the item was reassigned to other subscale if it related conceptually to the other subscale construct. Otherwise, the item was eliminated; and,
(4) Item-total other subscale correlations were calculated for the remaining items to confirm that they were assigned to the correct subscales. The item was reassigned if it had a higher item-subscale total correlation with the other subscale, and was related conceptually to the other subscale.
(5) Other non-homogeneous items were identified and eliminated by repeating the correlational analysis using the reduced scale and repeating Steps (2) – (4).

For steps (3) and (4), the three authors (SR, KC, PR) and one of the project research therapists collectively reviewed each item with a higher item-total "other" subscale correlation than the correlation with its own scale. Items were reassigned to the new subscale only if all researchers agreed that the item was related conceptually to the other subscale construct. Otherwise, the item remained assigned to its original scale.

To evaluate the internal consistency of the revised FIATS, we calculated Cronbach's alpha for the total scale and subscales using data from the first administration of the FIATS. We estimated test-retest reliability using intraclass correlation coefficients (ICCs) and data from the two administrations of the FIATS. Measurement authorities suggest homogeneous scales should have alphas between .7 – .9, and test-retest reliability ICCs should be in the range of .65 – .90 for research purposes.[13, 14]

RESULTS

Demographics Forty-eight mothers and two fathers of children who met the inclusion criteria participated in the study. Eight-six percent of the parents had at least two children. Forty-three parents had children with CP who attended either elementary or nursery school during the week either full-time or part-time, and the remaining seven parents had children with CP who were too young to attend school.

At the time of study enrolment, most children had some form of assistive technology that they used in the home. The most common assistive device was a wheelchair or stroller with specialized seating. When not in the wheelchair, parents reported their children had to be positioned by an assortment of pillows, family members, or using modified juvenile equipment such as a high chair or car seat. Homemade devices such as modified potty seats and corner seats were less common, but were used occasionally to provide alternate positioning for children.

Item Reduction We used the a priori strategy above to identify items that did not correlate well with the overall FIATS scale and its own subscale. Two statements received the same rating 80% of the time or more, 27 items had low item-total FIATS correlations (i.e., $| r | < .2$) and 7 items had low item-subscale total correlations. All items on the Technology Acceptance subscale had low correlations with the total FIATS. However, only one of the ten items on this subscale had a low item-total correlation with its own subscale.

Eight statements on specific scales had item-total scores above the lower correlation threshold (i.e., $| r | < .2$), but had higher correlations with other subscales. Upon our review of the relevance of these eight items to the other subscales, we concurred that all items should remain assigned to their original subscales.

Initially, 36 items were eliminated from the FIATS. Upon recalculating the item-total scale and subscale correlations for the reduced version of FIATS, two more items were eliminated due an absolute item-total correlation of less than .2, thereby leaving a total of 55 contributing items on the FIATS.

A summary of the descriptive and reliability statistics for the item-reduced version of FIATS, its eight contributing subscales and the Technology Assistance subscale is provided in Table 4.2. Seven subscales had Cronbach's alphas that were within the range of .70 – .90. The two remaining subscales had alphas above .60. Alpha for the total the FIATS scale exceeded .90.

The point estimate of the test-retest reliability for the overall FIATS scale was .92, as measured by the intraclass correlation (ICC). The ICC point estimates for test-retest reliability for all subscales were between .77 and .92. The 95% confidence intervals for all subscale ICCs extended from .59 to .96.

Scale	No. of Items	Mean	SD	Cronbach's Alpha	ICC	95% Confidence Intervals for ICC	
						Lower	Upper
Autonomy	5	4.12	1.19	.73	.84	.73	.91
Caregiver Relief	9	3.57	1.26	.89	.89	.80	.94
Contentment	9	4.13	.93	.72	.87	.77	.93
Doing Activities	5	5.11	1.04	.68	.89	.80	.94
Effort	8	2.95	1.26	.81	.83	.70	.90
Family/Social Interaction	4	5.45	.77	.64	.77	.59	.87
Safety	8	3.25	.89	.70	.87	.77	.93
Supervision	7	3.67	1.15	.73	.92	.87	.96
Total Sum of Means for Revised FIATS	55	32.25	6.63	.94	.92	.86	.95
Technology Acceptance	9	6.46	.57	.92	.81	.66	.89

Table 4.2: Selected descriptive statistics for scales, alpha coefficients and test-retest reliability intraclass correlations of the revised version of the FIATS, its eight subscales and the technology acceptance subscale

DISCUSSION

Following our a priori strategy to reduce the items, we eliminated 40% of the items from the FIATS. Although all nine items on the Technology Acceptance subscale had item-total FIATS scale correlations below the r=.2 threshold, its internal consistency was high (α=.92) and the test-retest reliability was good (ICC=.81, 95% CI=.66, .89). This suggests that the items on the subscale do not contribute to the overall FIATS score, but do tap into another construct that appears to be stable over time. Consequently, we retained the Technology Acceptance subscale as a separate measure within the FIATS, but its ratings did not contribute to the overall scoring for the FIATS.

The FIATS had a high internal consistency as measured by its coefficient, which exceeded .90. This suggests that there may have been some redundancy within the scale caused by a few items measuring the same attributes.[13] Six contributing subscales on the FIATS showed acceptable internal consistency. The items on these scales related well to the subscale total and the overall FIATS total score. Only the Family/Social Interaction and Doing Activities subscales had alphas below the preferred range of .70 to .90, suggesting possible inconsistency across items that comprised these scales.

Of interest are the very good test-retest reliabilities of the FIATS and its subscales. All scales have estimates of reliability that are within the preferred limits for measures of group performance[13]. Only one subscale (i.e., Family/Social Interaction) had a lower 95% confidence interval that was below an acceptable test-retest ICC of .65.

The parents who participated in this study were similar in that they had young children with CP whom we would expect to benefit from the use of assistive technology for positioning, mobility and activities for daily living. Many children had assistive devices for mobility, while very few had other commercial devices for postural control.

We calculated the revised FIATS score by determining the sum of the mean subscale scores. Hence, overall FIATS scores could range from 8 to 56. In this study, the mean FIATS score was 32.3 (SD = 6.6) or about 67% of the total possible score. This suggests that for this sample of parents of children with disabilities, there is room on the FIATS to measure an effect on family life due to the introduction and use of postural control devices by children.

CONCLUSIONS

It is important for rehabilitation clinicians to adopt and use measures that are sensitive to understand the impact that enabling interventions like assistive devices have on family life. Although it is important to know the extent to which the measured differences are also meaningful to children and their families, we must first show that the measures are internally reliable and stable over time.

The FIATS shows promise as a stable measure of the perceived impact of postural control devices used by young children with cerebral palsy in their home environments. Our study suggests that in its revised form overall the FIATS has acceptable internal consistency and test-retest reliability. This is the first study that explored the homogeneity and reproducibility of the FIATS and its subscales. With additional estimates of the test-retest reliability in other well-designed studies, the psychometric rigour of this new measure will be strengthened.

We plan to evaluate the sensitivity and responsiveness of the FIATS to measure change in child and family life due to introduction and use of postural control devices. We also intend to explore the relationship of the FIATS with other standardized outcome measures and other populations of children who need assistive devices. With this additional evidence of validity, we expect that the FIATS will provide clinicians and researchers with a new measurement scale to study the role that assistive devices play in the lives of families of children with CP and other complex needs.

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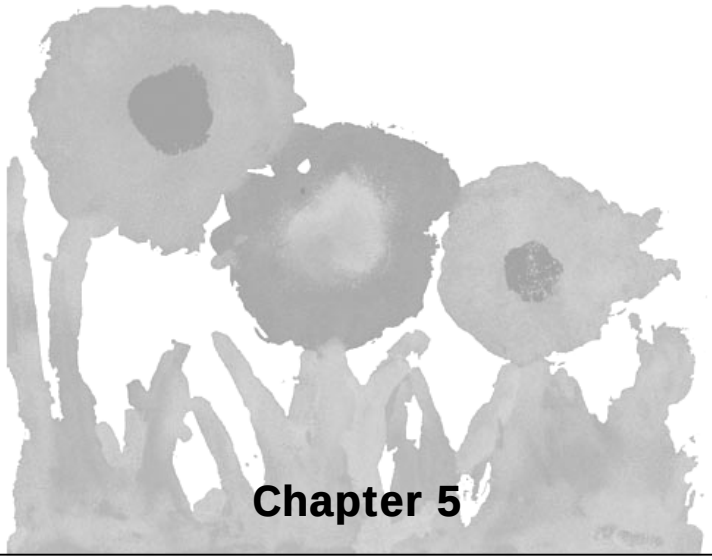

Chapter 5

Impact of adaptive seating devices on children with cerebral palsy and their families

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ABSTRACT

Objective: To determine the parent-perceived effect of adaptive seating devices on the lives of young children with cerebral palsy, aged 2 to 7 years, and their families.

Design: Baseline-intervention-baseline study.

Setting: Homes of participating families.

Participants: Thirty parents and their children with Gross Motor Function Classification System Level III or IV cerebral palsy.

Interventions: Two special-purpose seating devices – one for sitting support on the floor or on a chair, the other for postural control on a toilet.

Main Outcome Measures: Family Impact of Assistive Technology Scale (FIATS) and Impact on Family Scale (IFS).

Results: Thirty parents (29 mothers, 1 father) and their children with cerebral palsy participated. Repeated measures analysis of variance detected significant mean differences among the FIATS scores ($F(1.4, 40.6) = 19.25$, $p < .0005$). Post-hoc testing confirmed significant mean differences in overall FIATS scores between baseline and intervention and intervention and post-intervention phases. The test of within-subject effects did not detect a significant change among IFS mean scores.

Conclusions: The introduction of adaptive seating devices for young children who need support to sit had a meaningful, positive impact on child and family life. Removal of the study devices showed a concomitant negative impact on key aspects of child and family life. Environmental resources, such as seating and other assistive technology devices, may have an important role to play in the lives of young children with physical disabilities and their families.

Assistive technology devices are environmental resources that can play an important role in improving the lives of children with physical disabilities, such as CP. An assistive technology device can be described as "any item, piece of equipment or product system…that is used to increase, maintain, or improve the functional abilities of a child with disabilities."[1] Children may benefit from using many different types and forms of assistive technology devices to communicate, ambulate, and participate in everyday activities at home, at school and in the community.

The effects of assistive technology devices may extend beyond young technology users to their parents and other family members. For example, 2 regional surveys of parents of children with disabilities suggest positive associations between the use of devices and improved child function and reduced caregiver burden.[2,3] Although survey methodologies do not permit causal relationships to be established between assistive technology device use and child and family factors, one could argue that the positive influence of these technologies on children, their parents, and their families is self-evident, and the need to confirm the beneficial effects through more rigorous empirical research is unwarranted. However, evidence of pervasive assistive technology device discontinuance, dissatisfaction, and nonuse weakens this line of reasoning.[4-6]

In the context of scarce health care funding for assistive technology devices and associated services, it is important for assistive technology practitioners, administrators, third-party payers, and families to understand the effectiveness of existing and emerging assistive technologies. In this way, they may make informed decisions about how to make best use of their limited resources for assistive technology products and related services for children.

To explore the strength of evidence of the effect of assistive technology devices for children with functional impairments on child and caregiver function, Henderson et al[7]conducted a comprehensive literature review of intervention studies published in English between 1996 and 2006. The authors classified the rigor of the study designs and determined whether assistive technology outcomes focused on the children, their caregivers, and/or their families. Although the review team identified "overwhelmingly positive" child-focused outcomes among the 54 articles cited, most studies were of lower quality, used measures with unknown levels of reliability and validity, and/or did not report statistically significant results. Further, only 1 in 5 articles focused on caregiver outcomes, and none explored the effect of children's assistive technology devices on their families.

Among the assistive technology devices considered in the review were interventions for seated postural control. The review team identified only 2 relevant articles that related to adaptive seating products for postural control. The articles reported on the outcomes of 1 intervention study involving 6 school-aged

children with CP who used a novel adaptive seating device for five weeks of an 11-week long community-based trial.[8,9] Parents and their children reported significant functional improvements in the performance of and satisfaction with targeted bimanual tasks, and parents claimed that their children required less assistance for many of these tasks during the intervention period.

Assistive technology practitioners routinely recommend adaptive seating devices for children with CP to support their trunk, pelvis, and lower extremities and thereby provide more control for volitional movement of their arms and hands.[10-12] A variety of seating devices is available to offer children the postural control needed to engage in common childhood activities at home such as playing on the floor, eating at the kitchen table with family members, and performing personal care activities in the bathroom.[13]

Because limited empirical evidence exists regarding the effect of these devices, we proposed to explore the parent-perceived effect of special purpose seating devices on the lives of 30 young children with CP and their families. We designed our study to answer the research question: Do adaptive seating devices used in the home improve family life as measured by the FIATS and IFS according to parents of children, aged 2 to 7 years, with GMFCS Level III or IV cerebral palsy?

METHODS

The present study involved 30 parents and was part of a larger project involving 50 parents and their children with CP. The larger study allowed us to confirm the acceptability of the internal consistency and test-retest reliability of the FIATS. We chose a repeated measures, within-subjects design for the present study to increase the likelihood of detecting a change in child and family outcomes due to the introduction of adaptive seating devices.

We received ethical clearance for this study from the research ethics board at our institution.

Participants We invited parents and their young children who were clients of our facility and 2 other regional children's treatment centers. Children who participated had a primary diagnosis of CP with function categorized as GMFCS Level III or IV[14*] and were between 2 years 6 months and 7 years 6 months of age.

We conducted screening interviews to identify and recruit parents who were

[*] Children with GMFCS Level III or IV CP can sit upright independently or with support, but generally need pelvic or trunk support or an adaptive seating device to optimize hand function. Children with Level III or IV function either need an assistive device to walk or have limited independent mobility in a manual wheeled mobility device.

primary caregivers of the child with CP. We defined a primary caregiver as an adult who provided at least 10 hours of direct supervision per day as determined by self-report. Further, we recruited only parents whose child did not use specialized postural control devices at home for floor sitting, chair sitting, and toileting activities. We mailed eligible and interested parents a letter to explain the project protocol and their roles as a research participant. Caregivers who agreed to participate in the 12-week long home trial provided signed consent.

We expected to have difficulty recruiting 30 families from our facility alone, so we involved 2 other children's centers to increase our participant pool. We adopted 2 different recruitment strategies: 1 for our facility and another for the other 2 centers. At our institution, we reviewed our electronic medical records and identified 155 children who met the initial inclusion criteria. We mailed a brief introductory letter about the study to the parents of these children, and then phoned families 1 to 2 weeks later. A randomized selection process provided each family an equal opportunity of being contacted. Of the 143 families we contacted, 85 families did not satisfy the screening requirements, 14 families declined due to scheduling conflicts, 9 families met the screening criteria but later decided not to participate after receiving the detailed study information letter, 5 children were deemed clinically inappropriate for the study devices as judged by the research occupational therapist during the first home visit, and 25 families participated in the full home trial.

To maintain the confidentiality of families at the other 2 centers, site clinicians reviewed their own medical records to identify children who met our age and diagnostic criteria, and identified 46 potential families. Site administrative staff mailed these parents an introductory letter inviting them to contact our study coordinator if interested. Seventeen parents contacted our coordinator, 11 of these did not meet the initial screening criteria, 1 child was judged clinically inappropriate at the first home appointment, and 5 families participated in the trial.

Main Outcome Measures We previously developed the multidimensional, parent-report FIATS to detect the impact of assistive technology device use on the lives of children with physical disabilities and their families. The FIATS measures this impact by the contribution of 8 related constructs (subscales) that include: child autonomy, caregiver relief, child contentment, doing activities, parent effort, family and social interaction, caregiver supervision, and safety. These constructs tap into aspects of child and family life that assistive technology devices may influence, such as the degree to which a child can perform activities independently (autonomy), interacts with others (family and social interaction), and requires attention from family members (supervision).

Parents use the FIATS to indicate the degree to which they agree or disagree with items on a 7-point Likert scale. The FIATS also contains items that contribute to a

ninth independent subscale (technology acceptance) to measure parents' general receptiveness to assistive technology devices for their children. We modelled this subscale as a separate moderating construct that may temper the impact of technology on family life. Overall, the 9 subscales contribute 64 items to the FIATS (Appendix B).

Scoring on the FIATS is calculated by the sum of the means of the 8 related subscales. Because the range of each mean subscale scores is from 1 to 7, the overall range of FIATS scores is from 8 to 56. Lower FIATS scores are associated with lower child and family functioning on these dimensions. Because we designed the measure to detect changes in important aspects of family life that could be influenced by the introduction of seating devices, higher change scores suggest an overall positive impact on child and family life as defined by these constructs. Whereas, lower change scores suggest a negative effect on child and family life.

The FIATS has good content validity and face validity,[15] and acceptable internal consistency (α=.94) and test-retest reliability intraclass correlations (ICCs=.92; 95% confidence interval, .86–.95) for a 2 to 3 week retest period when used with families of young children with CP. Further, the FIATS 9 subscales have Cronbach's alphas between .64 and .92, and ICC point estimates of test-retest reliability between .77 and .92.[16]

Since the FIATS was an emerging measure of the impact of assistive technology devices on the lives of children and their families, we administered the standardized IFS to answer our research question and test the association between the 2 measures. The IFS measures parents' perceptions of the psychologic and social consequences of having a child with a chronic disability. It is a 15-item, single factor measure with a 4-point response scale ranging from "strongly disagree" to "strongly agree." The IFS had good internal reliability ($\alpha \geq .88$) and acceptable construct validity when completed by caregivers of young children with chronic physical conditions, such as CP.[17,18] Scoring is calculated by the sum of the items' scores, with a total scoring range of 15 to 60. Lower IFS scores indicate lesser parent-perceived psychosocial consequences of having a child with a disability.

We selected the IFS to administer with the FIATS because it measured a related construct, had acceptable psychometric properties, and had been used in other research studies with families of children with CP. Parents completed the IFS at the end of each stage of the study. Because the original version of the IFS was developed in 1978,[18] we made minor modifications to modernize its item wording. We changed "child illness" to "child condition" on 7 items that referred to the child with CP, and changed an adjective on 1 item to ask the parent to compare their child to a "typical" child rather than a "normal" child. We retained the original wording on all other items. We confirmed that the internal consistency of the

modified IFS for the first test administration (n=30) was acceptable (α=.94) in our study.

Secondary Outcome Measures At the first appointment and every other week during the trial, the research therapist either met with parents or contacted them by phone to complete the home activity log, a semi-structured interview guide developed for this study. The purpose of the log was to obtain parent reports of the types and impact of activities in which their child engaged during the week. We developed home activity log to capture child activity reports that were organized into occupational performance domains of self-care, productivity, and leisure. Parents reported how seated play, personal care, and recreational activities or behaviors changed over the week preceding the interview. During the intervention phase, the therapist asked the parent to tell her whether the study devices contributed to any changes in child and family activities. The therapist made field notes during the interview to record the perspectives of parents. We collected this additional information to help interpret the FIATS and IFS scores.

The therapist administered other standardized measurement scales during the home appointments. However, the primary purpose of these other scales was to explore the effect of the intervention on each child's functional performance, parent satisfaction, and caregiver assistance using individualized goals set by the parent. We focus on the main outcomes of study here and discuss the outcomes of these individualized goals elsewhere.

PROTOCOL

One of 2 experienced occupational therapists, working as research therapists on the study, conducted interviews in the homes of participating families at 4 different times over 3 phases that lasted 12 weeks. The baseline phase was 3 weeks long, the intervention occurred over the following 6 weeks, and the final postintervention (return to baseline) phase lasted 3 weeks.

At the start of the baseline phase, the therapist gathered basic demographic information such as the number of family members, the school schedule of the child, and the number of hours the parent worked out of the home. The therapist used a demographic interview form developed for the study.

Parents completed the FIATS twice during the initial baseline phase – once at the first home visit and again 2 to 3 weeks later. Immediately after the second FIATS administration, we provided 2 postural control devices – the Flip2Sit activity seat[a] for floor sitting and table level activities (figure 5.1), and the Aquanaut toileting system[a] for toileting and grooming in the bathroom (figure 5.2) – for use by the child with CP. Clinicians and parents reported in earlier pilot studies that both

devices provided functional support for a variety of home activities for young children with CP.[19,20] We also provided families a simple, self-standing breakfast tray,[b] so children could play on an elevated surface while they sat in the activity seat at floor level.

At the start of the intervention stage, the research therapist observed the child and used her clinical judgement to evaluate the suitability and safety of the products, installed a universal toilet seat adapter on the family's toilet, and showed parents how to use the products with their child. The therapist provided the products' owner's manuals and asked parents to read them to be sure they understood how to use the devices.

The therapist administered the FIATS a third time 6 weeks later at the end of the intervention stage. Based on previous experience measuring the impact of specialized seating devices on child functioning,[8,9] we chose a 6-week period to allow adequate time for the family and child to adjust and develop regular routines using these devices. At the end of this stage, the therapist reclaimed the products and met with the parent 3 weeks later to administer the FIATS a fourth and final time. We offered both devices, free of charge, to the families after the measures were administered at the end of the study. Figure 5.3 provides a summary of the research study schedule.

Statistical Analysis The first 2 administrations of the FIATS during the baseline phase were used in our larger study to estimate the test-retest reliability of the FIATS. To reduce the number of post hoc paired *t* tests, we estimated the effect of the study devices by comparing the mean scores for the FIATS and IFS for the second, third, and fourth test administrations using a 1-way repeated measures ANOVA. We used a type I error probability of alpha equal to .05 (2-sided) for the repeated measures ANOVA and a Bonferroni correction for multiple statistical testing during post hoc analyses.

The extent to which any measured effects are meaningful for families is arguable because no criterion standard methods or instruments exist for estimating a minimally important difference.[21] As recommended for quality of life studies, we considered an important effect size to be a magnitude of at least 50% of the SD of the mean difference scores.[22,23]

We lacked the statistical power to make inferences about the mean difference scores for each of the 8 subscales and the technology acceptance subscale of the FIATS. Hence, we conducted exploratory analyses of trends in the mean subscale scores over the 12-week study period. Descriptive statistics from the demographic form provided a profile of participants and a descriptive review of entries on the home activity log provided contextual information for our primary findings.

Figure 5.1: Flip2Sit activity seat

Figure 5.2: Aquanaut toileting system

Week											
1	2	3	4	5	6	7	8	9	10	11	12
Baseline			Intervention						Post-Intervention		
FIATS		FIATS IFS HAL		HAL		HAL		FIATS IFS HAL	HAL		FIATS IFS HAL

Outcome and Activity Measures Key: FIATS = Family Impact of Assistive Technology Scale; IFS = Impact on Family Scale; HAL = Home Activity Log

Fig 5.3: Research study schedule.

RESULTS

Demographics Twenty-nine mothers and 1 father participated in the study. Twenty-five parents had at least 2 children – 1 of whom was a child who met our inclusion criteria.

The mean age of the 30 children with CP was 4 years 6 months (range, 2y 6mo–6y 7mo). Twenty-four children attended school or daycare during the week. Of these, 11 attended school or daycare for 5 days per week, 11 attended for 3 or 4 days per week, and the remaining 2 children attended 2 or fewer days each week. Eleven children attended kindergarten, 8 attended nursery school and 2 attended grade 1. The remaining 9 children were cared for at home or in a daycare during the week and were too young to attend school.

Most children used some form of assistive technology device in the home. The most common device was a wheelchair or stroller with specialized seating. When not in the wheelchair, children were typically supported by an assortment of pillows, modified juvenile equipment (eg, a high chair or car seat), or family members. Homemade devices, such as modified potty seats and corner seats were less common, but were used occasionally to provide alternate positioning for children in the home.

Seventy-seven percent of the families had 5 or more people living in their homes. Although 15 parents who participated worked outside of their homes, only 4 had full-time jobs. All 12 families who had in-home support received seven hours or less of caregiver assistance per week.

Effect of Intervention Because the ANOVA's assumption of sphericity was not met, we adjusted the degrees of freedom by applying a Greenhouse-Geisser correction and found significant mean differences among the overall FIATS scores ($F_{1.4,40.6}=19.25$, $p<.001$). Post hoc testing confirmed significant mean differences in overall FIATS scores between baseline and intervention and intervention and postintervention phases. The magnitudes of our mean difference scores were 75% and 91% of the SD of mean change scores (table 5.1).

Table 5.2 provides the descriptive statistics for each test administration of the IFS. Tests of within-subject effects yielded no significant difference among the IFS mean difference scores ($F_{2,58}=1.63$, $p=.20$), with an observed power of 33% and a corresponding Type II error probability of beta equal to 67%. However, we found significant negative correlations ($-.68\leq r\leq-.54$) between the FIATS and the IFS total scores at the ends of week 3 (end of baseline stage), week 9 (intervention stage), and week 12 (end of postintervention stage) (table 5.3).

Figure 5.4 provides a plot of the mean scores for the FIATS subscales over the entire study period. Steeper positive slopes indicate greater positive impact on child and family life between administration periods; whereas, steeper negative slopes suggest a greater negative effect on child and family life between periods. Higher mean values indicate greater subscale contribution to the overall impact on families as measured by the FIATS.

Our descriptive analysis of the home activity log interviews suggested that 26 children used the activity seat and 24 children used the toileting system over the entire intervention period. Twenty-seven parents said that the use of one or both study devices increased the quantity and/or quality of their child's activities at home. For 8 families who did not use both study devices over the entire period, their principal reasons were that one or both devices did not provide sufficient postural support for their child and/or their child rejected the device.

Twenty-five parents reported that their children were happier, more autonomous, and/or able to interact more with siblings and other family members while using one or both of the study devices. Nearly three-quarters of these parents noted that their children's activity levels reduced after the devices were returned. During both the baseline and postintervention stages, almost half of the parents said that their children lied prone or supine on the floor or sat with the support of other family members. Most of these parents suggested that playing with their children in these positions was more difficult and occurred less frequently.

Parents said that their children used the activity seat for productivity and leisure activities primarily; whereas, the children mostly used the toileting system for self-care activities. Nineteen parents said that the duration, quality, and/or variety of play increased when their child used the activity seat. Seated activities reported only during the intervention period included coloring, playing with siblings, eating at the dinner table with family, watching television, and having a tea party with siblings.

Twelve parents reported that their children were unable, unwilling, or not ready to have a bowel movement while sitting on the toileting device during the intervention stage. These parents said that their children used the toileting product as a positioning device for playing or grooming activities in the bathroom. Because about one-third of the children had not started toilet training when they were enrolled in the study, parents reported more supervision of their children in the bathroom during the intervention stage than during the other two stages. Three parents said that their children who began to use the toilet during the intervention phase continued to ask to use the toilet after we withdrew the study devices.

Twenty-five of the thirty participants accepted our offer of one or both devices at the end of the postintervention phase.

DISCUSSION

Our results showed that the introduction of study devices had a significant positive effect on lives of families who have children with GMFCS Level III or IV CP as measured by the FIATS. We demonstrated that removing the devices from the home had a concomitant detrimental effect on important aspects of family life. Because the highest mean score accounted for only 75% of the total score possible on the FIATS, it may be that the introduction of other assistive technology devices could lead to further benefits for children and their families.

Regardless, the magnitudes of our mean difference scores suggest important positive and negative effects due to the presence and absence of the study devices, respectively. The FIATS difference scores imply that the devices had an overall positive impact on family life, the home activity log results support this overall effect, and nearly all participants noted that 1 or both devices benefited their child. Although the research therapist assessed the clinical suitability of the devices for the children during the first home visit and parents accepted these devices for their children at the second home visit, about 1 in 4 parents reported that their child did not use one or both devices during the intervention phase. However, this rate is consistent with other published discontinuance rates (≈30%) of assistive technology devices that were initially used by consumers.[4,6]

During the home activity log interviews, most participants described positive effects on child and family life due to the introduction of the study devices. In particular, they reported increases in the quantity and quality of their children's activities. Conversely, after we retrieved the devices from their homes, parents said that their children's activities reverted to baseline levels. Most families accepted one or both devices at the end of the study, providing further evidence that the parents valued these devices for their children and families.

We could not detect an effect of the postural control devices on the psychological and social consequences of having a child with a disability as measured by the IFS. Unlike the FIATS, the IFS was not constructed to be responsive to the effect of assistive technology devices. Despite this, we confirmed a significant, moderate correlation between the FIATS and IFS scores at the ends of each study phase. The negative correlation suggests an association between parents who assigned lower ratings on aspects of family life where seating devices could have an effect, and those who indicated higher psychosocial consequences due to their child's disability. Similarly, parents who reported that their families functioned at a higher level tended to report that their child's chronic condition had a lesser effect on them both personally and socially. This association suggests that parents who perceived higher psychosocial consequences of having a child with a disability than other families may derive more benefit from assistive technology devices for their children.

Because we selected a study sample size to provide sufficient statistical power to detect the overall impact of the seating devices on the lives of children and their families, we cannot make inferences about the contributory effects of dimensions of the FIATS. Nonetheless, our exploratory analyses of the mean subscale scores provide interesting avenues for future research.

The greatest effects derived from the study devices seemed to relate to the degree to which children did activities independently (autonomy) and parents were freed from worry about their child's security (safety). Parent reports during the biweekly home activity log interviews are consistent with this finding. Most parents recounted that the study devices improved their child's level of independence in daily activities and sitting ability.

To a lesser extent, the degree to which the children had control over their own actions (doing activities), how happy the children were during the day (contentment), their level of interaction with others (family and social interaction), the amount of energy parents expended in caring for their child (effort), and the amount of attention children needed from caregivers (supervision) also seemed to be influenced positively by the introduction of the study devices, and affected negatively by the removal of the technologies. During their interviews, most parents reported that the activity device promoted child contentment and interaction with other family members, and the toileting product freed them from holding their child in the bathroom.

Although the subscale outcomes are exploratory, our positive child-focused change scores appear to be consistent with the findings of the earlier empirical research about the benefits of seating interventions on children's functional abilities.[8,12] Interestingly, our study devices seemed to have little or no effect on the extent to which parents needed a break from caregiving (caregiver relief). These findings contrast with the outcomes of 2 surveys of parents of children with disabilities and one case series study involving 6 parents and their children with CP discussed earlier.[2,3,9]

The lack of evidence of effect in this area may be due to the specialized type of devices we used in our study, problems associated with incompatibility of the child and technology for some families, and/or the need for parental involvement during previously untried activities such as sitting on the toilet seat in the bathroom and in the activity seat on the floor. Further, the conceptual association of this and other caregiver dimensions with the psychosocial costs of having a child with a chronic disability may help to explain why we did not detect any effect on the IFS during our study.

The relative magnitudes of the mean subscale scores on the FIATS are also of interest. The technology acceptance subscale mean ranged between 6.3 and 6.5 out of a possible 7 at the ends of the phases. If the mean scores accurately reflect parents' perspectives, then they highly valued assistive technology devices for their

	Mean	SD	Absolute Difference of Means	SD of Difference	Ratio of Difference to SD of Difference	97.5% CI of Difference	
Baseline	32.3	6.3					
			4.0	5.3	.75	1.7	6.3
Intervention	36.3	6.0					
			5.2	5.7	.91	2.7	7.6
Post-intervention	31.2	6.3					

Table 5.1: Descriptive and 97.5% CIs for difference results for FIATS at baseline, intervention, and post-intervention phases.

	Min	Max	Mean	SD
Baseline	17.0	50.0	35.8	9.8
Intervention	18.0	52.0	36.1	9.4
Post-intervention	22.0	54.0	37.5	8.8

Table 5.2: Descriptive results for IFS at baseline, intervention, and post-intervention phases.

	Baseline IFS	Intervention IFS	Post-Intervention IFS
Baseline FIATS	-.54**	-.55**	-.64***
Intervention FIATS	-.44*	-.54**	-.52**
Post-Intervention FIATS	-.59**	-.57**	-.68***

*p<.05; **p<.01; ***p<.001 (2-tailed)

Table 5.3: Correlations (Pearson's r) between the FIATS and IFS scores at baseline, intervention and post-intervention phases.

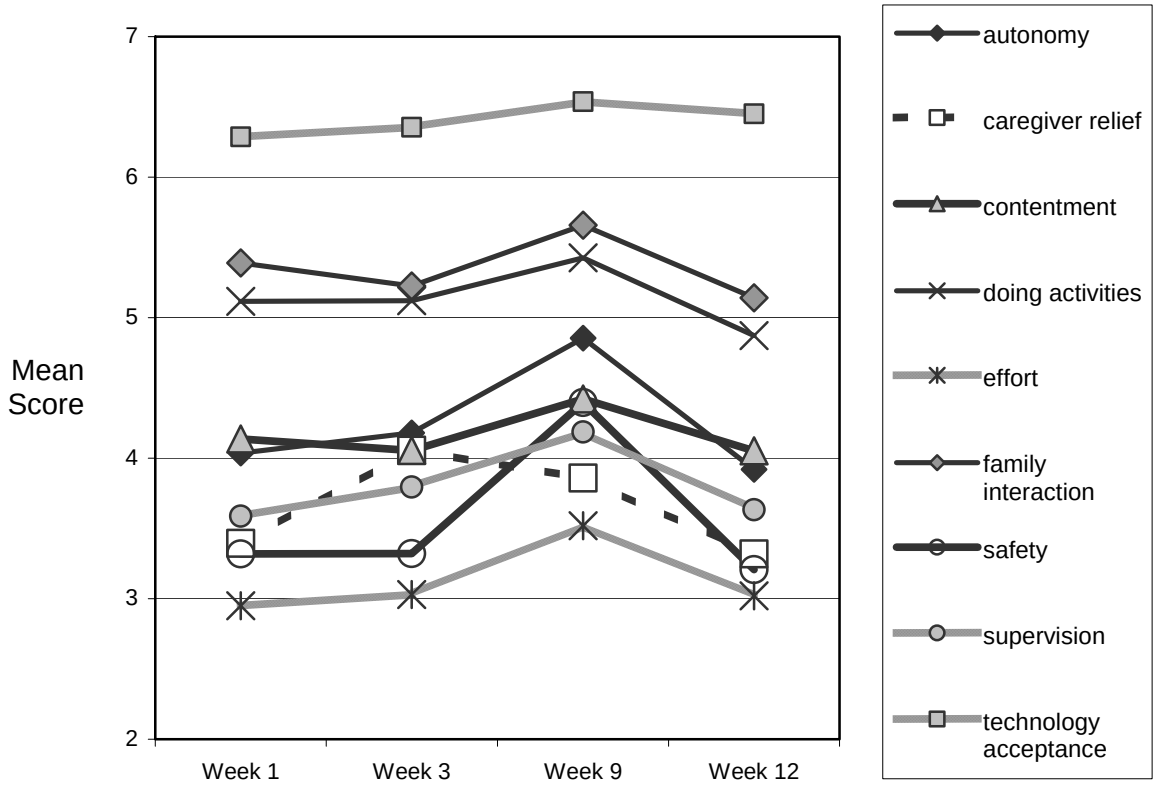

Figure 5.4: Mean scores at baseline (weeks 1 and 3), intervention (week 9), and post-intervention (week 12) phases for the technology acceptance and FIATS subscales.

children and the presence of the study devices did not affect this high level of acceptance.

The doing activities and family and social interaction subscales provided the highest scores contributing to assistive technology device impact with mean ratings between 5 and 6 during all phases; whereas, parents rated family efforts to assist their child below 4 over the entire trial. Although most parents reported positive changes in these areas due to the presence of the study devices, the FIATS subscale ratings may provide new insights into the perceived adequacy of the levels of child and family functioning in these and other domains.

As we mount larger studies, we may be able to make compelling arguments about the meaning of these ratings from the perspectives of parents and contributory influences of the introduction of technology. We expect that these explorations may inform health care providers and decision makers about the impact of seating and other forms of assistive technology devices on the lives of families.

Study Limitations Although we demonstrated important effects on family life due to the intervention, our study had limitations. Our study design was subject to more measurement error than more rigorous methodologies such as crossover designs or randomized controlled trials. Our sample size was sufficiently powered to detect an effect due to the introduction of the study devices using the FIATS. However, it was neither large enough to make inferences about the effect of the technology as measured by the FIATS subscales nor sufficient to judge the parent-perceived effect of the devices on psychosocial outcomes as measured by the IFS.

Participants in this study were mainly mothers of young children with CP, so mothers of children with different types of disabilities and other caregivers may have different views of the impact of assistive technology devices on family life. Moreover, we recruited parents whose children did not use specialized seating devices for toileting and sitting on the floor or at a table, but most families we contacted had children who used a device for at least 1 of these activities. Consequently, our sample may not be representative of the general population of families who have young children with CP.

Parents may have responded in ways that reduced the measured effect within dimensions that reflected on their abilities as parents. This self-enhancing bias may explain why we found lesser contribution toward assistive technology impact from dimensions such caregiver relief and parent supervision. Conversely, parents who participated may have responded in ways that made it seem that the assistive technology impact was greater than the actual effect on family life. However, it could be argued that we should have also found significant changes in the mean ratings of the IFS if such a systematic bias existed.

CONCLUSIONS

Our research provides an important first step towards understanding the multidimensional influence of assistive technology devices on the lives of families who have children with chronic disabilities. We demonstrated that the introduction of special seating devices for young children who need support to sit could have a meaningful positive impact on important aspects of family life.

The findings from our study will help health professionals by adding much needed evidence to support the provision, development, and funding of new assistive technology devices and related services for children. Ultimately, children and their families will benefit from the availability of more efficient funding programs and clinical services for assistive technology devices, optimal assistive technology prescriptions, and improved technologies.

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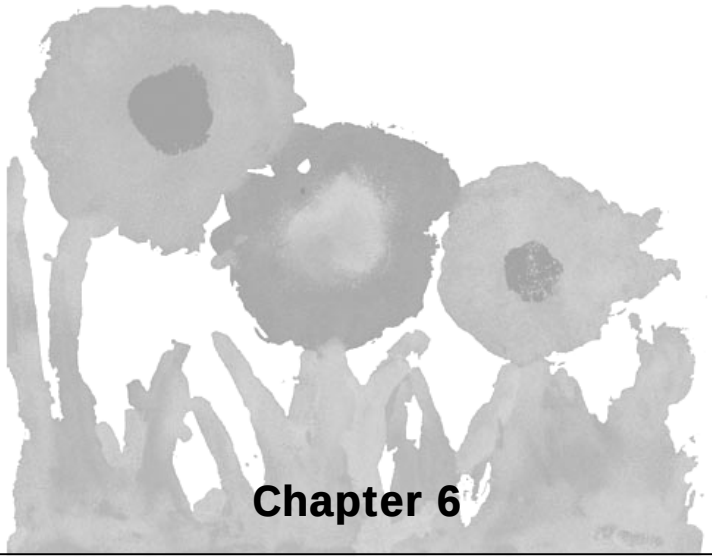

Chapter 6

Effect of Adaptive Seating Devices on the Activity Performance of Children with Cerebral Palsy

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ABSTRACT

Objective: To evaluate the short-term impact of two adaptive seating devices on the activity performance and satisfaction with performance of children with cerebral palsy (CP), as observed by their parents.

Design: Baseline-intervention-baseline study.

Setting: Homes of participating families.

Participants: Parents and their children (N=30), mean age of 4 years 6 months, with Gross Motor Function Classification System level III and IV CP.

Intervention: Two special purpose seating devices – one for sitting support on the floor or on a chair, the other for postural control on a toilet.

Main Outcome Measures: Changes in activity performance and satisfaction were measured through parent ratings on the Canadian Occupational Performance Measure. We interviewed parents biweekly using the Home Activity Log to describe and explain their child's activity performance during the 3 study phases.

Results: Parents identified 139 activity performance issues (4.6 per child); 58.3% in self-care, 34.5% in play, and 7.2% in socialization and quiet recreation. We used paired t-tests to demonstrate significantly improved performance and satisfaction with self-care and play activities when the children used the adaptive seating devices during the 6-week intervention phase. Three themes arose from the analysis of comments made by parents during Home Activity Log interviews: adaptive seating can have an enabling influence on child; caregivers and family find adaptive seating useful; the adaptive seating devices did not meet every family's needs.

Conclusion: Parents reported that their young children with CP were more able to engage in self-care and play activities when using specific adaptive seating devices in their home. Parents indicated that their child's activity performance decreased after the seating devices were removed from their home.

Cerebral palsy (CP) is a non-progressive lesion of the immature brain that results in impairment of movement and postural control, and is the most common physical disability in childhood.[1] Many young children with CP cannot sit without support[2,3]. Thus, physical and occupational therapists routinely prescribe adaptive seating devices for them, to promote their function and improve their developmental capabilities.[1,2,3,4]

A number of studies have evaluated sitting posture and various features of adaptive seating devices for children with CP, and three authors have reviewed this literature.[2,3,5] Roxborough[2] found that postural control, pulmonary function and psychological skills improved with some adaptive seating interventions. However, she found little evidence for the effect of seating on self-care. Harris and Roxborough[5] concluded that seating interventions that stabilized the pelvis and increased the seating base of support optimized postural control. The review by Stavness[3] examined how sitting affected upper extremity function. She found that upper extremity function was better when children sat in an upright versus a reclined position, with a neutral to slightly forward orientation of the seat.

Harris and Roxborough[5] recommended that future studies should examine the impact of adaptive seating on children's functional abilities in their daily life. This is important because a primary goal for therapists who prescribe adaptive seating is to provide the child with CP with a safe, stable seated posture from which the child can engage in controlled upper extremity movements to enable the child to actively engage in many daily activities, including play and self-care.[3,6] Furthermore, contemporary models of rehabilitation and family-centered services recommend that rehabilitation practice and research should address the activity performance and participation of children with CP within family life, as outcomes of interest.[7,8,9]

Despite widespread clinical use, little is known about the effect of seating technologies on the activity performance of young children with cerebral palsy at home. To address this gap in knowledge, we conducted a study to examine the impact of two seating devices on important, parent-identified activity performance issues (APIs) at home. We asked the question: "Do special purpose seating devices used in the home improve the activity performance of young children with Gross Motor Function Classification System (GMFCS) level III and IV CP[10] as measured by the Canadian Occupational Performance Measure (COPM)?"[11]

METHODS

The present study was part of a larger project that examined the measurement properties of the Family Impact of Assistive Technology Scale (FIATS).[12] We received ethical clearance from the Research Ethics Board at Bloorview Kids Rehab.

We used a within-subject A1-B-A2 design to study the influence of postural control devices for seating on children's activity performance in daily life within their homes. The first baseline period (A1) lasted for 3 weeks, followed by a 6-week seating intervention period (B), then another 3-week return to baseline period (A2), as shown in Figure 6.1. This design eliminates between subject effects by using parents and their children as their own controls. While a cross-over protocol would have been a stronger design, this case series design was chosen for the larger measurement study.

The baseline period of 3 weeks was considered a sufficient length to demonstrate stable functional behaviors.[13 (p. 186)] Based on our previous experience, an intervention period of 6 weeks provided adequate time for the children and their family to adjust to using the seating technologies and to establish regular activity routines.[14]

Participants Thirty parents and their young children (mean age of 4 years 6 months; range 2 years 6 months to 6 years 7 months), who were clients of three children's rehabilitation centres in south-central Ontario, Canada, agreed to participate in this study. All parents provided informed consent for themselves and their children. Eligible families included children who had a primary diagnosis of CP with a functional status defined by the GMFCS level III or IV.[10] This functional level meant that each child had some ability to move around on the floor (e.g. by rolling or creeping), but had difficulty in maintaining floor sitting, or required trunk support to maximize hand function when sitting on a chair.[10] We found that our sample size exceeded the number of participants needed for a power of 80% and α=.05 (2 sided), when we examined data from a comparable within-subjects study wherein the COPM was used to evaluate performance differences with and without an adaptive seating intervention.[14] Details on recruitment procedures can be found in an earlier publication.[15]

While we recruited children who did not use special purpose seating devices for floor sitting, chair sitting, or toileting, most participants did use some form of assistive technology in the home at the time of enrolment in the study. All children either used a wheelchair or a stroller in their home. Parents also reported that they positioned their children by using an assortment of pillows, or the help of family members, or by using modified juvenile seating systems such as a highchair or a car seat. Some families also used homemade devices such as modified potty seats and corner seats to provide seating support.

Intervention In the study, we supplied the Flip2Sit activity seat[a] for floor sitting and table level activities, the Aquanaut toileting system[a] for toileting and grooming in the bathroom. Both devices are intended to provide sitting support for children with CP who have postural instability. Clinicians and parents

have reported that both devices provide appropriate postural support in sitting to help young children with CP participate in a variety of important home activities.[16,17] We also provided families with a simple, self-standing bed tray,[b] so children could play on an elevated surface while they sat in the activity seat at floor level.

Outcome Measures

Canadian Occupational Performance Measure [11] The Canadian Occupational Performance Measure (COPM) is a criterion-referenced outcome measure that has demonstrated responsiveness to change over time,[14,18,19] and has been found useful for evaluating the effectiveness of assistive technologies.[14,20,21] It has been successfully used with parents for the evaluation of children's occupational performance problems or issues as identified by the child's parents,[22] and to evaluate the effect of adaptive seating devices for children with CP.[14] The reliability and validity of the COPM is well documented.[11,18] A change of two or more points on the performance or satisfaction with performance scales on the COPM is considered to be a clinically important change.[11]

We chose the COPM as it is administered through a semi-structured interview and allowed us to ask each parent to identify up to five important problems that their child was experiencing in the areas of self-care, play and leisure within their daily life at home.[18] In order to evaluate the impact of the seating devices, we adapted the COPM questions and asked the parents to focus on activities that the child required seated postural control to do, and which were difficult for the child to do. Consequently, we identified these as activity performance issues (APIs), rather than occupational performance issues as parents had targeted specific aspects, or steps of the occupation that their child had difficulty doing.

Home Activity Log Interview We developed the home activity log (HAL) interview (see Appendix C) for this study to monitor, biweekly, the parent's perspectives about their child's activity performance over the 12-week study. Parents were asked to describe any changes that they observed in their child's daily behaviors and activity performance in the 3 categories of self-care, play and quiet recreation/leisure. They were also asked how the seating devices influenced the activity performance of their child during the intervention phase. We collected these perspectives from parents to help us interpret the COPM change scores.

Data Collection One of two experienced occupational therapists (who had 12 and 20 years experience with children with physical disabilities, respectively) visited each parent and child in their homes at selected times to administer the outcome measures. The COPM was administered four times in total; during weeks 1 and 3 (the beginning and end of the baseline period), during week 9 (at the end of the 6 week intervention period), and during week 12 (at the end

of the second baseline period), as shown in figure 6.1. It was impossible to blind the occupational therapists due to the nature of this intervention.

On each administration, the parent used the 10-point COPM scales to rate their child's performance and satisfaction with their child's performance on each of the API's that they had identified during the baseline COPM interview during week 1. On the performance rating scale, a "1" meant that the child was not able to do the activity whereas, a rating of "10" meant that the child was able to do the activity extremely well. On the satisfaction scale, a rating of "1" meant that the parent was not satisfied at all with the child's performance whereas a rating of "10" meant that the parent was extremely satisfied with the child's performance of that activity.

The study therapist administered the HAL every other week either through a phone interview or in-person during the home visit. The study therapist used the HAL as a guide to interview parents and record changes in the child's activity performance, and any changes in family routines over the proceeding week. The therapist recorded the parents' comments during the interview.

The therapist delivered and set up the study devices for each family at the end of the first baseline phase. Parents were shown how to use the devices with their child and given precautions and safety instructions. Parents were also given the device owner's manuals, and were asked to read them to ensure they understood how to use the devices. Families used the study devices for 6 weeks and the therapist retrieved the devices at the end of the intervention phase, at the end of week 9. Once the measures were administered a final time, the research therapist offered the two devices to parents free of charge to show our appreciation of their participation in our study.

Week											
1	2	3	4	5	6	7	8	9	10	11	12
Pre-Intervention [A1]			Intervention [B] (seating systems used)						Post-Intervention [A2]		
COPM Initial Interview HAL		COPM HAL		HAL		HAL		COPM HAL	HAL		COPM HAL

Figure 6.1: Research design schedule

Data Analysis The COPM data were aggregated, as others have done[19,23,24], into three categories: self-care, play, and socialization/quiet recreation. Parametric statistics were used as recommended in the COPM manual,[11] and based upon examination of the distribution of our results. We used paired t-tests to

compare mean scores between weeks 3 and 9, and between weeks 9 and 12. We used a Type I error rate of α = .05 (2-sided) with Bonferroni correction for multiple testing for the performance and satisfaction t-tests. With 16 tests, this led to a statistical significance being defined as a p-value < .003 for any of the t-tests.

We collated the HAL data from six data collection points and then conducted a thematic analysis through an iterative process of sorting the data into common themes. We integrated the interpretation of HAL and COPM results using the, 'follow a thread' strategy described by Moran-Ellis and colleagues [25] which involved an iterative examination of common threads across both datasets. This process helped us to explain and further understand the families' experiences with the seating interventions and their COPM ratings.

RESULTS

Canadian Occupational Performance Measure The thirty participating parents (29 mothers, 1 father) each identified 3 to 5 APIs for their children. We then organized the 139 APIs (average of 4.6 APIs per family) into the three categories. All 30 parents identified API's in self-care (58.3% of the API's), while 27 parents identified that their child had challenges playing (34.5% of the API's), and only 6 parents identified API's in socialization and quiet recreation (7.2% of the API's). Figure 6.2 provides examples of APIs reported by parents in each category.

The aggregate mean scores for each COPM category and the total are shown in table 6.1. The mean scores shown for weeks 3, 9, and 12 are from the baseline, intervention, and return to baseline (or post-intervention) phases (A1, B, and A2). The performance scores on the COPM increased by an average of 4.6 (on a ten point scale) during the intervention phases, while the satisfaction scores on the COPM increased by an average of 4.9. The results of paired t-tests, mean differences, and the 99% confidence intervals around the differences (table 6.1) confirm that the effect of the seating intervention on parent ratings of the children's activity performance resulted in significant changes in performance and satisfaction scores between intervention phase and two baseline phases overall and within the self-care and play API categories.

Category	Examples of API's
Self-care	self-feeding; eat at table with family; drink from a cup; eat meals at restaurant/ relative's/friend's; use the toilet; sitting independently on toilet; brushing teeth; taking shoes and socks off; take off upper garments in dressing; sit up properly for dressing and undressing
Play	sitting on floor to play; holding/playing with toys; coloring, writing, playing, playing games, using computer while sitting at table;
Socialization and Quiet Recreation	sitting and socializing at table; sitting up and watch TV; reading a book; turning pages of book

Figure 6.2: Categories and examples of API's identified on COPM

The t-test results were neither significant for performance and satisfaction scores comparing week 3 to 9, nor for performance and satisfaction scores comparing week 9 to 12. Parents rated their children's performance of most of the activities, and their satisfaction with their child's performance as much greater when the children used the study devices, than during the baseline and post-intervention weeks, when their children did not use the devices.

Home Activity Log Three themes arose from the thematic analysis of sorted data. The findings largely reflect the parents' views about the impact of the study devices, because there were two additional questions asked during the intervention phase.

Theme 1: Adaptive seating can have an enabling influence on child

Most parents reported positive benefits from using the adaptive seating devices, including that their child was sitting better, was doing more, was more engaged, and was doing the activities identified on the COPM for longer periods of time when using the adaptive seats during the intervention phase. Several parents reported that their child's skills improved, while others reported that their children were happier and more eager to sit and do activities and were now able to engage in face-to-face social interactions resulting in more socialization with members of the family and with friends. After the devices were removed at the end of the intervention phase, several parents reported that their children became more passive, or were less interested and less engaged; while other parents described their child as less social and less interactive.

Activity Performance Categories		Mean Scores				Mean change (99% CI) p value	
		Week 1	Week 3	Week 9	Week 12	Wks 9-3	Wks 12-9
Self-care	Performance	2.37	2.13	7.48	2.14	5.38 (3.80 to 6.96) p<.001**	-5.34 (-6.98 to -3.71) p<.001**
	Satisfaction	2.67	2.23	8.07	2.21	5.79 (4.08 to 7.51) p<.001**	-5.86 (-7.69 to -4.03) p<.001**
Play/School	Performance	2.35	2.10	6.21	2.50	4.11 (2.21 to 6.00) p<.001**	-3.71 (-5.62 to -1.81) p<.001**
	Satisfaction	2.57	2.18	6.57	2.15	4.39 (2.28 to 6.50) p<.001**	-4.17 (-6.39 to -1.97) p<.001**
Social/Quiet Recreation	Performance	2.00	2.83	6.33	2.83	3.50 (3.23 to 10.23) p=.076	-3.50 (-9.27 to -2.27) p=.058
	Satisfaction	2.50	3.33	7.17	2.50	3.83 (3.11 to 10.77) p=.090	-4.67 (-10.80 to -1.46) p=.028
Overall Mean Score	Performance	2.31	2.22	6.83	2.33	4.61 (3.14 to 6.09) p<.001**	-4.50 (-6.01 to -2.99) p<.001**
	Satisfaction	2.60	2.35	7.27	2.36	4.92 (3.39 to 6.45) p<.001**	-4.92 (-6.66 to -3.18) p<.001**

*99% CI's are around differences in the t-tests.
** statistically significant

Table 6.1: Paired comparisons of COPM total and category scores

Theme 2: Caregivers and family find adaptive seating useful

During the intervention phase parents found the seating devices convenient and easy to use, and many reported that their child needed less caregiver help. Nearly one quarter of the parents described how their child was able to now join the family for meals, games and social interactions. The comments made by one mother reflected how several parents felt about being able to sit facing their child, when using the study devices, rather than holding their child from behind. She noted that she had more eye contact and more communication when she played with her child. She felt she understood his wants and needs faster because she could see his face.

Parents also commented favorably about the portability of the activity seat, saying they used it on various chairs within their home, such as kitchen or computer chairs; they took the seat with them when visiting family and friends in their homes, and they used it successfully at restaurants. For example, one parent noted that they take the [activity seat] everywhere including restaurants, and think it's great. For some of those who used the activity seat for quiet recreation, they described feeling safer leaving their child to watch television or listen to music.

Theme 3: The adaptive seating devices didn't meet every family's needs

A few families reported little to no change in how their child completed the activities identified on the COPM during the intervention phase. The most common complaints were that the activity seat did not provide enough support or that it lacked the stability their child needed on the floor. These parents reported that they supervised their child more closely when using the activity seat. A few parents said that their child complained about the straps on the activity seat and did not like to be constrained, preferring instead to be mobile.

Descriptive Results A descriptive analysis of the parent interviews showed that 26 children used the activity seat and 24 children used the toileting system over the entire intervention period. The toilet seat was used primarily for self-care, including toileting, grooming, and brushing teeth; whereas the activity seat was used for play, mealtime, and social or leisure activities. The activity seat was used on the floor or on a variety of chairs, including kitchen/dining room/office chairs, couches or restaurant chairs. For families who did not use both study devices, their principal reasons were that one or both devices did not provide sufficient postural support for their child and/or the child rejected the device.

When offered the devices at the end of the study, twenty-five families (83%) kept at least one device, while 19 (63%) families kept both devices. Four families (13%) kept the activity seat and returned the toilet seat, while two families kept

the toilet seat and returned the activity seat. Five families (17%) returned both devices.

DISCUSSION

Our COPM results indicate that statistically and clinically significant improvements in activity performance and performance satisfaction were achieved when the children used adaptive seating devices in their homes for specific self-care and play activities. These findings were supported by the views expressed by their parents during the HAL interviews.

When the study devices were removed from their homes during the post-intervention phase, the children's activity performance and parents' satisfaction with their child's performance returned to baseline levels on the COPM, and parents described their children's loss of abilities on the HAL. The magnitude and precision of the change scores on the overall, self-care, and playing activities on the COPM suggest that the removal of these devices had a negative effect that was both statistically significant and meaningful to parents.

It is also important to note that the mean performance scores for self-care and play were less than 3 points on the 10-point scale at weeks 3 and 12, which demonstrates that the children were not able to do the activities very well without the seating devices. Whereas they were able to do the activities quite well with a self-care mean score of 7.48 and play mean score of 6.21, when they used the seating devices, as measured in week 9. Our study provides preliminary evidence that adaptive seating interventions can be used successfully to help children with GMFCS level III or IV CP to attain a supported sitting posture, which enabled them to perform a variety of childhood activities more successfully within their daily life at home.

Although the point estimates of the true difference scores between the intervention and baseline phases for performance and satisfaction were greater than 2 for the category of quiet recreation and socialization, which is considered a clinically significant change,[11] our corrected confidence limits were too large to infer a statistical effect. We do not believe that we lost significance by using a parametric versus a nonparametric approach to examine the differences in scores. The loss of precision in this estimate was because parents only reported 10 APIs overall. Consequently, we could not conclude that the study devices made a significant difference to COPM performance and satisfaction scores for this category.

The API's identified by the parents demonstrate that parents focused on very specific functional challenges within the child's daily life, many of which directly involved sitting, and others that were greatly influenced by the child's ability to sit.

For example, most of the self-care and play activities involved manual manipulation of materials, such as toys, feeding and grooming utensils. The seating interventions appear to have enabled most children to gain a stable, supported sitting posture, from which they could use their hands to engage in various activities.

While we cannot make inferences about the impact of the seating devices on hand function, our findings do support the clinical assumption that achieving a stable seated posture from a seating intervention has an enabling effect on a child's hand function.[4] Our results build upon the findings from studies reviewed by Roxborough[2] and Stavness[3], which demonstrated how specific seating interventions improve postural control and upper extremity function.

Our results are also consistent with an earlier study, not included in the Stavness review[3], which examined the clinical assumption that a stable pelvis leads to improved hand function. Reid and colleagues[14] used the COPM to evaluate the impact of a wheelchair mounted rigid pelvic stabilizer on bimanual task performance for six school-aged children with CP, using a within-subject A1-B-A2 design over 11 weeks. They found that participants and their parents agreed that the child's bimanual task performance was better when the postural control device was used to stabilize the child's pelvis, compared with a lap belt. Satisfaction ratings were also higher during the intervention phase.

Our HAL findings provide context and explanation for the COPM outcomes. During the HAL interviews, parents described the changes in how some activities were performed over the 3 phases of the study. It was evident that for many families, the child was not doing some activities, or was doing those activities very differently prior to the introduction of the seating intervention. Then, during the intervention phase, the child became accustomed to being able to do an activity and both children and their parents wanted to continue that activity after the study device was removed.

For example, many children were using diapers rather than a toilet prior to the introduction of the toileting device. Some families reported that their children were somewhat successful in using the toilet while positioned on the toileting device. During the post-intervention phase, some parents expected their children to continue to do that occupation (e.g., toileting) using the method adopted during the intervention phase. However, without the study device, parents then had to hold their child instead. The absence of the device made it more difficult to perform this activity because the way in which the child was supported on the toilet was different. This was reflected in the lower performance and satisfaction scores on the COPM at the end of the final phase.

These findings lead to speculation that, given a longer intervention phase, the children could be exposed to and given more opportunity to engage in activities that were previously not accessible to them because of their inability to sit independently. Because the activity seat is multi-purpose, portable, and easy to set up and use, several families reported using it in a variety of ways during the intervention phase. For example, some families took the activity seat to restaurants or relatives' homes for meals, while others used it outdoors for play.

Future research could be designed to explore the impact of this and other seating devices over longer periods than we used in our study. Lenker and Paquet[26] propose that the impact of assistive technology is a predictor of future use of that technology. Based on their arguments, we would expect that the children and families from our study would continue to find the seating devices useful over time, particularly if families find the benefits outweigh any shortcomings in the technology itself, and the ease of use.

While our results were largely positive, a few families found that one or both seats did not help their child. Although our research therapists evaluated the appropriateness of the devices for the children, the parent or child rejected the device(s) part way through the intervention phase. Neither level of acuity of GMFCS level nor age were a factor here. Further, some families had limited space available in their home (e.g., lived in a small apartment, or had a crowded home) and they could not easily store the device when it was not in use by the child.

Study Limitations Our study has several limitations. The baseline-intervention-baseline design is more vulnerable to measurement error (bias) than a randomized controlled trial or a crossover design. Bias may have been inadvertently introduced into the parent interviews since the research therapists were aware of the study objectives. Parents were not aware of the study objectives; however, they may have made their own assumptions, which could have influenced them to respond in ways to make it appear that the impact of the devices was greater than it actually was. However, our results are consistent with the findings of our broader study where we used the FIATS and the Impact on Family Scale to measure the impact of the study devices on the lives of children and their families.[15]

The findings from our study may not generalize to children with differing physical disabilities nor those who live in different geographic regions, as our respondents were parents of children with CP who lived within or close to a large metropolitan city.

Clinical Implications Two important implications for clinical practice and future assistive technology research arise from our study. First, during recruitment for the study we learned that there were many children who were not using

adaptive seating devices in their homes. We suspect that this may be due to several factors: many therapists in our region provide services primarily to children in schools, and may not be mandated to assess or make recommendations regarding a child's home environment; families may not be aware of the adaptive seating options available to them for their home; alternative 'ad-hoc' approaches were being used by families (e.g., using an assortment of pillows to provide the child with postural support on the floor); and financial support for special types of assistive technology, such as our study devices, is not available from traditional government sources. This finding also raises questions about how aware therapists are about seating technologies that could be used to support functional outcomes for children in their homes.

Secondly, we found the COPM to be a very useful and responsive outcome measure for detecting families' perceptions of meaningful change in their child's activity performance when examining the impact of adaptive seating interventions. These clinically meaningful results are consistent with the findings of our study using the FIATS as a primary outcome measure of the impact of the devices on child and family life[15] and with previous studies where the COPM was used to demonstrate the effectiveness of assistive technology devices on children's activity performance and on their parents' level of satisfaction with this performance.[14,21]

The COPM also enables the clinician prescribing adaptive seating interventions to use a family-centered perspective[9] as parents and/or children evaluate self-identified occupational or activity performance issues that matter to them. Our experiences with the COPM add to the growing interest in the benefits of using individualized outcome measures, such as the COPM in assistive technology research.[27,28]

CONCLUSIONS

Parents reported that their young children with CP were more able to engage in self-care and play activities when they used the study seating devices in their homes during the intervention phase. Parents were also more satisfied with their child's activity performance when the study devices were used, and described the enabling influence provided by the study devices, and how the devices helped in their interactions with and care of their child. A few parents, however, felt the study devices were not well suited to their child's needs. Our study findings reinforce the need to remind rehabilitation technology practitioners to be mindful of the match between the goals and circumstances of individual children with CP and their families, and the opportunities for functional gains afforded by adaptive seating devices.

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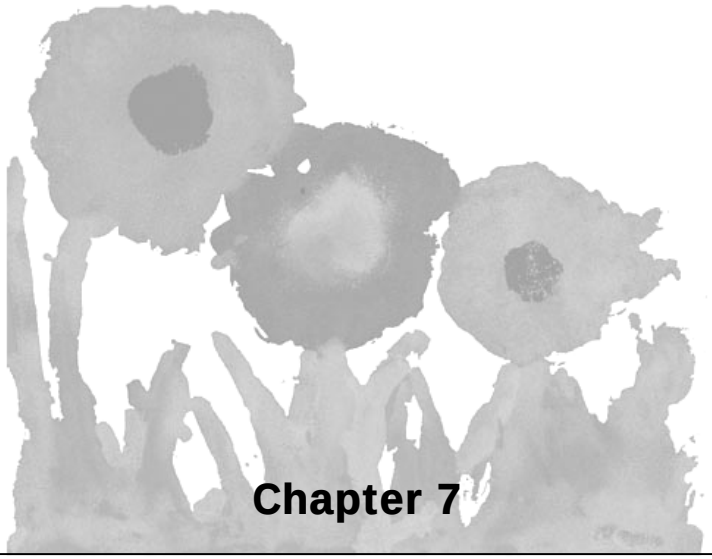

Chapter 7

General Discussion

Stephen E. Ryan

It is widely accepted by clinicians, parents, and other caregivers that assistive technology (AT) devices augment the functioning of children with cerebral palsy (CP) and other physical disabilities. AT devices are essential environmental resources because they enable children to participate in important activities of daily living. Alternative and augmentative communication systems provide children who are non-verbal the ability to articulate their thoughts; manual wheelchairs give children who have mobility impairments the ability to travel efficiently; and adaptive seating devices (ASDs) provide children who are posturally insecure the physical support they need for sedentary tasks at home, in school, and in the community.

It is clear from the systematic reviews in Chapter 1 that support for the putative effect of ASDs is limited to studies that have methodological limitations. Empirical research has mainly explored the influence of these devices on body structure and function outcomes, such as quality or speed of upper extremity movements and seated postural control. The few ASD studies that explored activity and participation outcomes had limited application to child performance in real world settings. Further, research teams often used questionnaires with unestablished levels of reliability and validity, thereby compromising their study findings.

The studies described in this thesis illustrate three different measurement approaches that have advanced ASD outcomes research and our understanding of the functional impact of these technologies in children with cerebral palsy and their families. Each measurement approach is considered below within the context of the International Classification of Functioning, Disability and Health - Children and Youth Version (ICF-CY) framework and our study outcomes.

1: ADAPTING A STANDARDIZED MEASURE TO DETECT THE EFFECT OF SCHOOL FURNITURE CONFIGURATIONS ON THE PRINTING PERFORMANCE OF CHILDREN WITH CP

Since access to high quality education is a fundamental entitlement of all children,[1] rehabilitation clinicians need to know which interventions optimize the activity performance of students with functional impairments in classroom settings. *Learning and Applying Knowledge* is one of the nine key chapters within the activity and participation domains of the ICF-CY.[2] Within this chapter of the ICF-CY, acquiring the elementary skills needed to write the alphabet[2 (d1451)] is a fundamental occupation of children. Handwriting legibility is of primary importance to elementary school teachers who often refer their students for remedial handwriting support.[3] Similarly, identifying the determinants of 'good' handwriting performance is of fundamental interest to therapists who recommend clinical strategies to improve the printing quality of young children.[4]

Therapists who work with elementary school students with CP accept that a relationship exists between good seated posture and the process and output of optimal handwriting performance.[5] Good seated posture – which includes proper sitting balance and alignment – is thought to affect a child's ability to achieve distal control.[6] While researchers have reported weak associations between proper sitting biomechanics and proficient handwriting in typical elementary school students,[7] the interaction and consequences of seating interventions in children with CP is not clearly understood.

We recognized that rigorous empirical studies were needed to explore whether a causal relationship existed between important handwriting outcomes and special ASDs for school-age children with CP. Our randomized controlled trial (RCT) was the first study of the efficacy of ergonomic school chairs and desks on the printing legibility of first and second graders with CP.

During the development of the research question for our study, we searched for a standardized scale to assess the printing quality of children with CP at this academic level. However, no handwriting outcome measures were available for this purpose. Rather than developing a new scale, measurement experts advise that adopting an existing standardized measure is a preferred if it is generally appropriate for the research objectives.[8] We selected the Minnesota Handwriting Assessment (MHA) because it was norm-referenced, was developmentally appropriate, and had acceptable intra- and inter-rater reliabilities for children with typical development. However, our investigation (Chapter 2) highlighted the importance of confirming the measurement properties of standardized outcome measures for "untested" populations. Our initial reliability estimates for the MHA were not only lower than the estimates reported in other studies, they were below reliability levels recommended for research applications.[8-10]

To reduce measurement error, we clarified the MHA scoring rules to account for atypical letter formations made by children with CP. We demonstrated that the scoring addendum (Appendix A) increased rater reliabilities to very high levels. This novel measurement strategy provided the tool to acquire important empirical evidence about the efficacy of school furniture configurations on the printing performance of children with ambulatory CP.

This study was the most rigorous scientific experiment we could conduct to assess the same-session influence of this type of adaptive seating device on manuscript handwriting performance. Importantly, we showed that the "true" effect of ergonomic school furniture on the handwriting legibility of children with CP would likely be too small to be clinically meaningful. However, we acknowledged that this finding must be applied in the context of the experiment we conducted. Other factors that may modify this effect must be explored before conclusions can be made about the effect of these special ASDs on handwriting performance.

As Fuhrer and colleagues[11] contend, we must view ASD and other AT device outcomes within a temporal framework to understand the influence of these technologies over periods that include introductory and long-term use. For our RCT, we measured outcomes following the immediate introduction of the ASDs. It is possible that longer-term use may yield different results since children may adapt to the technology over time.

Future research must include longitudinal studies of the efficacy (under ideal conditions) and effectiveness (under typical classroom conditions) to understand the influence school furniture on handwriting performance. For example, American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) Level III scientific evidence may be obtained using prospective cohort designs that control for known effect modifiers by matching children on key demographic characteristics and applying advanced analytic techniques, such as multilevel modeling and multiple linear regression.[12]

This way of thinking about the influence of ASDs and other factors on activity performance outcomes is consistent with the ICF-CY-related models discussed in Chapter 1. It is conceivable that printing performance may also be affected by other interacting factors that include dimensions of body structure/function (e.g., muscle tonicity), activity (e.g., ability to change and maintain a sitting posture), participation (e.g., social interactions with teachers and fellow students), personal attributes (e.g., attitudes of the child toward handwriting), and other environmental resources (e.g., pencil grip device that can be used to improve handwriting control).

The accumulated evidence from our RCT and other efficacy and effectiveness studies will help to explain the contextual effects of special ASDs and other factors on the handwriting performance of children with CP.

2: DEVELOPING A NEW MEASURE TO STUDY THE IMPACT OF ADAPTIVE SEATING DEVICES ON CHILD AND FAMILY FUNCTIONING

Although ASDs may have a role in optimizing the academic performance of children with CP in the classroom, little is known about the influence of these resources on child and family functioning in home environments.[13] Preschoolers and early school-age children with CP spend most of their time at home under the supervision of their parents and other caregivers so the influence of other factors must be considered to evaluate the impact of ASDs in this setting.[14,15] Children with CP who need support to sit typically use a variety of AT devices to support regular mobility, self-care, and social activities at home.[16]

We theorized that ASDs could increase child autonomy and thereby reduce the caregiving demands on their parents and other family members. Since no health outcome measures were available to test our theory,[17] we could not use or adapt existing measures as we did in our handwriting RCT. Instead, we conceptualized a new measure – the Family Impact of Assistive Technology Scale (FIATS) – to measure of the multidimensional impact of ASDs on child and family functioning.

As detailed in Chapters 3 and 4, we undertook an arduous process to develop this new measure by evaluating its content validity, face validity, internal consistency, and stability over time. The constructs of the FIATS were grounded in literature on child and family functioning, consistent with the ICF-CY dimensions, and confirmed by content experts that included healthcare providers, AT practitioners, and parents of children with CP. Since a universally-accepted method to establish face validity did not exist,[8] we conceived an innovative, mixed-methods approach to measurement development that other researchers may adopt for future AT outcomes research.

Our empirical approach to reduce measurement error and estimate the reliability of the FIATS and its subscales was adopted from classical test theory (CTT). This methodological approach allowed us to identify and eliminate scale items that had high endorsement rates and/or poor item homogeneity within the scale. Further, we used CTT methods to demonstrate that the reliabilities of the revised FIATS and its subscales were acceptable for research purposes. [8-10,18]

Although CTT is an accepted way to develop questionnaires like the FIATS, rehabilitation researchers have promoted two alternative strategies for measurement development – factor analysis and item response theory – as alternatives to the CTT approach we used.

Factor analysis allows scale developers to search for constructs (exploratory) or test a priori relationships (confirmatory) so related items may be grouped based on empirical grounds.[8] However, we based the development of the FIATS on theoretical domains identified in the literature that were endorsed by content experts. Our main concern with factor analysis was that this approach could lead to arbitrary decisions about the relevance of items and domains.

Item response theory (IRT) has replaced CTT in some rehabilitation settings[19] because it does not require the assumption that items contribute equally to the total score, items have equal variance, and each item is measured on the same interval scale. However, IRT would not be appropriate to develop questionnaires like ours, because it requires an assumption of unidimensionality. This assumption was not met for the FIATS because within this measurement model, the impact of

AT devices was conceptualized by the contribution of nine "causal" indicators (Figure 7.1), as opposed to a single underlying construct.

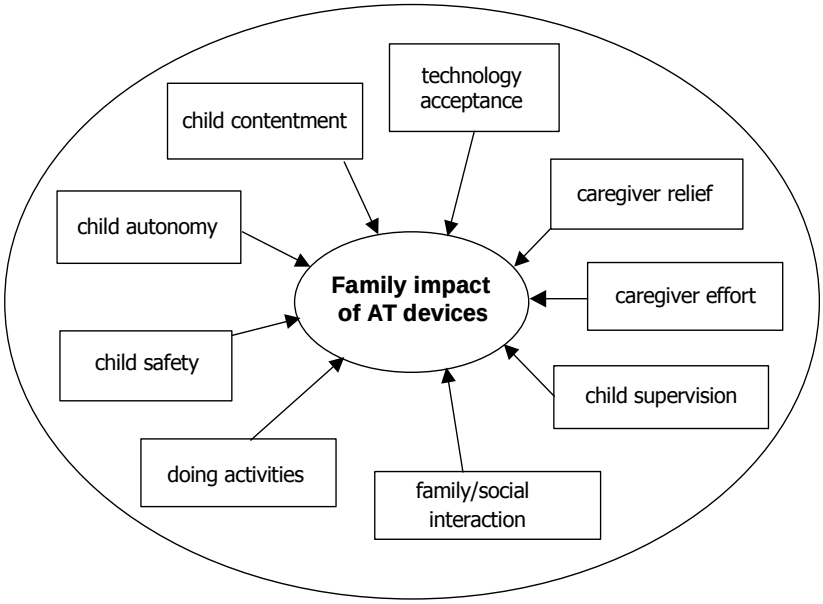

Figure 7.1: The preliminary FIATS as defined by the measurement of nine causal indicators.

We showed the FIATS to have suitable content validity and acceptable reliability. Therefore, our empirical study in Chapter 5 served two related purposes. First, we designed the study to answer the research question: "Do adaptive seating devices used in the home improve family life according to parents of children, aged 2 to 7 years, with GMFCS Level III or IV CP as measured by the FIATS?" Second, we examined the construct validity of the FIATS by determining whether it showed meaningful change (responsiveness), and whether the FIATS and the standardized Impact on Family Scale (IFS) measured similar constructs (convergent validity). (The IFS measured the parent-perceived physical and psychological consequences of having a child with a chronic disability.)

Our study was a Level IV case series design according to the AACPDM levels of evidence.[20] We used a baseline-intervention-baseline design to investigate the magnitude and direction of ASD outcomes. The FIATS showed that the short-term use of special-purpose ASDs led to meaningful improvements in the lives of children with CP and their families, and the removal of these devices led to

negative changes in child and family functioning. Although ours was the first empirical study to show the multidimensional effect of ASDs, more research is needed to disentangle the study device effects from the influence of other factors.

Our study also demonstrated strong evidence of responsiveness for the FIATS by showing a positive, meaningful functional change while children used the study devices and negative functional change after families returned the devices. Further, we showed good evidence of convergent construct validity by showing that the FIATS total scores had moderate, significant correlations with the IFS scores.

The development of the FIATS, described in Chapters 3 through 5, were in response to the call from rehabilitation researchers for outcome measures with high levels of reliability and validity.[17] The FIATS provides a new way to explore the influence of ASDs on the functioning of children with physical disabilities and their families.

3: USING A CHILD-SPECIFIC SCALE TO EXPLORE THE INFLUENCE OF ADAPTIVE SEATING DEVICES ON ACTIVITY PERFORMANCE

While outcome measures, such as the FIATS and MHA, provide the tools needed to understand the multidimensional effects of ASDs at a population level, individualized outcome measures provide the means to explore effects at the level of the child. In Chapter 6, we reported on our investigation of the impact of ASDs on parents' perception of and satisfaction with their child's activity performance. Parents used the Canadian Occupational Performance Measure (COPM) to rate their child's performance for sitting activities that were important to their child.

We found that most parents believed that their child's performance improved dramatically during specific play and self-care activities when the two adaptive seating devices were used. Parents also reported a meaningful loss in functional performance for their children three weeks after returning the devices. These findings are consistent with important gains in child and family functioning we detected using the FIATS.

Although our overall findings using the FIATS and COPM were consistent, the individualized measurements provided a deeper understanding of child-specific influence of ASDs and allowed us to explore individual differences. For example, experienced research occupational therapists confirmed the clinical appropriateness of the seating devices before providing them to each child in the study. Despite this, some parents reported device dissatisfaction and disuse because their children's activity performance levels did not change over the study

period. The mismatch of child, family, and AT devices and resulting device abandonment is similarly reported in other studies,[21-23] and resonates with the need to consider clinical assessment as well as the time-dependent AT outcomes[11] described earlier.

While the COPM findings suggest that ASDs had an overall positive effect on important child-specific issues, we could not discern the cause of this effect because parents identified different child-specific activity performance issues. The adoption of individualized measures such as the COPM in future applications may be limited to detecting an overall impact due to the introduction of ASDs, rather than understanding the causal factors linked to this effect. Population-based studies require the use of standardized measures with common items to understand factors that contribute to the impact of these ASDs and other devices.

CONCLUSION

In summary, these three measurement approaches provide clinicians, researchers, decision-makers, and other stakeholders with different strategies to examine the functional impact of ASDs in children with cerebral palsy. We learned that these measurement approaches provide different advantages, challenges, and outcomes.

Using an existing standardized measure readily provided an ability to evaluate the role that ASDs play in a specific activity performance area (handwriting) for children with CP. However, published measurement properties for one population (children with typical development) did not readily transfer to another population (children with CP).

The development of the FIATS yielded a scale designed to detect the parent-perceived effect of ASDs on the functioning of children with CP and their families. Using the FIATS, our intervention study provided strong evidence to support the putative effect of special purpose seating devices in the home. Adoption of the FIATS in other studies will lead to other empirical evidence of the role that these devices play in the lives of children with physical disabilities and their families.

In our final study, we showed the value of an individualized measure when used to understand the effect of ASDs on a child's specific activity issues. However, this measurement strategy makes it difficult to identify common causal factors and combine results with the findings from other studies to make causal inferences about the effect of ASDs.

RECOMMENDATIONS FOR FUTURE RESEARCH

Acquiring empirical evidence for the efficacy and effectiveness of ASDs on the functioning of children with CP and their families appears daunting, because it requires a long-term commitment. Further, the advancement and availability of new, "better" AT devices, medical treatments, and rehabilitation therapies for children with CP and other disabilities make the timely measurement and evaluation of adaptive seating and other AT device outcomes much more challenging. However, as proposed in Chapter 1, we have an international commitment to ensure that children 'enjoy a full and decent life.' It is because of our obligations to families and children, our communities, and the international community that we must continue to build upon these research activities.

We have sufficient knowledge through systematic reviews of adaptive seating outcomes to know 'precisely where the boundary between current knowledge and ignorance lies.'[24, pg 5] A paucity of sound scientific evidence exists to support the clinical contention that the use of AT devices leads to positive functional outcomes for children with CP and their families. The reason for the lack of sound scientific evidence is partly due to the lower quality of studies providing empirical evidence, the lack of appropriate outcome indicators to measure these multilevel effects, and the ill-defined nature of the populations and devices being studied.

With the availability of the adapted scoring criteria for the MHA, the FIATS, and the COPM, rehabilitation researchers are provided new approaches to study the effect of adaptive seating interventions on important functional aspects of child and family life. Although we demonstrated that the FIATS has adequate levels of reliability and validity for future research, Guyatt and colleagues[25] assert that confidence in the validity of a measure increases as it is used more frequently, in different settings, and performs as we would expect. In this respect, the FIATS is an emerging measure of AT impact. Researchers are encouraged to test new hypotheses and in so doing, strengthen the evidence for its validity.

The ICF-CY framework conceptualizes the health status of a child as an outcome of the dynamic interaction of the child's health condition, environmental influences, and personal factors. The outcomes of this complex interaction are manifested as changes to the child's body functioning and structure, activity performance, and participation in everyday events. Rehabilitation theorists have embraced this biopsychosocial approach to functioning, health, and disability, but advise that AT researchers consider the influence and interaction of the developing child,[26] relevant settings,[27] temporal factors,[11] and modifiable contextual factors[28] when considering new research studies.

This broad, complex interaction of factors suggests that the FIATS be used with other key outcome measures to broaden our understanding of the consequences

of adaptive seating and other assistive technology devices on child outcomes. It would be insufficient to rely on parent views solely to understand the functional impact of adaptive seating devices on young children with CP. Doing so would discount or neglect the important perspectives of others, such as child users and health care providers.

Future research questions must be framed to specify the development stage and functional level of the population sample, the AT intervention to be evaluated, the ICF-CY outcomes to be measured, and the length of follow-up. Only then can future systematic reviews combine studies with homogeneous outcomes in meta-analyses to make powerful inferences about the effect of these and other technologies in children with CP.

Measuring both specific AT device impact and usage leads to predictions of future AT device performance and use.[29] In the same way that the Gross Motor Function Classification System and Manual Ability Classification System have helped describe the functional motor levels of children with CP, a taxonomy of adaptive seating and related AT devices would help to understand which technologies have unique consequences for specific populations of children. A new classification system that parents could use to characterize and quantify their child's use of AT devices is one promising technique.[30] However, this preliminary classification and usage reporting technique needs further validation before it can be adopted as a measure of AT device 'exposure.'

Finally, we must be prepared to answer important ASD-related research questions using a variety of research methodologies. High-quality, double-blinded randomized controlled trials provide the highest of evidence for a single study, but are generally impractical for AT device outcomes research. Rehabilitation researchers must be encouraged to add important methodologically-rigorous evidence from prospective cohort analytic designs, single-subject methodologies, and qualitative inquiry.[28] It is important that teams adopt a battery of methodologies and use a core group of evaluative measures to answer clinical questions about the impact of ASDs and other AT interventions. Demonstrating the strength of association, consistency of results, temporal sequence, and other causal indicators for ICF-CY related outcomes will lead to a totality of evidence to confirm hypotheses, refute theories, and direct future investigations of the functional impact of adaptive seating technology in children with CP and their families.

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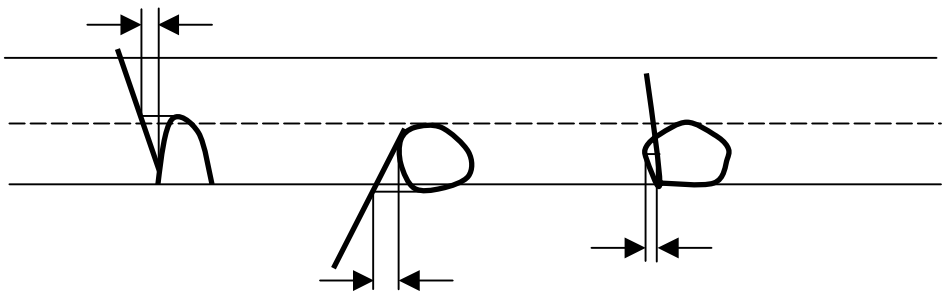
Appendices

Appendix A: Minnesota Handwriting Assessment – Scoring Addendum

General Notes

The following criteria are provided to clarify the scoring criteria in the Minnesota Handwriting Assessment (MHA) manual. In addition to the specific criteria provided for the letters below, the following general guidelines will apply to error scoring:

- letters and words out of sequence are scored as if they were in sequence
- if a sample has duplicate letters, score the first occurrence and ignore the duplicate(s) for all scoring categories
- duplicate letters are counted to calculate 'rate' up to a maximum score of 34
- ignore extraneous periods, dots, or short line segments that do not form part of letters
- extensions greater than 1/8" for ball and stick letters and greater than 1/16" for other letters are form errors unless noted for specific letters below; lines that are added to finish letters are considered extensions and error scoring follows these same rules
- the second of any two letters that touch earns a spacing error
- leniency rule: a letter does not earn an error score if its measurement could be viewed as either an error or not an error
- measure the gap size horizontally for a letter loop and between ascender/descender and curved portion of a letter (see below)



	Legibility	Form	Alignment	Size
a	• the ascender length above and below the highest curved portion must <u>not</u> differ by more than 1/8" to be recognized as an 'a'	• the overall width must not exceed its overall height by more than 1/8" • extra loop gap must not exceed 1/8"	• all parts of the letter must be within 1/16" of the solid line	• all parts of letter must be within 1/16" of dotted line
b	• the ascender must extend vertically at least 1/8" above the highest point on the ball to be considered a 'b'	• the overall width must not exceed its overall height by more than 1/8" • extra loop gap must not exceed 1/8"	• the short descender (if present) must be within 1/16" of the base line	
c	• the letter will <u>not</u> earn an error if it appears to be capitalized	• the overall width must not exceed its overall height by more than 1/8" • the top and bottom of the 'c' must visibly turn the corner (i.e., curl beyond the horizontal)		
d	• the ascender must extend vertically at least 1/8" above the highest point on the ball to be considered a 'd'	• the overall width must not exceed its overall height by more than 1/8" • extra loop gap must not exceed 1/8"	• the short descender (if present) must be within 1/16" of the base line	• curved portion must be within 1/16" of dotted line; stick must be within 1/16" of top solid line
e	• provide greater flexibility for recognition of this letter	• the overall width must not exceed its overall height by more than 1/8" • the bottom of the 'e' must visibly 'turn the corner' (i.e., curl up beyond the horizontal)		• curved portion must be within 1/16" of the dotted line

	Legibility	Form	Alignment	Size
f	• overlaying a 't' in the letter f is acceptable for legibility, but would earn a form error	• the overall width must not exceed its overall height by more than 1/8" • all parts of the cross must be within 1/16" of the dotted line • the staff must not extend vertically below the cross		
g	• the descender must extend vertically at least 1/8" below the lowest point on the ball to be considered a 'g'	• the overall width must not exceed its overall height by more than 1/8" • the tail must visibly 'turn the corner' (i.e., curl beyond the horizontal) • the tail must not extend vertically above the lowest point on the ball • extra loop gap must not exceed 1/8"		• curved portion and ascender must be within 1/16" of the dotted line
h	• the ascender length must be within 1/4" above the highest curved portion to be mistaken as a 'n'	• the overall width must not exceed its overall height by more than 1/8" • extra loop gap must not exceed 1/16"	• both lower vertical lines of the letter must be within 1/16" of the solid line	• curved portion must be within 1/16" of the dotted line; stick must be within 1/16" of top solid line
i	• if an oversized 'circle' is used to dot the 'i', then it may be mistaken as a 'ball and stick' letter and earn a legibility error	• must see daylight between the dot and stick • score a form error if a small 'circle' touches the stick, but the letter still looks like an 'i'		• stick must be within 1/16" of the dotted line

	Legibility	Form	Alignment	Size
j	• if an oversized 'circle' is used to dot the 'j', then it may be mistaken as a 'ball and stick' letter and earn a legibility error	• the overall width must not exceed its overall height by more than 1/8" • must see daylight between the dot and stick • the tail must visibly 'turn the corner' (i.e., curl beyond the horizontal) • score a form error if a small 'circle' touches the stick, but the letter still looks like a 'j'	• lower tail of letter must be within 1/16" of the lower dotted line • the upper portion of the stick must be within 1/16" of the dotted line	• sizing is judged between either the two solid or two dotted lines; the tail must be within 1/16" of the lower dotted line (or base line) and the upper stick must be within 1/16" of the dotted line (or top solid line)
k	• if point of contact for the short legs is more than halfway up the left stick, then the letter earns a legibility error	• the overall width must not exceed its overall height by more than 1/8" • the two short legs of the 'k' must touch	• all parts of the letter must be within 1/16" of the base line	• left stick must not extend more than 1/16" above the top solid line
l			• stick must not be within 1/16" of the base line	• stick must not extend more than 1/16" above the top solid line
m		• the overall width must not exceed 2x its overall height • no visible extension earns a form error • extra loop gap must not exceed 1/16" • a visible gap between the two curved portions does <u>not</u> earn an error	• all parts of the letter must be within 1/16" of the solid line	• curved portion and ascender (if present) must be within 1/16" of the dotted line

	Legibility	Form	Alignment	Size
n	• the ascender length must extend vertically more than 1/4" beyond the highest curved portion to be viewed as a 'h'	• the overall width must not exceed its overall height by more than 1/8" • no visible extension earns a form error • extra loop gap must not exceed 1/16"	• both legs must be within 1/16" of the solid line	• curved portion and ascender (if present) must be within 1/16" of the dotted line
o	• the letter will not earn an error if it appears to be capitalized	• extra loop gap must not exceed 1/8"		
p	• the letter will not earn an error if it appears to be capitalized • the descender must extend vertically at least 1/8" below the lowest point on the ball to be considered a 'p'	• the overall width must not exceed its overall height by more than 1/8" • extra loop gap must not exceed 1/8"		• curved portion and ascender (if present) must be within 1/16" of the dotted line
q	• the descender must extend vertically at least 1/8" below the lowest point on the ball to be considered a 'q'	• the overall width must not exceed its overall height by more than 1/8" • the apex of the tail must be pointed (i.e., must not have a curve) • extra loop gap must not exceed 1/8" • the tail must not extend vertically above the lowest point on the ball		• curved portion and ascender (if present) must be within 1/16" of the dotted line

	Legibility	Form	Alignment	Size
r	• provide greater flexibility for recognition of letter • vertical length of right hand leg must be within 1/8" of the vertical length of left hand leg to be viewed as a 'n' or 'h'	• the overall width must not exceed its overall height by more than 1/8" • no visible extension earns a form error • extra loop gap must not exceed 1/16"		• curved portion and ascender (if present) must be within 1/16" of the dotted line
s	• the letter will <u>not</u> earn an error if it appears to be capitalized	• the overall width must not exceed its overall height by more than 1/8" • the top and bottom of the 's' must visibly 'turn the corner' (i.e., curl up beyond the horizontal)	• all parts of the letter must be within 1/16" of the solid line	
t		• the overall width must not exceed its overall height by more than 1/8" • all parts of the cross must be within 1/16" of the dotted line		• stick must extend more than 1/16" above the dotted line, but <u>not</u> extend more than 1/16" above the top solid line
u	• if the curved portion of the letter is <u>not</u> part of the ascender and <u>not</u> pointed, then recognize it as a 'u' • the letter will <u>not</u> earn an error if it appears to be capitalized	• the overall width must not exceed its overall height by more than 1/8" • no visible extension earns an error • extra loop gap must not exceed 1/16"	• ascender (if present) must be within 1/16" of the base line	• ascender (if present) must be within 1/16" of dotted line • both legs must be within 1/16" of the dotted line

	Legibility	Form	Alignment	Size
v	• if apex of the letter is pointed, then recognize it as a 'v' • the letter will not earn an error if it appears to be capitalized	• the overall width must not exceed its overall height by more than 1/8"		• both legs must be within 1/16" of the dotted line
w	• the letter will not earn an error if it appears to be capitalized	• the overall width must not be greater than 2x its overall height • the lower points must be pointed, not curved	• all parts of the letter must be within 1/16" of the base line	• both legs must be within 1/16" of the dotted line • no error is earned if the midpoint is more than 1/16" below the dotted line
x	• the line lengths must extend at least 1/8" beyond the intersection to be recognized as a 'x' • the letter will not earn an error if it appears to be capitalized	• the overall width must not exceed its overall height by more than 1/8"	• all parts of the letter must be within 1/16" of the base line	• all parts of letter must be within 1/16" of the dotted line
y	• the descender must extend vertically at least 1/8" below the lowest point on the apex to be considered a 'y'	• the overall width must not exceed its overall height by more than 1/8" • extra loop gap must not exceed 1/16"	• apex must be within 1/16" of the base line	• all parts of letter must be within 1/16" of the dotted line
z	• the letter will not earn an error if it appears to be capitalized	• the overall width must not exceed its overall height by more than 1/8"	• all parts of the lower horizontal line must be within 1/16" of the solid line	• all parts of letter must be within 1/16" of the dotted line

Appendix B: Family Impact of Assistive Technology Scale

PLEASE READ: We want to learn your opinions about your child, family life, and assistive devices. Assistive devices are products that your child may use such as wheelchairs, special seats, walkers, communication devices, and leg braces.

Please respond by saying how much you agree with a statement. For instance, the first statement says: "*My child socializes with others at mealtime."* If you **strongly agree** with this statement because your child always socializes with others at mealtime, circle '7'. If you **strongly disagree** because your child never socializes with others at mealtime, then circle '1'. Circle one of the other numbers if you **agree** or **disagree** to a lesser amount. Choose only one rating for each statement.

For statements about your child, assume that s/he is using the assistive devices that are in your home now.

		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
1	My child socializes with others at mealtime.	7	6	5	4	3	2	1
2	I have little time to get chores done around the house.	7	6	5	4	3	2	1
3	I feel comfortable leaving my child sitting in the bathroom.	7	6	5	4	3	2	1
4	My child can communicate with others.	7	6	5	4	3	2	1

		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
5	Other family members need to help me care for my child.	7	6	5	4	3	2	1
6	My child must be with others to be content.	7	6	5	4	3	2	1
7	I am concerned about my child's safety when s/he is left alone.	7	6	5	4	3	2	1
8	My child gets frustrated easily.	7	6	5	4	3	2	1
9	I believe that assistive devices can help my child to learn.	7	6	5	4	3	2	1
10	My child wants to be with me when I leave the room.	7	6	5	4	3	2	1
11	My child is learning to do more activities without help.	7	6	5	4	3	2	1
12	I must take my child with me when I go from one room to another.	7	6	5	4	3	2	1

		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
13	Assistive devices make it easier for my child to play with others.	7	6	5	4	3	2	1
14	Others are happy when my child can join in on family activities.	7	6	5	4	3	2	1
15	I am concerned about my child's safety while seated.	7	6	5	4	3	2	1
16	Assistive devices can make my child's life easier.	7	6	5	4	3	2	1
17	It takes me a long time to get chores done around the house.	7	6	5	4	3	2	1
18	I spend much of the day caring for my child.	7	6	5	4	3	2	1
19	I have trouble coping with the demands of caring for my child.	7	6	5	4	3	2	1
20	Watching my child during the day is exhausting.	7	6	5	4	3	2	1

		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
21	My child needs me to hold her/him while playing with others.	7	6	5	4	3	2	1
22	I would like to spend more time with my other family members.	7	6	5	4	3	2	1
23	Assistive devices can play an important role in my child's life.	7	6	5	4	3	2	1
24	I worry that sitting upright is dangerous for my child.	7	6	5	4	3	2	1
25	I need help to take care of my child.	7	6	5	4	3	2	1
26	It is easier to play with my child when someone is holding her/him.	7	6	5	4	3	2	1
27	My child can play games.	7	6	5	4	3	2	1
28	I feel proud when my child can use an assistive device.	7	6	5	4	3	2	1

		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
29	My child likes to know where I am.	7	6	5	4	3	2	1
30	My child gets bored easily.	7	6	5	4	3	2	1
31	I wish my child could give me a few minutes to myself each day.	7	6	5	4	3	2	1
32	I need help to hold my child in a sitting position.	7	6	5	4	3	2	1
33	I worry about my child's safety if s/he is left alone.	7	6	5	4	3	2	1
34	I believe that my child should use assistive devices for everyday activities.	7	6	5	4	3	2	1
35	My child can use his/her hands to play.	7	6	5	4	3	2	1
36	I must take my child with me when I go to the bathroom.	7	6	5	4	3	2	1

		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
37	I can manage my child on my own.	7	6	5	4	3	2	1
38	My child can play without someone holding her/him.	7	6	5	4	3	2	1
39	My child needs support from a family member to eat at the kitchen table.	7	6	5	4	3	2	1
40	A family member needs to be near my child during the day.	7	6	5	4	3	2	1
41	I believe that assistive devices can help my child do more activities.	7	6	5	4	3	2	1
42	My child feels self-confident.	7	6	5	4	3	2	1
43	I worry about my child playing outdoors.	7	6	5	4	3	2	1
44	I think that assistive devices can play an important role in my child's life.	7	6	5	4	3	2	1

		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
45	It is difficult to manage my child's posture.	7	6	5	4	3	2	1
46	My child likes to be near me.	7	6	5	4	3	2	1
47	I have little energy at the end of each day.	7	6	5	4	3	2	1
48	I find it easy to play with my child.	7	6	5	4	3	2	1
49	I need to get more things done around the house.	7	6	5	4	3	2	1
50	I worry about my child falling off a chair.	7	6	5	4	3	2	1
51	It is hard to hold my child when s/he is playing on the floor.	7	6	5	4	3	2	1
52	My child can control toys without help.	7	6	5	4	3	2	1

		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
53	My child likes to explore his/her surroundings.	7	6	5	4	3	2	1
54	My child can keep herself/himself occupied.	7	6	5	4	3	2	1
55	Assistive devices can make family life easier.	7	6	5	4	3	2	1
56	I spend more time caring for my child than doing other things.	7	6	5	4	3	2	1
57	I need longer breaks from watching my child.	7	6	5	4	3	2	1
58	My child can be happy when I am not holding her/him.	7	6	5	4	3	2	1
59	My child needs me nearby to do many activities.	7	6	5	4	3	2	1
60	My child is safe when left sitting alone on the floor.	7	6	5	4	3	2	1

		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
61	I would like to get more breaks from caring for my child.	7	6	5	4	3	2	1
62	My child can spend a long time doing one activity.	7	6	5	4	3	2	1
63	My child can be happy when left alone to play.	7	6	5	4	3	2	1
64	My child is safe when playing independently.	7	6	5	4	3	2	1

Appendix C: Home Activity Log (HAL) Interview

Activity Performance Areas	Activity – In the past week, please tell me how…
Play	... your child played while seated at home. For example, did s/he actively play more or less with friends/ family members, change how s/he did tabletop or floor level activities such as colouring, or change how s/he played with objects such as toys or games?
Self-Care	... your child participated in self-care while seated at home. For example, did s/he actively participate more or less during activities such as getting dressed, brushing teeth, or using the toilet?
Leisure	... your child participated in leisure while seated at home. For example, did s/he actively participate more or less in recreational activities such as singing, listening to music or watching TV?
Were there any changes in your family routines or caregiver routines that changed your child's activities at home over the past two weeks? (e.g., holidays, visitors, special events, illness …)	
Intervention Phase Only	
Please tell me how using Aquanaut influenced how you, your child, and other family members did activities in the bathroom over the past two weeks.	
Please tell me how using Flip2Sit influenced how you, your child and other family members did activities over the past two weeks.	

Summary

Summary

Many young children with cerebral palsy have motor impairments that affect their ability to sit and do activities unsupported. Consequently, they often rely on special adaptive seating devices for postural control and stability. Healthcare practitioners generally accept that these products improve the physiological functioning, activity performance, and participation of young children with cerebral palsy at home, at school, and in the community. However, little empirical proof exists to support these putative effects. In part, the lack of compelling evidence is because of the need to develop sound ways to measure and interpret adaptive seating device outcomes.

The objective of this thesis is to propose a theoretical foundation to ground adaptive seating outcomes research, present original studies that build upon this conceptual approach, and provide evidence of the functional effect of these technologies on children with cerebral palsy and their families.

Chapter 1 describes a measurement framework based on an adaptation of the World Health Organization's International Classification of Functioning for Children and Youth (ICF-CY). The interactionist approach to the ICF-CY is promoted as one way to think about the multidimensional effect of adaptive seating devices on the lives of children and their families. Included in this chapter is an overview and critique of current scientific evidence of the influence of adaptive seating devices on the functioning of young children with cerebral palsy. The measurement framework and research overview serve as a conceptual and scientific underpinning for the investigations that follow.

Chapter 2 presents a randomized controlled crossover trial designed to detect immediate changes in the printing legibility of 30 first and second graders with cerebral palsy who used two different types of school furniture. This chapter also explains the process used to estimate the rater reliability of the adapted Minnesota Handwriting Assessment – the primary outcome measure used to score errors in key printing performance areas. The trial found that compared to the use of conventional school furniture, the use of special ergonomic school furniture did not appear to change the immediate printing legibility or other aspects of handwriting quality for ambulatory children with cerebral palsy.

Chapter 3 reports on the conceptual development and content validation of the parent-report Family Impact of Assistive Technology Scale (FIATS) – a new measure of the effect of adaptive seating devices on the lives of children with cerebral palsy and their families. The study showed that the preliminary version of the FIATS provided good content coverage according to clinical experts and a sample of parents of children with cerebral palsy. At this first stage of

development, the preliminary FIATS included 89 items within nine contributing subscales that measured child autonomy, caregiver relief, child contentment, activity performance, caregiver effort, family and social interaction, caregiver supervision, child safety, and technology acceptance.

Chapter 4 describes an item reduction process used to improve the measurement properties of the FIATS. This process identified and eliminated 25 items on the FIATS that contributed to measurement error and reduced the reliability of the scale. With the assistance of 50 parents of children with cerebral palsy who completed the questionnaire on two occasions, we showed that the total FIATS and its subscales had acceptable internal consistencies and two-week test-retest reliabilities.

In Chapter 5, the FIATS was used in a 12-week long intervention study to estimate the effect of two special-purpose, adaptive seating devices on the functioning of 30 non-ambulatory young children with cerebral palsy and their families. One device (Aquanaut toileting system) provided a child postural support during toileting activities, while the other device (Flip2Sit activity seat) offered sitting support for a child on the floor or in a chair. This study offers empirical support for the responsiveness of the FIATS and, more importantly, provides convincing evidence of the meaningful effect of these devices on the lives of children, and their parents and family members.

Chapter 6 further explains the findings of our FIATS intervention study (Chapter 5) by examining the influence of the same two seating devices on parents' reports of their child's activity performance using the Canadian Occupational Performance Measure. We showed clinically important differences in activity performance and parental satisfaction with this performance for important self-care and play activities when their children used the study devices at home.

Chapter 7 provides a general synthesis of the preceding chapters and describes the contribution of the thesis to the scientific literature on adaptive seating device outcomes. Future research directions are proposed to measure and advance awareness of the time-dependent, multidimensional impact of adaptive seating devices on the functioning of children with cerebral palsy and their families.

Nederlandse samenvatting

Nederlandse samenvatting

Veel jonge kinderen met cerebrale parese hebben motorische beperkingen die hen (volledig of gedeeltelijk) verhinderen om zonder extra steun te zitten en activiteiten te verrichten. Daarom zijn zij vaak afhankelijk van speciale adaptieve steunvlakhulpmiddelen voor controle over en stabiliteit van hun houding. Doorgaans beamen werkers in de gezondheidszorg dat deze producten fysiologisch functioneren, fysieke prestaties en participatie van jonge kinderen met cerebrale parese thuis, op school en in de maatschappij verbeteren. Er zijn echter weinig empirische aanknopingspunten voor deze veronderstelde effecten. Het gebrek aan doorslaggevend bewijs is gedeeltelijk te wijten aan de noodzaak om degelijke methodes voor meting en interpretatie van uitkomsten van adaptieve steunvlakhulpmiddelen te ontwikkelen.

Het doel van dit proefschrift is om een theoretische onderbouwing ter ondersteuning van onderzoek naar adaptieve steunvlakuitkomsten op te zetten, middels originele studies te presenteren. Deze conceptuele benadering verder uit te breiden en bewijslast aan te dragen voor het functionele effect van adaptieve steunvlakhulpmiddelen op kinderen met cerebrale parese en hun gezinnen.

Hoofdstuk 1 beschrijft een meetsysteem gebaseerd op een bewerking van de Internationale Classificatie van het Functioneren van Kinderen en Jonge Volwassenen van de Wereld Gezondheidsorganisatie 'World Health Organization's 'International Classification of Functioning for Children and Youth' (ICF-CY). Het interactieve gezichtspunt van de ICF-CY wordt gepropageerd als de manier om het multidimensionaal effect van adaptieve steunvlakhulpmiddelen op de levens van kinderen en hun gezinnen te benaderen. Dit hoofdstuk bevat een overzicht en kritische beschouwing van de huidige wetenschappelijke publicaties over de invloed van adaptieve steunvlakhulpmiddelen op het functioneren van jonge kinderen met cerebrale parese. Het meetsysteem en het researchoverzicht dienen als een conceptuele en wetenschappelijke onderbouwing voor de hierna beschreven onderzoeken.

Hoofdstuk 2 beschrijft een gerandomiseerd cross-over onderzoek met controlegroep dat werd ontworpen om onmiddellijke veranderingen op te sporen in de leesbaarheid van het blokletterschrift van 30 leerlingen uit de eerste en tweede klas met cerebrale parese die twee verschillende soorten schoolmeubilair gebruikten. Dit hoofdstuk behandelt tevens het proces dat gebruikt wordt om de betrouwbaarheid in te schatten van de scores op de 'Adapted Minnesota Handwriting Assessment' – de meest gebruikte uitkomstmaat om fouten te scoren voor schrift in blokletters. Uit het onderzoek bleek dat gebruik van speciaal ergonomisch schoolmeubilair, in vergelijking met gebruik van traditioneel schoolmeubilair, geen invloed leek te hebben op de onmiddellijke leesbaarheid van

blokletterschrift of andere aspecten van de kwaliteit van het handschrift van ambulante kinderen met cerebrale parese.

Hoofdstuk 3 gaat over de conceptuele ontwikkeling en inhoudelijke validatie van the 'Family Impact of Assistive Technology Scale' (FIATS) – een nieuwe maat voor het effect van adaptieve steunvlakhulpmiddelen op de levens van kinderen met cerebrale parese en hun gezinnen. Deze studie toonde aan dat de voorlopige versie van de FIATS een goede inhoudelijke dekking verschafte volgens klinische experts en een steekproef bij ouders van kinderen met cerebrale parese. In dit primair ontwikkelingsstadium werden 89 items in de voorlopige FIATS-versie opgenomen, met negen bijbehorende subschalen. Deze maten de autonomie van het kind, verlichting voor de hulpverlener(s), tevredenheid van het kind, fysieke prestaties, inspanning van de hulpverlener(s), interactie van het gezin en sociale interactie, toezicht door de hulpverlener(s), veiligheid van het kind en acceptatie van de technieken.

Hoofdstuk 4 beschrijft een itemreductieproces dat wordt toegepast om de meeteigenschappen van de FIATS te verbeteren. Met dit proces werden 25 items van de FIATS opgespoord en verwijderd die aanleiding gaven tot meetfouten en verminderde betrouwbaarheid van de schaal. Met hulp van 50 ouders van kinderen met cerebrale parese die de enquête op twee verschillende tijdstippen invulden konden wij aantonen dat de totale FIATS, met de subschalen, acceptabele interne consistenties en tweewekelijkse test-retest betrouwbaarheden bezat.

In hoofdstuk 5 werd de FIATS gebruikt in een 12 weken durende interventiestudie om het effect van twee specifieke adaptieve steunvlakhulpmiddelen op het functioneren van 30 niet-ambulante jonge kinderen met cerebrale parese en hun gezinnen te peilen. Met een hulpmiddel (Aquanaut toiletsysteem) werd de zithouding van een kind gesteund tijdens de stoelgang. Een ander hulpmiddel (Flip2Sit activity seat) verschafte steun voor een kind tijdens zitten op de vloer of in een stoel. Deze studie draagt bij aan de empirische onderbouwing van de responsiviteit van de FIATS, maar nog belangrijker is het overtuigende bewijs, dat door deze studie wordt geleverd voor het waardevolle effect van deze hulpmiddelen op de levens van de kinderen, hun ouders en hun gezinsleden.

Hoofdstuk 6 voorziet in een verdere uitleg van de bevindingen van onze FIATS interventiestudie (hoofdstuk 5): de invloed van dezelfde twee steunvlakhulpmiddelen op basis van de verslagen van de ouders over de fysieke prestaties van hun kind werd onderzocht met behulp van de 'Canadian Occupational Performance Measure'. Wij konden hiermee klinisch relevante veranderingen aantonen in fysieke prestaties, en tevredenheid van de ouders met deze prestaties, met betrekking tot belangrijke zelfhulp- en spelactiviteiten tijdens gebruik van de onderzoekhulpmiddelen door hun kinderen in de thuissituatie.

Hoofdstuk 7 geeft een algemene synthese van de voorgaande hoofdstukken en beschrijft de bijdrage van het proefschrift aan de wetenschappelijke literatuur met betrekking tot adaptieve steunvlakhulpmiddeluitkomsten. Er worden toekomstige richtlijnen voor onderzoek voorgesteld om de bekendheid van het tijdsafhankelijke, multidimensionaal effect van adaptieve steunvlakhulpmiddelen op het functioneren van kinderen met cerebrale parese en hun gezinnen te meten en te bevorderen.

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List of Publications and Awards

List of Publications and Awards (since 2000)

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Jordan R, Rigby PJ, Ryan SE. Flip2Sit™ activity seat. Licenced to Otto Bock HealthCare Limited. (In production since 2003).

Al-Temen I, Rigby PJ, Ryan SE. Embrace Pelvic Positioner™. Licenced to BodyTech NW, Multikeo, WA. (In production since 2004).

Curriculum Vitae

Curriculum Vitae

Stephen Edward Ryan was born in Ottawa, Ontario, Canada on December 6, 1957. He spent most of his life in Toronto, Ontario, but lived his early childhood and elementary school years in other Canadian cities, including Ottawa, Montreal, and Vancouver. He graduated in 1980 from The University of Western Ontario in London, Ontario with a BESc in mechanical engineering, and worked for 5 years as a design engineer at Atomic Energy of Canada Limited in Mississauga, Ontario. In 1985, Steve joined the Rehabilitation Engineering Department as a research design engineer at what was then The Hugh MacMillan Medical Centre – now Bloorview Kids Rehab – in Toronto. Over the next 24 years, Steve led more than 40 research projects involving teams of exceptional therapists, researchers, engineers, designers, tool makers, and students. These collaborations yielded more than a dozen commercial adaptive seating, mobility, and orthotic devices for children and youth with disabilities. Steve's desire to understand the influence of assistive devices in the lives of children with physical disabilities led him to graduate school in 2003. In 2007, he received a MSc in Health Research Methodology (Clinical Epidemiology) from McMaster University in Hamilton, Ontario. Steve has authored more than 70 journal articles, conference papers and abstracts, and he and his team have received 20 patents and innovative new product awards. He is currently a Scientist in the Bloorview Research Institute at Bloorview Kids Rehab and an Assistant Professor in the Department of Occupational Science and Occupational Therapy at the University of Toronto. Steve lives in Mississauga with his wife, Linda, and their four children – Emily, Alex, Carley, and Claire.