

Construct Validity of the Family Impact of Assistive  
Technology Scale for Augmentative and Alternative  
Communication: A Parent-Report Measure for Children with  
Complex Communication Needs

by

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The Rehabilitation Sciences Institute  
University of Toronto

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## Abstract

**Background:** Valid and reliable parent-report outcome measures that detect the functional performance of children who use augmentative and alternative communication (AAC) systems are unavailable. The Family Impact of Assistive Technology Scale for AAC (FIATS-AAC) was developed to fill this measurement need.

**Objective:** To evaluate the construct validity of the FIATS-AAC as a measure of the functional status of children with AAC needs and their families.

**Methods:** Phase 1: Forty-seven parents of children, 6 to 12 years, with AAC needs, completed a mail-out survey that included the FIATS-AAC and two measures of quality of life and child participation in the community. Phase 2: Six parents also participated in a face-to-face interview.

**Results:** Low-to-moderate correlations between the FIATS-AAC and the standardized measures were found. Interviews suggest some consistency between measurement scores and analyzed narratives.

**Conclusion:** The FIATS-AAC has the potential to assess functional status as it relates to community participation and quality of life of children with AAC needs.

## Dedication

I would like to dedicate this thesis to all the families whose lives have been touched by someone with communication needs. May this work bring you hope for a better future for you and your families.

## Acknowledgments

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## List of Abbreviations

AAC – augmentative and alternative communication

CCN - complex communication needs

CFCS – Communication Function Classification System

CHQ-PF28 - Child Health Questionnaire: Parent Form 28

FIATS-AAC – Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication

FOCUS© – Focus on the Outcomes of Communication Under Six

HRQOL – health-related quality of life

ICC – intra-class correlation coefficient

ICF-CY - International Classification of Functioning, Disability, and Health – Child and Youth Version

MACS – Manual Ability Classification System

PEM-CY - Participation and Environment Measure for Children and Youth

PPOLD – Parent Perceptions of Language Development

VABS-II – Vineland Adaptive Behavior Scale - 2<sup>nd</sup> Edition

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# Chapter 1

## Introduction

### 1.1 Profile of young people with complex communication needs

In Canada alone, an estimated 80,000 children between the ages of 5 and 14 years have speech-related disabilities (Statistics Canada, 2006). Speech-related disabilities are commonly associated with developmental disabilities such as developmental delay, cerebral palsy, and autism spectrum disorders (Light & McNaughton, 2012). However, other childhood-onset disabilities, such as acquired brain injury, may also impair speech (Murdoch & Theodoros, 2001).

A subset of children with speech-related disabilities have complex communication needs (CCN). CCN may be characterized as the inability to produce speech, difficulty in understanding spoken language communicated by others, and/or difficulty being understood. Although no reliable prevalence data exist in Canada, population estimates from a systematic review of epidemiological studies suggest that more than 18,500 Canadians who are 5 to 14 years of age have CCN (Law, Boyle, Harris, Harkness, & Nye, 2000).

### 1.2 Efficacy and effectiveness of AAC interventions: State of science

Children with CCN often use augmentative and alternative communication (AAC) systems to improve their everyday functional communication. AAC systems replace or augment speech, through the use of body language – such as gestures and sign language (unaided AAC) – and/or through devices that are used externally by the child – such as speech-generating devices or flashcards (aided AAC). This provision is clinically important because children who are unable to communicate in everyday settings may lack the linguistic, operational, social, and strategic skills necessary to support further language development (Light & Drager, 2007). For example, proper meaning and pronunciation may be absent, which in turn can adversely affect an ability to communicate in social contexts and make decisions based on these interactions. Lack of these

skills can prevent children with CCN from taking on personally satisfying roles in society and promote social isolation (Lindsay & Tsybina, 2011).

Much evidence has been generated that illustrates the *efficacy* of both aided and unaided AAC interventions in a diverse population of children with CCN. For the purposes of this study, *efficacy* refers to the impact an intervention has on a specific population in a highly controlled environment, while *effectiveness* refers to the impact an intervention has in a more variable, ‘real-world’ environment (Hulley, Cummings, Browner, Grady, & Newman, 2013). Ganz et al. (2012) conducted a meta-analysis of individuals with autism spectrum disorders who use AAC and found that aided AAC interventions had positive effects on targeted behavioural outcomes. In a recent systematic review, further evidence emerged for the use of AAC interventions to educate children with autism on how to improve their communicative function for social interactions beyond just object requests (Logan, Iacono, & Trembath, 2017).

Another systematic review looked at the effects of AAC interventions across children who have a wide range of disabilities (Branson & Demchak, 2009). All studies assessed in this review reported that AAC interventions improved communication among children. AAC interventions have also shown positive benefits in the development of expressive and receptive language skills in infants and toddlers with CCN (Drager, Light, & McNaughton, 2010).

### 1.3 Challenges to the implementation of AAC interventions

It is important to note that the evidence compiled from these systematic reviews focused on the clinical outcomes of AAC interventions on children in controlled clinical environments. AAC interventions may also lead to improved functional communication in everyday environments that children frequent. Yet, their parents report high unmet needs for communication devices for reasons that are not fully understood (Statistics Canada, 2006).

Evidently, a knowledge gap exists between research-reported efficacy and the ‘real-world’ effectiveness of AAC interventions for children with CCN. This research gap calls for the

development and use of measurement tools that can assess the functional status and performance of a child in their ‘real-world’ environment (i.e. home, school, community).

The parent-report Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication (FIATS-AAC) is an emerging measure of the multidimensional effects of AAC systems for children 6–18 years of age and their families (Delarosa et al., 2012). While previous studies have confirmed its content and face validity, test-retest reliability, and internal consistency for groups of children with CCN (Delarosa et al., 2012), further support for the construct validity of the FIATS-AAC as a measure for clinical and research applications is required. Using measures with empirical evidence to support their reliability and validity, clinicians will have the information needed to inform practice by better understanding the effectiveness of their AAC interventions.

## 1.4 Thesis aim and organization

The primary aim of this thesis is to evaluate the convergent construct validity of the FIATS-AAC as a measure of the functional status of children with AAC needs and their families. Validation of the FIATS-AAC involved examining the strength of its association with two other standardized parent-report questionnaires that reflect community participation and health-related quality of life (HRQOL): the Participation and Environment Measure for Children and Youth (PEM-CY) (Coster et al., 2011) and the Child Health Questionnaire – Parent Form 28 (CHQ-PF28) (Raat, Botterweck, Landgraf, Hoogeveen, & Essink-Bot, 2005).

In support of this primary aim, thematic analyses of interviews with a subset of parents were also conducted to add further evidence in the validity investigation. This latter approach provides a novel methodological contribution within this thesis as it applies a mixed methods approach to assess construct validity. Rationale for the use of this method in future validation studies is argued herein.

This thesis has four chapters and is presented in manuscript format.

*Chapter 1* introduces the clinical population, AAC interventions, gaps in the outcome measurement, and the purpose and objectives of the thesis.

*Chapter 2* posits a model for AAC outcomes based on a framework for measuring assistive technology outcomes and details a systematic literature review of functional outcome measures for children with communication needs.

*Chapter 3* consists of a manuscript titled ‘Construct validity of the Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication: A parent-report measure for children with complex communication needs’. *Chapter 3* summarizes the research rationale from *Chapters 1 and 2* and details the main study protocol, results, discussion and conclusions.

*Chapter 4* reviews the key findings from the main study and their implications for rehabilitation practice. Limitations of the study and family engagement throughout the research process are also highlighted.

Supplementary information is presented in the Appendices.

## Chapter 2

### Literature Review

#### 2.1 Measurement challenges associated with AAC interventions

Despite evidence of AAC *efficacy*, challenges still exist in regard to understanding the *effectiveness* of AAC intervention strategies (Light & McNaughton, 2012). Advancements in evidence-based practice continues to be difficult due to the minimal work being conducted in outcomes research (Fuhrer, Jutai, Scherer, & DeRuyter, 2003; Henderson, Skelton, & Rosenbaum, 2008; McNaughton & Light, 2015). Outcomes research may have received little attention for at least two reasons: (1) stakeholders believe that the effectiveness of AAC is apparent from stories of personal experience, and (2) researchers tend to focus on the development of efficacious AAC rather than testing its effectiveness. But perhaps most notably, implementing evidence-based intervention strategies has been difficult due to lack of sound measurement tools that assess the functional outcomes of AAC interventions in the child's 'real world' environment (Fuhrer et al., 2003).

Enderby (2014) conducted a review of outcome measures for AAC applications and found that current measures lack key properties needed to assess overall communication. For example, key psychometric properties were either inadequate or unpublished, and/or the measures failed to assess the influence of AAC interventions on the well-being of the client and their parent or caregiver. Without well-targeted, comprehensive outcome measures, clinicians lack the tools necessary to make better decisions regarding AAC intervention strategies.

#### 2.2 A theoretical framework for measuring health outcomes in rehabilitation

The selection of an appropriate outcome measurement scale may be guided by a conceptual framework that can be applied to a variety of AAC systems and/or interventions. Most outcome measures have been developed to focus on the particular behaviour(s) of a client who has a specific diagnosis rather than their overall functioning using a holistic framework (Simeonsson, Björck-Åkesson, & Lollar, 2012). *Overall functioning* is defined according to the



characterisation of functioning provided by the World Health Organization – “positive or neutral aspects of the interaction between a person’s health condition(s) and that individual’s contextual factors (environment and personal factors)” (WHO, 2001, p. 8, 10). This definition of *overall functioning* was adopted for this study. Measurement authorities in AAC suggest that outcome measures be designed based on the International Classification of Functioning, Disability, and Health and its derived version for children and youth – the International Classification of Functioning, Disability, and Health - Child and Youth Version (ICF-CY) framework (WHO, 2007; Enderby, 2014).

The ICF-CY is a multi-dimensional classification system for health and health-related outcomes (Simeonsson et al., 2012; WHO, 2007). The framework takes a holistic approach to assessment by focusing on how the interactions among a child’s *body structures and functions, activity, participation, personal and environmental factors*, characterize levels of functioning and disability. In this way, the ICF-CY classifies functioning from an integrated perspective to provide researchers with a useful theoretical foundation for measuring functioning and functional outcomes.

## 2.3 An AAC outcomes model for children with complex communication needs

A conceptual framework to support the modelling of assistive technology outcomes has been proposed (Fuhrer et al., 2003). This framework helps guide the development of outcome models of specific assistive technology systems and devices by identifying important domains and co-factors that are involved at different stages of device use.

Many assumptions underlie the framework: (a) use of this framework will guide assistive technology-specific outcome models to improve outcomes research; (b) use of the assistive device from initial uptake and long-term use should be considered; (c) the framework should include objective and subjective perspectives; (d) the views of device outcomes should include those of multiple stakeholders; (e) the framework should include concepts that have been widely discussed, and are applicable to the outcomes (e.g., ICF-CY); (f) the active involvement of end

users should be emphasized; (g) outcomes should prioritize assessment towards the end user's objectives and needs; (h) mediating factors, such as introductory and long-term use of the device, should be present in the framework; and, (i) the framework should highlight factors that can influence the longer-term outcomes (i.e., continued or discontinued device use).

Fuhrer and colleagues' theory can be used as a theoretical foundation for the modelling of AAC outcomes. An AAC specific outcomes model for children who use AAC is proposed (Figure 1). Proposing such a model requires one to define what is meant by the different stages of device use, all within the context of AAC. The stages of AAC system acquisition and use vary by individual needs and circumstances but generally include: assessment/procurement, introductory use, short term use, and long-term use as well as their associated outcomes.

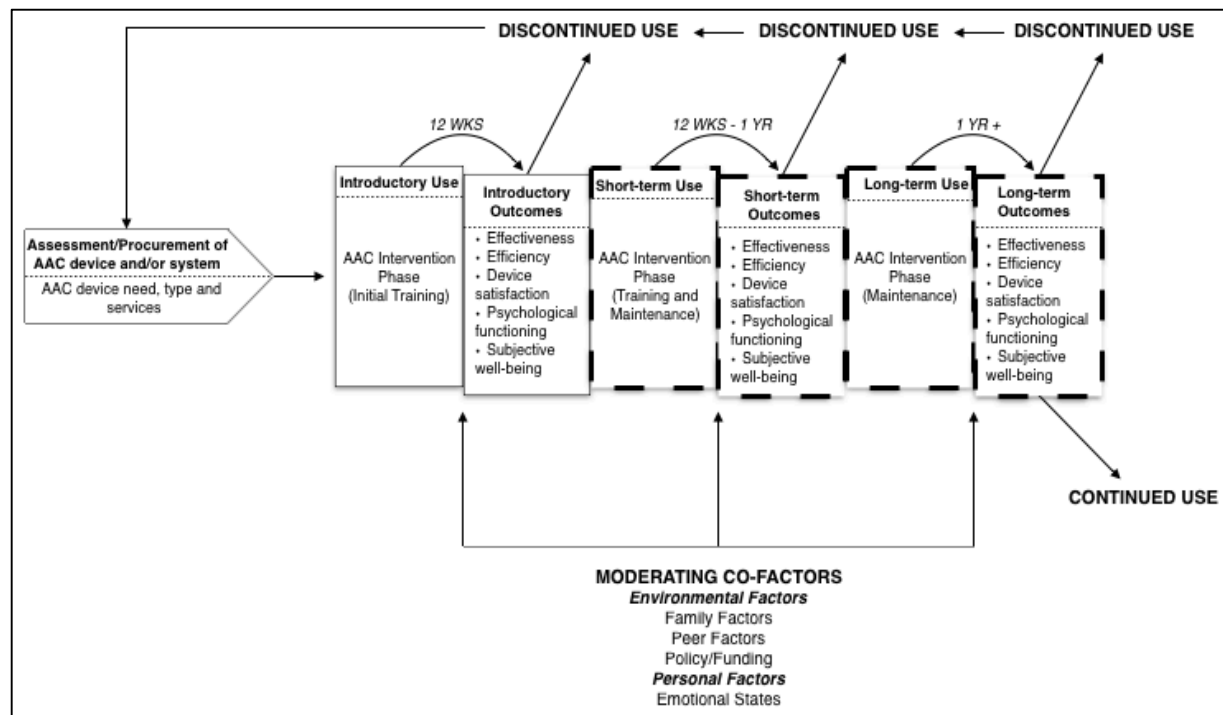


Figure 1. Proposed augmentative and alternative communication devices outcomes model for children (Adapted from Fuhrer et al., 2003 by graduate researcher (AK)).

*Assessment/Procurement of AAC device and/or system* refers to the events that take place before children and their families integrate an AAC device into their daily routines. For example, discussions are centred around the device need, type, and services that may be involved. The

need for an AAC device can be assessed by the AAC clinic team in consultation with the client and family. The AAC system may include the device, vocabulary, symbols and communication strategies that will be used (i.e. gesture type, device type) (Granlund, Björck-Åkesson, Wilder, & Ylvén, 2008). The services that are involved can include how the client will receive the device (e.g., through an Internet vendor) as well as assessment of the client's personal functional goals and a communication training plan.

*Introductory use* is the AAC intervention phase whereby the initial training of the client to use the device occurs. AAC interventions refer to the applied use of new, alternate modes of communication, whether they be aided or unaided, and the associated client and communication partner training (Granlund et al., 2008). AAC interventions also include shared setting of individual client and family goals that clinicians target when planning AAC interventions. More general intervention methods include the instruction techniques, strategies for maintaining AAC device use, and implementing the intervention in a collaborative manner (i.e. involving families in the development of the communicative competencies) (Granlund et al., 2008).

*Short-term use* includes a maintenance component in addition to ongoing training. The maintenance phase is a time-dependent component of the intervention process whereby adaptations to the device may occur (Fuhrer et al., 2003). For example, children may adapt physically, emotionally, or cognitively to use of the device. The maintenance phase helps clinicians and stakeholders determine whether the device is appropriate for the child and family environment (Fuhrer et al., 2003). *Short-term use* or *discontinued use* stems from *introductory outcomes*.

Maintenance continues during *long-term use*. In the long term, the goal is to further strengthen communicative competence in a manner that will advance the child's long-term goals of meaningful participation and enhanced HRQOL. *Long-term use* or *discontinued use* stems from *short-term outcomes*. *Introductory, short-term, and long-term outcomes* may include: effectiveness and efficiency of device use, device satisfaction, psychological functioning, and subjective well-being. Although all these concepts may be applied within all fields of assistive

technology, specifying the type of AAC device and user will allow clinicians to compare outcomes between specific AAC devices and populations (Fuhrer et al., 2003).

Like the assistive technology outcomes mentioned in Fuhrer's framework, the outcomes of AAC interventions can be organized across the domains of the ICF-CY including *environmental factors* (i.e. family factors, peer factors, policy/funding) and *personal (child) factors*. In the proposed AAC outcomes model for children, these contextual domains are labelled as *moderating co-factors*. *Introductory, short-term, and long-term outcomes* result from interactions between *introductory, short-term and long-term use, and moderating co-factors*.

*Environmental factors* include the social and physical aspects of the environment. Included are *family factors* and *peer factors* that refer to how parents, other family members, and peers influence intervention outcomes (Simeonsson et al., 2012). For example, parents need to be educated on the use of the AAC device (i.e. partner training). Peers also need to be equipped with the skills necessary to interact appropriately so children with CCN may improve their communicative competence. *Policy/Funding* refers to the AAC assessment/intervention protocols in place throughout institutions, and provincial and federal regulations regarding the amount of AAC device funding available to families in need of an AAC device.

*Personal factors* are not defined well within the ICF-CY, but include emotional states that can influence child functioning (e.g., contentment) (Simeonsson et al., 2012). The *introductory, short-term and long-term outcomes* encompass the same domains of the ICF-CY, although their importance in each stage may take on different forms depending on the child's needs, the nature and types of communication encounters, and environment. *Long-term outcomes* are followed by continued/discontinued use and (possible) re-initiation of the AAC assessment.

*Introductory outcomes* may emerge during initial training blocks conceptualized to occur up to 12 weeks after dispensing the device. *Short-term outcomes* may occur during training blocks and maintenance phases that occur after introductory use and up to 1 year after dispensing the device. *Long-term outcomes* may focus on functioning more than 1 year after device dispense.

Occupational and speech-language pathologists working in the AAC field frame AAC outcomes this way (Renzoni & Shepherd, personal communication, March 2, 2016). There may be overlaps among phases depending on the individual. The present study focuses on parent-perceived functioning during *short-term and long-term use* (outlined with dashed lines) to provide sufficient opportunity for an AAC device to integrate fully into the child's daily life. Further, this period should provide parents sufficient time to observe and reflect on their child's functional status as it relates to everyday communication.

## 2.4 Systematic review of parent-report functional outcome measures in AAC

Family-centered care is an integral part of AAC and other health services for children with disabilities (Mandak, O'Neil, Light & Fosco, 2017). According to Dunst (2002), family-centered care includes: respecting families; making individualized and flexible decisions that accommodate family situations; providing families with the necessary information they need to make educated decisions for their child's care; giving families choices with respect to different health service options; fostering collaborative efforts between parents and other stakeholders; and ensuring parents have the proper training and supports to properly care for their child.

In the past few decades, AAC clinicians have taken a family-centred approach to service provision as primary caregivers ('parents') can have a strong impact on the reception, implementation, and maintenance of AAC systems (Granlund et al., 2008). Parents are involved in the evaluation process since they hold key information regarding a child's level of functioning in home, school, and community environments.

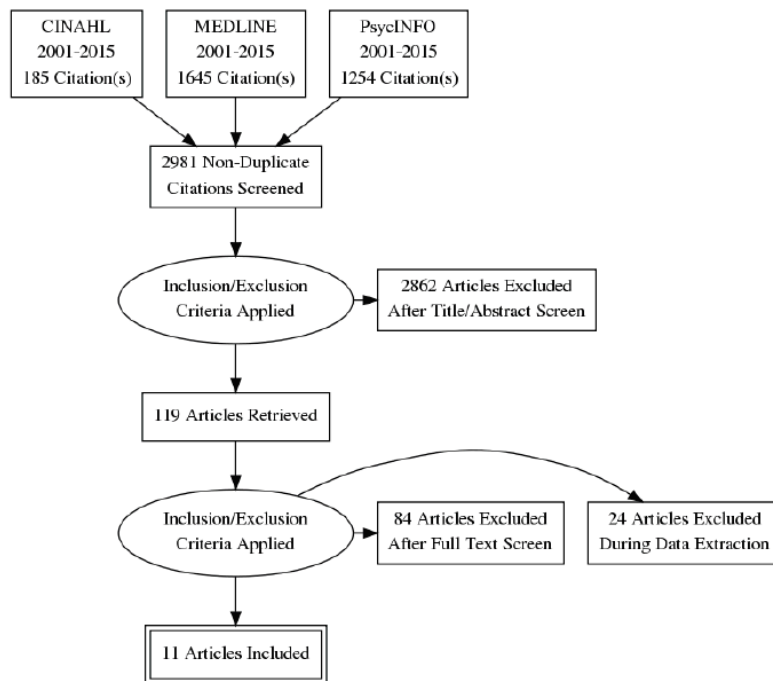
However, current knowledge on parent perceptions of the child's communicative performance is limited – only a few studies collect parent perceptions, and most approach evaluation from a qualitative perspective (Smith & Hustad, 2015). This limits the objectivity of functional outcomes data. A systematic review of functional outcomes associated with assistive technology interventions showed that knowledge of family and child outcomes is limited in part by the lack

of sound outcome measurement tools that report on the child's level of functioning from the parent's perspective (Henderson et al., 2008).

To provide an AAC outcomes focus and update past reviews, members of our research team conducted a systematic review of contemporary literature to identify candidate parent-report health measurement scales intended to assess functional outcomes of AAC interventions in children under 18 years of age (Kron & Ryan, 2016). The search included peer-reviewed original research studies identified in MEDLINE, PsycINFO, and CINAHL electronic databases. Keywords were mapped to suggested subject headings in each database and a multipurpose keyword search used word stem descriptors of the ICF-CY, 'children using AAC', 'children with CCN', 'outcome/intervention studies', and 'measurement'. A sample search strategy is found in Appendix A.

The search strategy used the following inclusion criteria: (i) English, peer-reviewed, original research study; (ii) published between 01/01/2001 and 31/12/2015 (to include articles published after the international endorsement of the ICF in 2001) (WHO, 2001); (iii) all participants under 18 years of age; (iv) child used any type of aided AAC device or system; and (vi) at least one participant received an AAC intervention.

Tools were included if: (i) the target population, domains, and scale items provided sufficient information to understand tool subject matter; and (ii) the tools assessed functional outcomes from the perspective of the participant's parent. A total of 2918 non-duplicated articles were screened by title and 119 were retrieved following an initial title/abstract screening. Eleven publications met all inclusion criteria after a full-text review of each (Figure 2). An updated search was conducted including articles published between 01/01/2016 and 03/31/2017 with no articles added. Articles describing the development of new parent-report questionnaires were not eligible for inclusion. Only measures used to evaluate functional outcomes of children receiving an AAC intervention were included in this review.



*Figure 2.* Article selection flowchart.

The 11 articles included six parent-report measurement scales that were implemented to assess various AAC interventions in children with different levels of CCN. Of these, only three tools were formally constructed and had their measurement properties examined empirically across groups of children with AAC needs. The three tools were: Focus on the Outcomes of Communication Under Six (FOCUS©), the socialization and communication domains of the Vineland Adaptive Behavior Scale – 2<sup>nd</sup> Ed (VABS-II), and the Parent Perception of Language Development (PPOLD). The other tools included three non-standardized questionnaires and interviews.

The FOCUS© was designed to assess the ‘real-world’ communication outcomes of preschoolers who need speech language services (Thomas-Stonell, Oddson, Robertson, & Rosenbaum, 2010). The VABS-II was originally developed to measure functional communication following intervention in individuals from birth to 90 years (Sparrow, Cicchetti, & Balla, 2005). The PPOLD was developed by Ronski and colleagues (2011), for their study in children with developmental delays who were undergoing language intervention. The VABS-II has acceptable levels of reliability and validity in groups of children with CCN (Sparrow et al., 2005), whereas

the PPOLD and FOCUS© have acceptable reliability and emerging validity in groups of children with developmental delays (Ronski et al., 2011; Washington et al., 2013).

Although these measures have been useful in studies assessing functional outcomes of AAC interventions in children with CCN, several important shortfalls exist. The FOCUS© only includes items tailored to children under six years of age (Thomas-Stonell et al., 2010). Therefore, researchers and clinicians are not able to evaluate communicative participation in older children who use AAC. While the VABS-II socialization and communication domains have been used to assess the efficacy of AAC interventions (Washington et al., 2013), many items are not applicable to children who are non-verbal and use AAC systems (J. Hanson, personal communication, August 31, 2015). Finally, the PPOLD scale only includes items with limited domains - success, difficulty, and neither factor (Ronski et al., 2011). Items in the *success* and *difficulty* domains refer to the ability to use and develop language. Items that did not fall into either of these domains were organized into the *neither factor* domain. This structure of limited domains does not appeal to clinicians who want to assess overall functioning as it relates to communication in their clients with CCN.

This systematic review confirmed the need for a sound parent-report measurement scale that targets children with AAC needs from the time they enter nursery school/JK (age 3) until they leave high school/enter post-secondary school (18 years). Further, the scale should measure functioning and detect functional change holistically, and have adequate levels of reliability and validity - including the ability to detect functional change over time at both individual and group levels.

## 2.5 Outcome measurement options for clinical applications in AAC

In the absence of both appropriate and valid parent-report measurement scales for AAC outcomes research, one may consider studying the psychometric properties of ‘unproven’ measurement scales to detect AAC functional outcomes at an individual and/or group level.



These measurement scales include three main types: individualized measures, generic functional measures, and disability-specific or needs-specific measures.

Individualized outcome measures are client-centred assessments, where goals are specific and are generally identified by the child or child and parent (Streiner & Norman, 2008). For example, goal attainment scaling measures the level of expected outcomes on a five-point scale for different goals. This type of measurement scale has the main advantage of individualizing the goals for each client. Although this permits clinicians to understand whether an intervention was successful or not, it does not allow clinicians to identify where exactly the intervention was effective for the individual client (Streiner & Norman, 2008). For example, low scores may be the result of goals that were not properly chosen, rather than an ineffective program. Since clients have varying goals, goal attainment scaling also poses a disadvantage for clinicians who seek to compare scores between clients.

Generic functional measures are applicable to all persons who have a range of disabilities and assess health-related constructs (Patrick & Deyo, 1989). For example, the Participation and Environment Measure for Children and Youth (PEM-CY) is a parent-report measure that assesses participation involvement and variety in children aged 5 to 17 years in home, school and community environments (Coster et al., 2011). Although generic measures can measure functioning in several individuals, the focus may be on domains that may be less important or irrelevant to specific populations (Chen, Li, & Kochen, 2005).

Disability- and needs-specific outcome measures detect outcomes in specific client populations. For example, the Pediatric Quality of Life Inventory™ Cerebral Palsy Module was designed to measure aspects of functioning and HRQOL in children with this common developmental disability (Varni et al., 2006). While disability-specific measures can assess difficulties common to a specific client population, outcomes are difficult to compare across client populations (Chen et al., 2005). Whereas, needs-based measures support cross-disability use and comparisons.

Delarosa and colleagues (2012) developed a multidimensional, needs-based, parent-report measure called the Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication (FIATS-AAC) (Appendix B). The FIATS-AAC items are similar to those that were developed for the original FIATS, which assessed the functional outcomes of adaptive seating interventions rather than AAC (Ryan et al., 2006). The rationale for the development of the FIATS-AAC was to fill the need for a parent-report AAC measure that detects functional change over time (i.e. assessment/procurement of AAC device and/or system, introductory use, short-term use, long-term use, etc.). While the FIATS-AAC fills the need for a holistic, parent-report measure of functioning in children with CCN, evidence supporting its reliability and validity is limited. Nevertheless, in the absence of a suitable alternative, the FIATS-AAC was optimally suited for a test of construct validity (Chapter 3).

## 2.6 Measurement status of the FIATS-AAC

The FIATS-AAC is grounded in the ICF-CY framework. By using the ICF-CY as a theoretical basis for item development, the FIATS-AAC takes a more holistic approach to measurement of AAC outcomes, making it suitable as a measure of functioning in the child's 'real-world' environment. The FIATS-AAC is intended to measure the functional outcomes of AAC interventions in children 6-18 years of age and their families.

A total of 89 items map onto 1 of 13 child- and family-related domains: behaviour, caregiver relief, contentment, doing activities, education, energy, face-to-face communication, family roles, finances, security, self-reliance, social versatility, and supervision (Appendix C). The parent rates the degree of agreement/disagreement with each item using a 7-point Likert scale. The sum of mean scores on each domain achieves a FIATS-AAC total score.

The FIATS-AAC has evidence of content and face validity, internal consistency, and test-retest reliability (Delarosa et al., 2012). The team supported its content validity by having five AAC specialists and two parents of children with CCN rate the relevance of candidate domains, definitions, and sample items pertinent to the AAC literature. There was a general consensus among the participants that the candidate domains were relevant for the stated purpose of the

FIATS-AAC. To assess face validity, a group of parents ( $n = 7$ ) of children with CCN between 6 to 18 years reviewed and rated the relevance of a pool of potential FIATS-AAC items. The majority of participants found that almost all items were easily understood. The few items that were unclear were either reworded or eliminated by parent participants.

The FIATS-AAC total score was estimated to have high internal consistency (Cronbach's alpha = .91). Cronbach's alpha for the individual domains varied from .66 – .90, with two of the domains – Family Roles and Contentment – falling just below the recommended threshold for internal consistency (alpha = .7) (Streiner & Norman, 2008). The point estimates for intra-class correlation coefficients (ICCs) were high for test-retest reliability varying from .86 – .97 across the thirteen domains. All values for the lower confidence limit exceeded guidelines for reliability thresholds for research purposes (i.e.  $ICC \geq .70$ ) (Streiner & Norman, 2008).

The convergent construct validity of the FIATS-AAC was also assessed by comparing its scoring with the standardized Impact on Family Scale (Delarosa et al., 2012). The Impact on Family Scale is a parent-report measurement tool that assesses the impact of pediatric illness and disability on families (Stein & Jessop, 2003). Although a significant moderate association was found between the Impact on Family Scale and the FIATS-AAC ( $r = -.66, p < .001$ ), 66% of the variance in the total FIATS-AAC score was unexplained by the Impact on Family Scale. This can be interpreted to mean that the construct measured in the Impact on Family Scale is related to but not identical to that measured in the FIATS-AAC. Indeed, closer analysis revealed that family-related factors had stronger associations with the Impact on Family Scale than child-related factors. Since the FIATS-AAC measures constructs of both child and family functioning, it is important to show empirically that the FIATS-AAC taps into both constructs.

Comparing the FIATS-AAC to other parent-report AAC outcome assessments that are focused on child functioning may reveal that the FIATS-AAC is also measuring aspects related to a child's functioning. These child-related constructs of the FIATS-AAC may account for some of the extra variance that was not captured in the analysis of the associations between the FIATS-AAC and the Impact on Family Scale.

## Chapter 3

# Construct Validity of the Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication: A Parent-Report Measure for Children with Complex Communication Needs

### 3.1 Abstract

Augmentative and alternative communication (AAC) systems have the potential to improve functioning in children with complex communication needs (CCN). However, their parents and other family members play a vital role in the successful uptake of AAC. The Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication (FIATS-AAC) is an emerging parent-report health measurement scale that detects the functional impact of an AAC system on the everyday lives of young people ages 6 to 18 years. This article examines further the construct validity of the FIATS-AAC by comparing it to two measures that evaluate HRQOL and community participation in children. This study was conducted using a novel, cross-sectional, mixed methods design. A survey was mailed to 365 parents with 47 responses received from eligible parents. Six parents also participated in face-to-face interviews to explore more deeply child and family functioning, and study the concordance of narratives with FIATS-AAC scores. Results suggest significant correlations between the FIATS-AAC and aspects of HRQOL overall and community participation at a FIATS-AAC domain level. FIATS-AAC domain scores showed fair agreement with valences assigned to interviews. The study provides emerging evidence for the construct validity of the FIATS-AAC for both clinical and research applications.

### 3.2 Introduction and study aim

In Canada alone, an estimated 80,000 children between the ages of 5 and 14 years have speech-related disabilities (Statistics Canada, 2006). Speech-related disabilities are commonly associated with developmental disabilities such as developmental delay, cerebral palsy, and autism spectrum disorders (Light & McNaughton, 2012). However, other childhood-onset

disabilities, such as acquired brain injury, may also impair speech (Murdoch & Theodoros, 2001).

A subset of children with speech-related disabilities have CCN which may be characterized as the inability to produce speech, difficulty in understanding spoken language communicated by others, and/or difficulty being understood. Children with CCN need AAC systems to improve their everyday functional communication.

AAC systems replace or augment speech, through the use of body movements, such as gestures and sign language (unaided AAC) and/or through devices that are used externally by the child such as speech-generating devices or flashcards (aided AAC). A plethora of evidence generated in the last decade illustrates the efficacy of both aided and unaided AAC interventions in a diverse population of children with CCN (Branson & Demchak, 2009; Ganz et al., 2012).

Despite evidence of AAC *efficacy*, challenges still exist in regard to understanding the *effectiveness* of evidence-based intervention strategies (Light & McNaughton, 2012). Evidence-based practice has become increasingly difficult due to the minimal work being conducted in outcomes research (Fuhrer et al., 2003; Henderson et al., 2008; McNaughton & Light, 2015). Most notably, implementing evidence-based intervention strategies has been difficult due to the lack of measurement tools available with adequate psychometric properties, that assess the functional outcomes of AAC interventions in the child's 'real world' environment (Fuhrer et al., 2003). Without well-targeted, comprehensive outcome measures, clinicians lack the tools necessary to make better informed decisions regarding AAC intervention strategies.

The selection of an appropriate outcome measurement scale may be guided by a conceptual framework that can be applied to a variety of AAC systems and/or interventions. Measurement authorities in AAC suggest that outcome measures be designed based on the ICF and its derived version for children and youth – the ICF-CY (WHO, 2007; Enderby, 2014). The ICF-CY is a multi-dimensional classification system for health and health-related outcomes (WHO, 2007). The framework takes a holistic approach to assessment by focusing on how the interactions

among a child's *body structures and functions, activity, participation, personal and environmental factors*, characterize levels of functioning and disability. In this way, the ICF-CY classifies functioning from an integrated perspective to provide researchers with a useful theoretical foundation for measuring functioning and functional outcomes.

Family-centered care is an integral part of AAC and other health services for children with disabilities (Mandak et al., 2017). In the past few decades, clinicians have taken a family-centred approach to AAC as primary caregivers ('parents') can have a strong impact on the reception, implementation, and maintenance of AAC systems (Granlund et al., 2008). Current knowledge on parent perceptions of communication is limited – only a few studies collect parent perceptions, and most approach evaluation from a qualitative perspective (Smith & Hustad, 2015).

A systematic review was conducted to identify candidate parent-report health measurement scales used to assess functional outcomes of AAC interventions in children under 18 years of age (Kron & Ryan, 2016). The review confirmed the need for a sound parent-report measurement scale that is targeted directly for children with AAC needs, detects functioning and functional change holistically, and has adequate levels of reliability and validity.

Delarosa et al. proposed a new multidimensional, needs-based, parent-report measure called the Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication (FIATS-AAC) (Delarosa et al., 2012). The FIATS-AAC is intended to measure the functional outcomes of AAC interventions in children 6-18 years of age and their families. The ICF-CY was used as a theoretical basis for item development in the FIATS-AAC. Aspects of both child- and family-related functioning are embedded within the thirteen domains of the FIATS-AAC. Family-related domains are included to measure their influence as environmental factors in the child's life.

In this way, the FIATS-AAC takes a more holistic approach to the measurement of AAC outcomes, making it suitable in the evaluation of functioning in the child's 'real-world'

environment. While the FIATS-AAC is a functional outcome measure for children with CCN that has the potential to fulfill the measurement need, no intervention studies have been published using this measure. Further evidence for the reliability and validity of the FIATS-AAC is needed to support its use in clinical and research applications.

Previous research using the FIATS-AAC provides emerging evidence of content and face validity, internal consistency, and test-retest reliability (Delarosa et al., 2012). The convergent construct validity of the FIATS-AAC was also assessed by comparing its scoring with the standardized Impact on Family Scale (Delarosa et al., 2012). The Impact on Family Scale is a parent-report measurement tool that assesses the impact of pediatric illness and disability on families (Stein & Jessop, 2003). Family-related factors of the FIATS-AAC had stronger associations with the Impact on Family Scale than child-related factors. Since the FIATS-AAC measures constructs of both child and family functioning, it is important to show empirically that the FIATS-AAC taps into both constructs.

In this paper, support for the convergent construct validity of the FIATS-AAC is sought by studying the relationships between the FIATS-AAC and other parent-report outcome measures that assess levels of community participation and HRQOL of children in general. Comparing the FIATS-AAC to these other assessments may confirm that the FIATS-AAC is measuring aspects related to child functioning. For the purposes of this study, *overall functioning* is defined according to the characterisation of functioning provided by the World Health Organization – “positive or neutral aspects of the interaction between a person’s health condition(s) and that individual’s contextual factors (environment and personal factors)” (WHO, 2001, p. 8, 10).

### 3.3 Research questions and hypotheses

The present study sought to answer the primary research question: ‘To what extent does the FIATS-AAC reflect real-world functioning in children who need AAC, aged 6 to 12 years, and their family compared to functioning as measured by two other parent-report questionnaires that focus on child participation and HRQOL?’. The study was also designed to answer a secondary research question: ‘Does the FIATS-AAC reflect real-world functioning in children who need AAC, aged 6 to 12 years, and their family compared to the functional performance descriptions reported by their parents?’

Accordingly, the objectives of the study were to: (1) assess the convergent construct validity of the FIATS-AAC when compared to the Participation and Environment Measure for Children and Youth (PEM-CY) and the Child Health Questionnaire – Parent Form 28 (CHQ-PF28), and (2) determine agreement between the functional status described by parents and functional status domain scores derived from the FIATS-AAC.

Proponents have argued that HRQOL be included as a distinct concept in a modified version of the ICF and ICF-CY models as it may interact and influence overall levels of functioning and disability in children (McDougall, Wright, & Rosenbaum, 2010). Since the FIATS-AAC is grounded in the ICF-CY, it was speculated that FIATS-AAC total and domain scores would be associated at low to moderate levels ( $.20 < r < .50$ ) with both the Physical and Psychosocial Summary Scores on the CHQ-PF28. Unlike the CHQ-PF28, the ICF-CY served as a conceptual basis for item development in the PEM-CY (Coster et al., 2011). Since the constructs of *activity* and *participation* were included in the FIATS-AAC and the PEM-CY as functional outcomes, it was hypothesized that a significant, moderate to strong, positive association ( $.50 < r < .70$ ) would be found between the PEM-CY and the FIATS-AAC.

For the second objective, it was hypothesized that there would be moderate agreement (weighted kappa = .41 – .60) (Viera & Garrett, 2005), between FIATS-AAC domain scores and researcher-assigned valence ratings for child and family functioning as described by parents. The gestalt



approach adopted for valence assignment provides rationale for hypothesizing moderate rather than strong agreement between these data sources.

In addition to these main objectives, an exploratory objective of this study was to assess the content validity of the FIATS-AAC based on parents' descriptions of the functional status of their children. The internal consistencies of the FIATS-AAC total and domain scores were also estimated as an exploratory aim.

## 3.4 Methods

This study was reviewed and approved by the Holland Bloorview Research Ethics Board and Research Ethics Office at the University of Toronto.

### 3.4.1 Study design

A novel cross-sectional mixed methods research design was employed in two phases to examine the convergent construct validity of the FIATS-AAC. Both quantitative and qualitative data were collected on the parental perspectives of child functional status within a communication context. Phase 1 (survey) was a quantitative approach that allowed for testing of specific hypotheses using statistical methods. Phase 2 (semi-structured interview) followed a novel mixed methods approach. A valence approach informed by the work of another research team (Ryan, Klejman, & Gibson, 2013), and a thematic content analysis (Braun & Clarke, 2006) allowed patterns of consistency regarding the validity of constructs to emerge.

The use of qualitative data to support the construct validity assessment of an emerging measure is an unconventional approach in measurement studies. Previous psychometric evaluation studies on assistive device outcome measures (Ryan et al., 2013; Stier, Chieu, Howell, & Ryan, 2016), provide support for the use of this approach in the present study.

### 3.4.2 Participants

A hospital-based, purposeful, sampling procedure was used to recruit parents of children who use AAC. Parents were eligible if: (a) they were the parent of a child (6-12 years old) who currently used an aided AAC system; (b) the child had at least 12 weeks of experience using their device; and (c) they did not require English translation services for clinical appointments. The electronic records department at the authors' institution prepared a list of parents whose child received AAC services within the previous 3 years. Parents self-screened for eligibility based on their child's experience using a communication device. Focusing the study on parents of school-aged children rather than across the full age range of 6 to 18 years helped to improve the uniformity of the study sample. Functional status of this age group will also be better represented by parents, as they would typically be more involved in their child's academic and social development at this stage.

### 3.4.3 Protocol

The study was conducted in two phases: survey (phase 1) and face-to-face interview (phase 2).

#### *Phase 1: Survey*

The recruitment strategy for this study followed a modified Tailored Design Method (Dillman, Smyth & Christian, 2008). An introductory letter was initially sent to 365 potential participants to notify them of the present research study and outline the responsibilities of each participant. A few days later, an informed consent form, demographic form and three questionnaires were sent as one package via mail to participants. A screening form was included at the front of the study package in order for parents to self-screen for eligibility. In the study package, a pen/stylus was also provided as a mild form of social exchange to encourage participation and to assist in the convenience of completing the questionnaires. Each parent was invited to complete three questionnaires combined into one booklet.

To accommodate the busy schedules of families, parents were requested to complete the survey package within a two-week period. Three weeks after the initial mailing, all parents received a reminder postcard. Those who returned their completed questionnaires were assumed to have

consented to being part of Phase 1. All recipients received postage paid envelopes to return their completed questionnaires and increase response rates (Dillman et al., 2008).

A brief summary of the interview component of the study was included in the consent form to provide parents with an overview of the general purpose and nature of the follow-up research interviews planned for Phase 2. Parents who completed the initial survey were asked to provide their names and contact information if interested in learning more about the interview phase of the study. Parents were advised that they may not be contacted if the target sample size was reached.

#### *Phase 2: Interview*

Parents who provided their contact information received a Phase 2 consent form by mail one week after receiving their completed survey. One week later, a researcher called parents in the order completed surveys were received, to discuss the elements of consent, answer questions, and seek verbal consent to participate in Phase 2. If parents chose to participate, the researcher negotiated an appointment time and location. The first six parents to have their verbal consent received were interviewed. Written consent was obtained at the start of the interview.

A research team member with training in interviewing techniques conducted a 1-hour face-to-face interview with the parent participant in a quiet and private meeting room at the authors' hospital. The interview took place two to four weeks after questionnaire completion to ensure that parents were not influenced by their recall of responses to questionnaire items. Further, no marked changes in the lives of children and their families were expected over this period.

### 3.4.4 Parent-report questionnaires (phase 1) and interview (phase 2)

*Phase 1.* Parents completed a demographic form designed for the study. The interview form collected descriptive information about the child who used aided AAC, including: child's age, reason for using AAC, gender, grade level, duration and setting of AAC use, AAC device access, and past AAC use. Parents also reported on their child's everyday functional communication and handling of everyday objects using two standardized classification systems: Communication

Function Classification System (CFCS) and Manual Ability Classification System (MACS) (Eliasson et al., 2006; Hidecker et al., 2011). The demographic data provided a detailed description of the study sample.

Three parent-report measures that assess aspects of functional status and levels of activity and participation, and HRQOL were used: FIATS-AAC, PEM-CY (Coster et al., 2011), and CHQ-P28 (Raat et al., 2005).

Previous studies of the measurement properties of the FIATS-AAC confirmed its content and face validity, test-retest reliability, and internal consistency for groups of children with CCN (Delarosa et al., 2012). *Chapter 2* provides further details related to the measurement properties of the FIATS-AAC. As earlier noted, the FIATS-AAC is limited in evidence suggesting that it is a measure of child-related functioning. Since child-related constructs are well represented within the PEM-CY and the CHQ-PF28, these measures were chosen as the best comparators for construct validity assessment in this study. Further, both the PEM-CY and CHQ-PF28 have adequate psychometric properties (Coster et al., 2011; Raat et al., 2005).

The PEM-CY is a standardized health measurement scale that examines levels of participation (i.e. frequency, variety, and involvement) in children with and without disabilities, age 5 to 17 years, in home, school, or community environments (Coster et al., 2011). The ‘school’ and ‘home’ portions of the PEM-CY were omitted in this study to focus on the association of the FIATS-AAC to community participation, and improve response rates by reducing the response burden. The ‘community’ portion of the PEM-CY requests parents to report on how often and how involved the child is in up to ten common community activities.

Focus groups and semi-structured interviews, with parents of children with and without disabilities, were conducted to identify important activities in which the children may participate (Bedell et al., 2011). Nine of ten community activities correspond to codes in the ICF-CY. Community activities included neighbourhood outings (e.g., shopping and going to a movie), community events (e.g., attending a play or concert), and unstructured physical activities (e.g.,

nature trail walks and bicycle riding). The reliability of the PEM-CY was evaluated using a web-based format administered to 576 caregivers of children with or without disabilities. Internal consistency and test-retest reliability estimates for participation ‘frequency’ and ‘involvement’ ranged from moderate to good for the ‘community’ portion of the PEM-CY (Coster et al., 2011).

The CHQ-PF28 is a questionnaire designed to measure HRQOL in children, 5 to 18 years, from the parent’s perspective (Raat et al., 2005). Fourteen physical and psychosocial concepts are represented in the CHQ-PF28. The physical domain represents physical functioning and includes items that cover limitations to physical/role/social activities as a result of ill health, while the psychosocial domain includes topics that cover limitations in social activities in different environments, and personal factors such as self-esteem (McCullough & Parkes, 2008). Based on responses from 234 parents of school children, the CHQ-PF28 showed acceptable levels of test-retest reliability and internal consistency (Raat et al., 2005).

Parents were asked to complete the FIATS-AAC first to reduce the effect of their responses on the comparative measures. The CHQ-PF28 was placed second since it was expected that there would be less conceptual overlap with the FIATS-AAC. Finally, parents filled out the ‘community’ portion of the PEM-CY to limit the effect of rating recall from the FIATS-AAC.

*Phase 2.* Semi-structured interviews explored child and family functioning from a subset of six parents who completed the questionnaires in phase 1. The purpose of phase 2 was to provide additional evidence for the construct validity of the FIATS-AAC. Semi-structured interviews with parent participants were conducted 2 – 4 weeks after questionnaire completion to mitigate the effects that changes in the lives of parents would have on the concordance of the valence ratings. All parents interviewed were unaware of their FIATS-AAC domain scores.

The ICF-CY framework served as a theoretical foundation for the development of the semi-structured interview guide (Appendix D). Each domain of the FIATS-AAC (i.e. a question for each domain) was represented within the guide to allow for the exploration of parents’ views of both child and family functioning. Parents were also questioned on whether they believed any

changes had occurred in their family life since their completion of the FIATS-AAC. Also probed were the personal and contextual factors that may facilitate or hinder the child's overall functioning as it relates to everyday communication.

### 3.4.5 Data analysis

*Objective 1: To assess the convergent construct validity of the FIATS-AAC when compared to the Participation and Environment Measure for Children and Youth (PEM-CY) and the Child Health Questionnaire – Parent Form 28 (CHQ-PF28).*

*Phase 1.* IBM SPSS Statistics 19 Software was used to conduct all statistical analyses for Phase 1. Descriptive statistics for the total scores of each questionnaire and the FIATS-AAC domain scores were calculated to allow for the comparisons of score distributions between the present study sample and those from previous research. Scores on parent-report measurement scales were plotted using visual mapping (scatterplots). Individual functional levels on the FIATS-AAC were compared to those levels reported elsewhere for the FIATS-AAC, PEM-CY and CHQ-PF28 total scores.

To address this objective, PEM-CY and CHQ-PF28 total scores, and FIATS-AAC total and domain scores were used. Interpretation for associations followed the guidelines put forth by Cohen (1988).

Total scores for the PEM-CY included the 'average frequency' and 'average involvement' scores, which represent how often and how involved a child was in up to ten common community activities.

Physical and Psychosocial Summary Scores were calculated for the CHQ-PF28. Cronbach's alpha was calculated for FIATS-AAC total and domain scores to assess the inter-relationships among domains for the total score and items for the domain scores. Appendix E contains the SPSS syntax and variable labels for the calculation of correlational levels between the

questionnaires. The syntax for scoring each questionnaire was checked by another researcher (SR) to ensure accuracy.

If the data exhibited non-normal distributions, such as severe skewness and kurtosis, parametric correlations (Pearson's correlations) were replaced with non-parametric correlations (Spearman's rank correlations). A p-value of less than .05 was assumed as a significant association for this study. Although multiple comparisons were performed, the p-value was not adjusted to allow evidence for the construct validity of the FIATS-AAC to emerge.

Exploratory analyses were also conducted for correlations among the FIATS-AAC domain scores and the PEM-CY and CHQ-PF28 total scores for future research directions. A p-value of less than .05 provided preliminary support for the construct validity of a FIATS-AAC domain.

*Objective 2: To determine how the functional status described by parents reflects functional status domain scores on the FIATS-AAC.*

*Phase 2.* The graduate student researcher of the study (AK) manually transcribed audio recordings of the face-to-face interview verbatim and another researcher (SR) reviewed the transcriptions for accuracy. A valence approach was used to evaluate the concordance between parents' FIATS-AAC domain scores and researcher-assigned valence ratings (Ryan et al. 2013) (Figure 3). Coding for this process followed a deductive approach, as passages were assigned to FIATS-AAC domains defined a priori (Braun & Clarke, 2006).

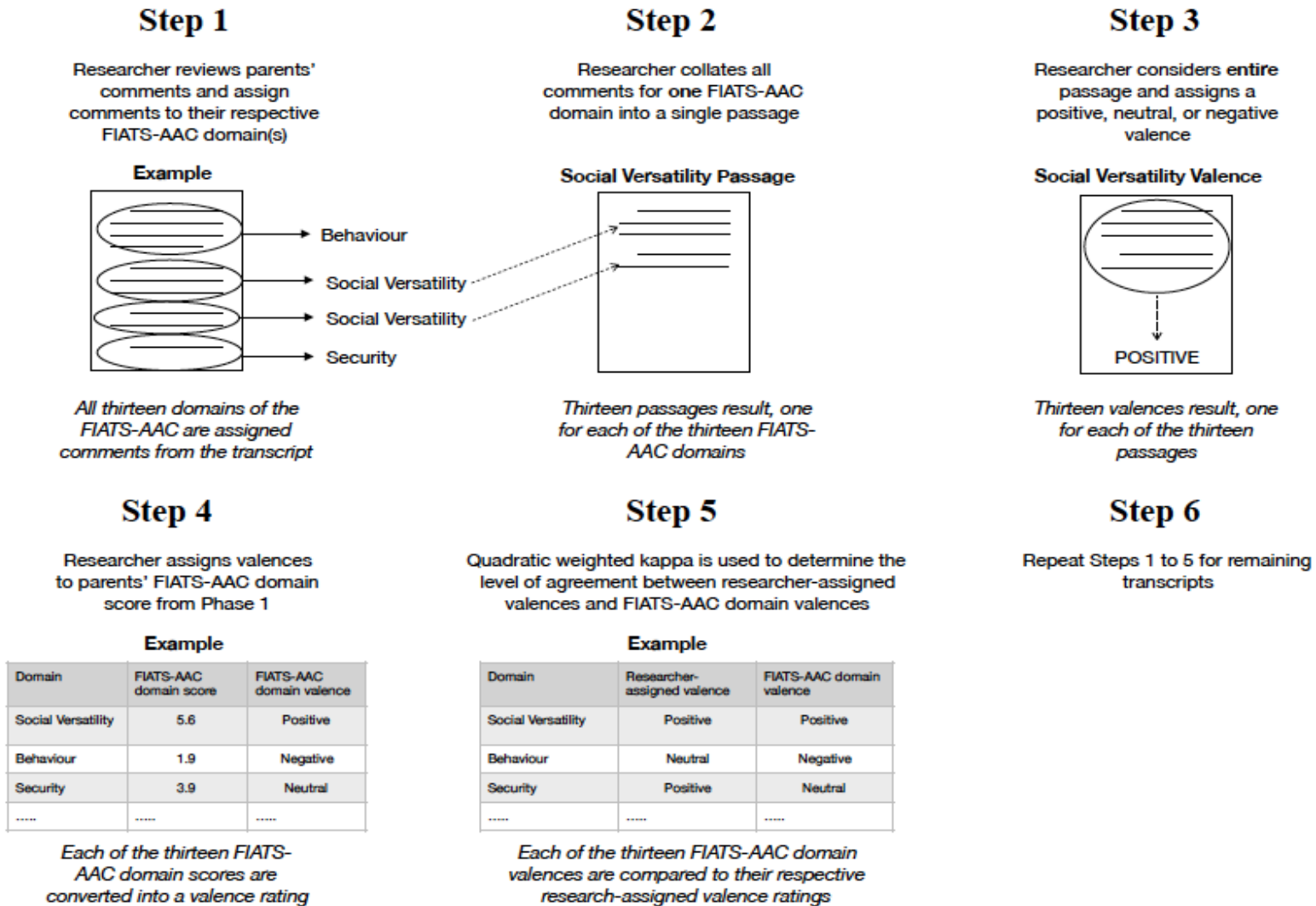
Two authors (AK and SR) blinded to the FIATS-AAC domain scores independently analyzed the first two transcripts to assign parents' comments to their respective FIATS-AAC domains. Each transcript was printed and parents' comments were highlighted based on the FIATS-AAC domain they corresponded to. The researchers then met to confirm agreement between their assignments. Each comment that corresponded to a particular domain on the FIATS-AAC was then combined to form a single passage. For each transcript, thirteen passages resulted – one passage per FIATS-AAC domain. The same two authors then independently reviewed and

assigned valence ratings for each passage. One valence was assigned to each passage, resulting in thirteen researcher-assigned valence ratings per transcript. The two researchers met subsequently to review and resolve differences in the valence assignments. Following the researchers' agreement on the method for identifying domain passages and assigning valence ratings, one author (AK) analyzed the remaining four transcripts.

A 3-point ordinal scale of 'negative', 'neutral', and 'positive' was used to assign a valence rating informed by the parent's narrative in each domain. The labels of 'negative', 'neutral', and 'positive' were assigned to maintain consistency with the valence labels used in earlier studies using a similar approach (Ryan et al., 2013; Stier et al., 2016). The labels of 'negative' and 'positive' are not indicative of whether the child has poor/excellent level of functioning for a specific domain. Instead, the 'negative', 'neutral', and 'positive' valences are gestalt levels based on the apparent tone of passages for a particular domain. For example, if a passage provided an overall sense that the parent would likely agree to items consistent with higher overall functioning for a FIATS-AAC domain, a 'positive' valence was assigned. If passages seemed to reflect a parent who would neither agree nor disagree with the items for a FIATS-AAC domain, a 'neutral' valence was assigned. Passages that reflected a general disagreement with items for a domain were assigned a 'negative' valence.



Figure 3. Process used to code, combine, and assign valence levels to transcript passages



To allow comparison of agreement between researcher-assigned valences and parents' ratings in the FIATS-AAC questionnaire, parents' scores for each domain on the FIATS-AAC completed in Phase 1, were converted to one of the three ordinal categories above. Domain scores from 1-2.9, 3-4.9, and 5-7 were assigned to 'negative', 'neutral', and 'positive' categories, respectively. Quadratic-weighted kappa statistics (Viera & Garrett, 2005) were calculated to determine the concordance between researcher-assigned valence ratings and the valence-converted domain scores of the FIATS-AAC for the group of six interviewees.

As part of an exploratory analysis, a collective case study design guided an inductive thematic content analysis of semi-structured interviews to identify domains beyond those included in the FIATS-AAC (Braun & Clarke, 2006; Yin, 2008). Two researchers (AK and SR) independently coded and analyzed the first two transcripts, making note of new, emerging constructs not represented in the thirteen domains of the FIATS-AAC. Coding occurred on hard copy transcripts using colored markers to organize emerging themes. The two researchers met to compare coding and resolve any differences by consensus. Following agreement on the coding approach, one researcher (AK) coded the remaining four interview transcripts. A reflexive journal tracked the thematic interpretation of the interviews.

### 3.4.6 Sample size considerations

*Phase 1.* A sample size of 30 parents provided sufficient power to detect a significant correlation of  $r = 0.5$  ( $\alpha = .05$ , power = 80%) between the FIATS-AAC, and PEM-CY and CHQ-PF28 measures. This sample size was also adequate for evaluating the convergent construct validity in an earlier FIATS-AAC study (Delarosa et al., 2012).

*Phase 2.* The primary goal of this phase was to use a novel mixed methods approach to provide emerging evidence for the construct validity of the FIATS-AAC. Six participants were interviewed as this is recommended as an adequate sample size for a collective case study (Yin, 2008). A sample size of six is also comparable to earlier studies that used a similar mixed methods approach to assess validity (Ryan et al., 2013; Stier et al., 2016)

## 3.5 Results

*Phase 1.* Three-hundred and sixty-five packages were mailed to potential participants. After receiving 13 unopened return-to-sender packages, it was assumed that 352 packages were received by parents of children who received AAC services from the authors' institution. Forty-nine parents returned the questionnaires by mail and 47 met the inclusion criteria and completed the survey (13% response rate). Most respondents who completed the surveys were reportedly the mothers of children with CCN, and most children were male (Table 1).

Developmental delay and autism spectrum disorder were the most commonly-reported diagnoses. Other diagnoses included cerebral palsy, acquired brain injury, and motor speech disorder. Approximately thirty percent of respondents reported their child to have more than one diagnosis. Consistent with the inclusion criteria, the most common AAC devices used by the children were picture/letter boards and electronic speech devices, including standard personal computers/tablets and/or single message devices.

Approximately 50% of the children did not have much difficulty handling everyday objects as indicated by the MACS. In some cases, most objects could be handled successfully, but with reduced accuracy and speed. Children were in the lower end of overall communicative performance as indicated by the CFCS, with about 80% being unable to effectively send and receive messages with familiar and unfamiliar partners in a timely manner.

Table 1. Participant and child characteristics

Characteristic	Number of participants	%
Child Sex		
Male	29	61.7
Female	18	38.3
Child age (y)	<i>M</i> = 8.9 <i>SD</i> = 2.0 Range = 6 - 12	—
Child education		
Kindergarten	2	4.3
Grade school	45	95.7
Relationship to child		
Mother	41	87.2
Father	5	10.6
Guardian	1	2.1
Duration of AAC use		
< 1 year	14	29.8
> 1 year	33	70.2
Commencement of AAC use		
< 5 years of age	25	53.2
> 5 years of age	22	46.8
Aided AAC device access		
Touch only	34	72.3
Eye gaze only	5	10.6
Touch and eye gaze	3	6.4
Other	5	10.6
MACS level		
I	8	17.0
II	14	29.8
III	2	4.3
IV	12	25.5
V	8	17.0
CFCS level		
I	4	8.5
II	6	12.8
III	10	21.3
IV	19	40.4
V	2	4.3

FIATS-AAC total scores can range from 13 to 91, with higher scores indicating greater overall functioning with respect to communication. The mean FIATS-AAC total score was 50.6 ( $SD = 9.1$ , minimum = 30.3, and maximum = 75.5). The internal consistency of the FIATS-AAC total score was .88 as measured by Cronbach's alpha. Descriptive statistics and alpha values for the thirteen domains of the FIATS-AAC are presented in Appendix F.

'Average frequency' values on the PEM-CY may vary from 1-7 and illustrate how often, on average, a child participates in activities that they are involved in. Higher scores indicate greater frequency, while lower scores indicate lesser frequency. On average, children in the present study had an 'average frequency' score of 3.8 ( $SD = 1.0$ ), meaning that participation in selected community activities was typically a 'few times a month'. In the community setting, children participated in an average of six out of the ten community activities. 'Average involvement' scores on the PEM-CY tell how engaged a child is in the selected activities. Scores vary from '1 = minimally involved' to '5 = very involved', with higher scores meaning greater involvement in activities. Children in the study sample were somewhat involved in the selected activities on average ( $M = 3.0$ ,  $SD = 1.0$ ).

Based on the scoring instructions in the CHQ-PF28 scoring manual, the Physical and Psychosocial Summary Scores were calculated using factor weights from a US representative sample of children, with higher values indicating higher life quality. Means for the Physical Summary Score and Psychosocial Summary Score were 39.5 ( $SD = 19.9$ ) and 40.7 ( $SD = 11.7$ ), respectively. Appendix G and H provides histograms for the total scores of each questionnaire and scatterplots for the correlation levels between the questionnaires, respectively. Table 2 shows the FIATS-AAC total and domain correlations with the PEM-CY and CHQ-PF28. Since the data from all comparative measures generally followed a normal distribution, parametric analyses (Pearson's  $r$ ) were used to estimate the strength and direction of each correlation.

Table 2. FIATS-AAC total and domain correlations with PEM-CY and CHQ-PF28

Total/Domain	Pearson Coefficient ( <i>r</i> )			
	<u>PEM-CY</u> Average Frequency	<u>PEM-CY</u> Average Involvement	<u>CHQ-PF28</u> Physical Summary Score	<u>CHQ-PF28</u> Psychosocial Summary Score
Total FIATS-AAC	<b>.29</b>	<b>.30</b>	<b>.31*</b>	<b>.54**</b>
Behaviour	.03	<b>.37*</b>	-.27	<b>.59**</b>
Caregiver relief	.23	.18	<b>.37*</b>	<b>.40**</b>
Contentment	.22	.24	<b>.35*</b>	<b>.44**</b>
Doing activities	.19	.21	.27	.11
Education	.11	<b>.32*</b>	-.07	<b>.58**</b>
Energy	.19	.04	<b>.45**</b>	<b>.34*</b>
Face-to-face communication	.20	.15	-.03	<b>.44**</b>
Family roles	.27	.10	.29	.07
Finances	.11	.13	.15	<b>.36*</b>
Security	<b>.35*</b>	.11	.18	.30
Self-reliance	<b>.40**</b>	.16	<b>.43**</b>	.10
Social versatility	.13	<b>.33*</b>	-.20	<b>.34*</b>
Supervision	.15	.26	<b>.51**</b>	.29

\*Correlation is significant at  $p < .05$ .

\*\*Correlation is significant at  $p < .01$ .

Low, non-significant associations ( $.29 < r < .30$ ) at a level of  $p > .05$  were found between the FIATS-AAC total score and the community participation levels of the PEM-CY (Objective 1). Exploratory analyses of domain correlations revealed moderate, significant correlations ( $.32 < r < .40, p < .05$ ) between five domains of the FIATS-AAC (self-reliance, behavior, education, social versatility, and security) and the how often/how involved scales of the PEM-CY.

Low-to-moderate, significant associations ( $.31 < r < .54, p < .05$ ) were found between the FIATS-AAC total score and CHQ-PF28 Summary Scores (Objective 1). Ten FIATS-AAC domain scores showed low-to-moderate, significant correlations ( $.34 < r < .59, p < .05$ ) with both CHQ-PF28 Summary Scores.

*Phase 2.* Six parents who completed the FIATS-AAC and other measures also participated in semi-structured interviews. Descriptive information for each of the families who participated is presented in Table 4. The children of the parents ranged in age from 6 – 11 years. Four children were male and all were in grade school. Overall, the FIATS-AAC total scores for each parent related well to the overall tone estimated from the researcher-assigned valence ratings. Those with lower FIATS-AAC scores had more negative researcher-assigned valence ratings, while those with higher FIATS-AAC scores had more positive researcher-assigned valence ratings. Each parent answered domain-related questions posed by the researcher generally following an interview guide developed for the study (Appendix D).

Table 3. Descriptive information of six interviewed families

<b>Interviewed parent</b>	<b>Age</b>	<b>Sex</b>	<b>Grade level</b>	<b>Diagnosis</b>	<b>AAC device used</b>	<b>MACS level</b>	<b>CFCS level</b>	<b>FIATS-AAC total score</b>	<b>Overall tone of interviews</b>
1	6	Male	1	Autism spectrum disorder	Picture Exchange Communication System	4	4	30.5	Negative
2	9	Male	4	Acquired brain injury	VOCA-Accent 800	4	1	55.7	Positive
3	11	Male	6	Developmental delay	Picture book	2	4	57.8	Positive
4	7	Female	1	Cerebral palsy	Picture book, iPad	2	4	57.7	Negative
5	8	Female	3	Developmental delay, motor speech disorder	Tablet Vantage	2	3	49.8	Negative
6	9	Male	4	Developmental delay	Picture board	1	3	43.2	Negative



Parents' comments were organized into passages based on content that related to each of the domains for the FIATS-AAC. Definitions of each domain and items within each domain helped guide the assignment of parents' comments into each respective domain. 'Positive', 'neutral', or 'negative' valences were assigned to the thirteen FIATS-AAC domains for each of the six transcripts. Appendix I provides the domain scores and researcher-assigned valence ratings for each of the six interviews. Overall, the valence ratings suggested more of a 'negative' tendency (Appendix J). Out of the 78 researcher-assigned valence ratings, 22 were positive, 13 were neutral, and 43 were negative.

Quadratic weighted quadratic kappa was .39, 95% CI [.22, .56] between the parents' responses and the researcher's valence ratings (Objective 2). Table 4 provides examples of responses by each parent and the assigned valence ratings by the researcher.

Table 4. Examples of parent ratings, selected passages, and researcher-assigned valence ratings

FIATS-AAC Domain	Definition	Domain score	Selected passage	Researcher's valence rating
<b>Education</b>	Degree to which the child is succeeding in school	1.0 (Negative)	<p>Comment 1: "So in terms of school and communication, [my child] finds it really difficult to communicate with teachers, because there is no specific training at school. So, you are going to an EA, you are trying to exchange with an EA and they are not able to exchange back or they have their own idea of what that communication system should look like or what the process is..."</p> <p>Comment 2: "I think [my child] enjoys the socialization piece. So when he goes into his classroom in the morning, he exchanges the HI icon with his friends at school and they are able to come up to him and greet him and he really really likes that aspect because it's like, you know a give and a take right?..."</p> <p>Comment 3: "So [the teacher is] old school, [he] will not communicate with her. He will just communicate with me when I'm in the room, and so you kind of have to push him to sort of communicate with her and it's just very, very cut and dry with him... and with me it's more like building the sentences and adding the descriptions, but with [the teacher], no..."[P1]</p>	Negative
<b>Finances</b>	Degree to which the family is free from financial stress	4.2 (Neutral)	<p>Comment 1: "Yah. We are still working on the speech therapy because I do want him to have that...I don't want him to lose words and the speech that he's mastered up to this point..."</p> <p>Comment 2: "Buy a little bit more toner maybe for the printer [laughs], but certainly in the big perspective [finances are] not [a concern]..."</p>	Positive*

<b>Security</b>	Degree to which the parent is free from worry about the child's safety	4.1 (Neutral)	<p>Comment 1: "...We put her into preschool before [school name] because we knew she needed to be out with other kids and she was doing speech therapy at that point and didn't have a communication book and had very rudimentary sign language. And we believed that she was being bullied in the classroom but we couldn't find out...and we'd always not had just any babysitter because we were concerned and we had a couple people say that their daughter would babysit and we just can't bring ourselves because we are concerned if something happened how could [she] tell us?..."</p> <p>Comment 2: "Well if she got abused...she's wouldn't be able to communicate. You know...when we've got her out in public with us I mean...I am just beside myself because I always think if she gets lost how is she going to tell anybody who she is or where she is. So yes, I am I am much more stressed out and because of that don't take her out as much. Or when she is out I make her hold my hand all the time..."</p> <p>Comment 3: "So she is with my son, her uncle, my son...when she is with my son I am not worried because he is super diligent he is trained...trained child and youth worker. He...you know...is more cautious than I am and he is tall big guy so you know [laughs]..." [P4]</p>	Negative*
<b>Contentment</b>	Degree to which the child is content during the day	4.3 (Neutral)	<p>Comment 1: "She is happy, she is a really happy kid..."</p> <p>Comment 2: "I think she is pretty happy and content as long as it's with her routine she's good. If anything changes she is not good...She is always smiling, she is always...if you ask her she will say 'yes, she's happy' or 'no, she's not'. She's...and I mean you can tell. She doesn't go through retching vomiting behavioural thing [laughs]. It's very clear when she is unhappy...if she is comfortable with people,</p>	Neutral

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familiar people she is good. If she is unfamiliar with them, then not so good [laughs]...”

Comment 3: “It took her a while to get into the routine and I don’t know what happened at the end of last year, it’s still a little bit of a mystery to her teachers and to us but this year she started off well, she looks forward to going to school, she was upset that yesterday was a PA day [laughs] because again that’s a disruption, that disrupts her routine so yes, she’s happy and her teachers all describe her as being extremely happy and smiley...”[P5]

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\*Research-assigned valence rating did not agree with parents’ FIATS-AAC domain score

A thematic content analysis of interview transcripts was performed to explore whether new domains emerged that may add to the dimensionality of the FIATS-AAC. Any comments made from parents that reflected information not captured within the thirteen dimensions of the FIATS-AAC were highlighted for further exploration. Through exploring parents' comments, insight was also gained into the contextual factors (i.e. barriers and facilitators) associated with the implementation of an AAC device and/or system on the child and family. The findings revealed two new domains that may influence the successful use of AAC devices within a 'real-world' environment: (a) communication partner adaptiveness, and (b) device practicality.

'Communication partner adaptiveness' reflects parents' descriptions of the features of the communication partner that influence communication interactions with the child who needs AAC. Most parents suggested that communication partners within the home, school, and community lacked training related to the use of the aided AAC device. For example, special educators and instructors in the community did not know how to use the device and successfully communicate with the child. One parent [P1] said, "In school is the exact same thing, we are finding a really hard time getting the support we need even from a special education standpoint, there is not enough protocols or resources in place to actually get the training that the teachers and the students need in order to exchange."

A few parents expressed concern that finding an alternate caregiver was difficult as many were not familiar with how to use aided AAC to communicate with the child. One parent [P4] noted: "And that's the other thing we can't just pick a babysitter...our son will come and babysit for us so we can go out and you know [her] mom, [her] great grandmother, she loves being with her but, she finds it difficult because she can't just talk to her." A few parents reported that communication partner training would support smoother communication interactions with their child.

Parents also noted that personal attributes of the communication partner contributed to productive interactions. For example, parents expressed the importance of the communication partner to be present within the context of the interaction, have the willingness, openness, and

receptiveness to communicate with the child, as well as have patience to allow the child to process and respond during a conversation. One participant [P4] expressed it this way: “She needs assistance because people tend to talk too quickly so it doesn’t give her a chance to process and then if she has a question it is really hard for her to get out and people are already moved on to step number 5...the communication partner has to be someone who is patient and willing to listen and willing to kind of think through what she is saying.”

The theme of ‘device practicality’ refers to aspects of the device that parents suggested as having an impact on the successful uptake of the AAC device by the child. Device maintenance was a topic that concerned most parents who were interviewed. For example, if the child used a picture book, the contents needed to be constantly updated so that child would have access to words and photos specific to a context. A mother [P3] illustrated this by saying: “...and of course the book has to be updated. There [are] new activities, new people in his life so, then there is that time of us, oh adding in pictures and sometimes we don’t have a picture for what he wants to say and then you are just stuck.”

Parents indicated that physical features of the device made it difficult for child to have access to the device across settings. The inability to use the device during physical community activities, since the device was not waterproof, was a concern that resonated with most parents. A parent [P3] noted: “Some other activities probably are more physical activities. So he does soccer, he’s doing skating, so...[communication] books [are] usually in the bag so it’s probably not particularly helpful when he is on the ice or he’s done swimming in the past...”

Parents also noted that devices were often too heavy and difficult to maneuver. These physical limitations made it difficult for their children to have ready access to the device when a communication opportunity arose. “The biggest drawback is that she can’t carry it around all the time because it is so heavy” [P5].

The low volume of speech generated by commercial AAC devices was another frustration expressed by many parents. This feature added to the difficulties concerning access to the device

across different environments. One parent described that connecting a device to Bluetooth speakers in school or during a social event allowed the child to be heard. Half of the parents conveyed that their child was often limited by the pictures and/or vocabulary of their device. For example, children were unable to communicate abstract concepts and add expressiveness to their statements. As one parent [P3] stated: “So there are the limitations of there is only the vocabulary that we have picked for the book so there are sometimes limitations...but I think that verbal communication whenever it is feasible, is so much more...I don’t know. It’s got so many more levels to it. You don’t have to look for the book, you are not limited by the pictures that are in the book, it’s just limitless once you have that speech.” Future research can focus on updating aided AAC devices to include vocabulary that allows children to engage in higher-order communication.

### 3.6 Discussion

This is the second study to examine the construct validity of the FIATS-AAC. Earlier validity evidence provides support for associations between the FIATS-AAC and communicative functioning within a familial context (Delarosa et al., 2012). Since aspects of both child and family functioning are encompassed by the domains of the FIATS-AAC, it is important to evaluate whether the measure taps into communicative participation specific to the child.

*Phase 1.* The mean FIATS-AAC total score for this present study sample was 50.6 ( $SD = 9.1$ ) which is nearly identical to the mean reported in a previous survey of 135 parents (Delarosa et al., 2012). The previous study also reported a high Cronbach’s alpha (.91) for the FIATS-AAC total score which compares well to the alpha calculated in this present study (.88). Both estimates exceed the recommended alpha of .7 for homogeneous scales (Streiner & Norman, 2008).

However, doing activities, contentment, family roles, security, and social versatility were five FIATS-AAC domains that fell below the recommended alpha threshold of .7 in this study. In a previous study, contentment and family roles were the only domains with alpha values less than the .7 but above .65 (Delarosa et al., 2012). Low inter-item correlations and large standard errors due to the smaller sample size may help explain the lower internal consistencies in the present study. This suggests that the internal consistencies of these scales may require further study.

While it was hypothesized that higher FIATS-AAC total scores would be moderately associated with greater involvement in a variety of community activities, the FIATS-AAC total score relationship with participation in community activities was low, and not significant. Different operationalization's of the concept of *participation* in the two measures may help to explain the smaller than expected levels of association. In developing the conceptual basis of the PEM-CY, the authors define *participation* as 'how often' a child is involved and 'how involved' a child is in common activities in different environments (Coster et al., 2011). For example, a child may participate in neighborhood outings (e.g. shopping at the store/mall, going to a movie, eating out a restaurant, visiting the local library/bookstore) a few times a month and be somewhat involved in this activity. The FIATS-AAC total score is composed of several health domains that measure aspects of *activity and participation*, and *contextual factors* (personal and environmental) that can influence functioning. Therefore, compared to the PEM-CY, it measures different aspects of a child's involvement in life situations. For example, the domains of 'doing activities', 'self-reliance', and 'social versatility' evaluate whether the child has control in their activities, performs activities independently, and interacts with others, respectively.

In a planned secondary analysis, individual domain correlations between the PEM-CY and FIATS-AAC were explored. The individual domains of interest were the thirteen domains of the FIATS-AAC, five of which map directly onto the *activity and participation* domain of the ICF-CY – face-to-face communication, doing activities, education, self-reliance, and social versatility. Four of the five significant domain correlations were child-related constructs of the FIATS-AAC. This suggests that child-related rather than family-related factors of the FIATS-AAC are more closely linked to community participation as measured by the PEM-CY. The domain associations provide emerging evidence for the FIATS-AAC as a measure associated with community participation when only child-related constructs of the measure are considered.

Significant, positive, moderate associations were found between the FIATS-AAC total score and the two CHQ-PF28 Summary Scores. In other words, higher levels of child and family functioning on the FIATS-AAC were linked with better HRQOL of the child as measured by the CHQ-PF28. While the significant associations between the FIATS-AAC total score and CHQ-



PF28 Summary Scores suggests that the FIATS-AAC is tapping into constructs related to HRQOL, it is important to note that only 10% and 29% of the variance ( $R^2$ ) was explained by the physical and psychosocial constructs, respectively. Therefore there is 90% and 71% of variance that is unexplained by the physical and psychosocial constructs, respectively. Further validation work is needed to account for this large amount of unexplained variance.

Considering the Physical Summary Score within the context of the ICF-CY, the limitations that the child may endure across physical and/or social activities as a result of their health would relate closely to the *body structures and functions* domain of the ICF-CY. Since the domains of the FIATS-AAC do not map directly onto this ICF-CY domain, this may help to explain why the Psychosocial Summary Score was more strongly associated with the FIATS-AAC total scores. The Psychosocial Summary Score considers limitation in *activity* and *participation*, as well as *personal factors* such as self-esteem. On the whole, these ICF-CY domains may influence the child's overall functioning. The FIATS-AAC is grounded in the *activity*, *participation*, and *contextual factors* domains of the ICF-CY. Future validity studies can be conducted using multivariate analyses to explore the contributory influence of other related constructs including family functioning.

According to the exploratory analysis of domain correlations, six of the significant domain correlations between the FIATS-AAC and the CHQ-PF28 are child-related constructs of the FIATS-AAC, and four are family-related constructs of the FIATS-AAC. Future research could consider combining the domain scores of the FIATS-AAC to provide child- and family-related composite scores rather than a single FIATS-AAC total score. The two composite scores may provide researchers with new interpretations of the FIATS-AAC scores that may not be realized if only the FIATS-AAC total score is considered.

'Average frequency' scores for the PEM-CY were derived by calculating the mean frequencies of selected community activities. Interestingly, the mean frequency score for children in this study was the same as the value calculated in a previous study that involved 576 parents of children with a disability from Canada and the US (Coster et al., 2011). In this larger sample,

children participated in approximately 60% of the community activities - the same proportion reported by parents in the present study. This finding implies that the study samples were similar in overall participation levels as measured by this dimension of the PEM-CY.

‘Average involvement’ scores of the PEM-CY were calculated by obtaining the means of the child’s involvement ratings for the activities selected in the community setting. Children from the previous PEM-CY study were involved in community activities at a level that was comparable to the involvement of children in the present study (Coster et al., 2011). Since the comparative data correspond to a sample that was not population-based, conclusions cannot be made about the representativeness of participation levels found in the present study.

For the CHQ-PF28, two summary scores were of interest. Each score was calculated and transformed using norm-based scoring methods with a mean of 50 and standard deviation of 10. The two summary scores can be compared to preliminary norms of the CHQ-PF28 based on a representative US population sample. Preliminary means and standard deviations from this representative sample were 53.2 ( $SD = 9.5$ ) for the Physical Summary Score, and 51.1 ( $SD = 9.6$ ) for the Psychosocial Summary Score. The present study sample was greater than one standard deviation below the normed sample for both the Physical Summary Score ( $M = 39.5$ ) and the Psychosocial Summary Score ( $M = 40.7$ ) (Raat et al., 2005). These lower scores were expected as the normative sample included children with and without disabilities. Several variables such as the child’s age, gender, and health status may account for the lower scores found in the present study.

*Phase 2.* According to interpretation guidelines (Viera & Garrett, 2005), the kappa value of 0.39 indicated fair agreement between the valence ratings assigned by the researcher and the valence ratings corresponding to FIATS-AAC domain scores. The fair level of agreement estimated here refutes the original hypothesis of moderate agreement between the paired ratings.

A few sources of error may have accounted for this lower than hypothesized kappa value for chance-adjusted agreement. Firstly, valence categories derived from the FIATS-AAC domain

ratings were ordinal, but assumed to be equally distributed. Categories with non-linear distances would result in a different kappa statistic. Unequal distances between categories may be considered in other validity studies that employ this novel mixed methods approach.

Secondly, it is likely that subjectivity influenced the gestalt assignment of valences. Comments relevant to a particular FIATS-AAC domain were collated into a passage, and the content of the entire passage for each domain was considered before a valence was assigned. Some comments within a passage may have had a greater influence than other comments which would impact the rating level assigned. Although consensus on valence assignment was reached for the first two coded transcripts, the final four transcripts were only coded by only one author (AK). This may have affected the overall level of agreement found across all interviews.

Lastly, since the interviews were conducted between 2-4 weeks after the questionnaires were completed, it is possible that the child's functioning may have changed since the parent completed the Phase 1 questionnaires. As a result, researcher assignments of valences may have differed from the questionnaire ratings. Despite these considerations, the fair level of agreement between the FIATS-AAC domain scores and functional status descriptions reported by parents provides additional evidence for the FIATS-AAC as a valid measure of functional status for children with CCN.

The two new themes that emerged from the exploratory study – communication partner adaptiveness and device practicality – map onto the *environmental factors* domain of the ICF-CY. The attributes of the communication partner and the physical aspects of the device encompass the social and physical aspects of the environment that may impact functional performance.

With regard to the theme of 'communication partner adaptiveness', the child's ability to be understood well by others is partially captured within the 'energy', 'family roles', and 'self-reliance' domains of the FIATS-AAC. The following items correspond to the 'energy', 'family roles', and 'self-reliance' domains, respectively: 'My child needs a lot of help to be understood';

‘Everyone in my family knows how to communicate with my child’; and ‘Other people understand my child’. Ratings assigned to each item would likely be impacted by the level of communication partner training by individuals who interact with the child, and their willingness to be patient and receptive to the child during communicative interactions. The conceptual overlap between the emerging theme of ‘communication partner adaptiveness’ and the domains within the FIATS-AAC suggests that inclusion of ‘communication partner adaptiveness’ as a new, separate domain within the FIATS-AAC would likely add little information.

Although the physical aspects of the device encompassed within the theme of ‘device practicality’ may influence the outcomes of an AAC intervention, this may not be applicable for children with CCN. That is, parents would be unable to respond to items related to ‘device practicality’ if the child was not using an AAC device at the time of measurement administration.

Overall, the two domains that emerged from the content analysis seem to be of limited measurement value when both the existing domains and utility of the FIATS-AAC are considered.

The results presented provide emerging evidence of the construct validity of the FIATS-AAC. Phase 1 results suggest that the FIATS-AAC measures constructs related to community participation and HRQOL. Phase 2 results suggest that the FIATS-AAC measures levels of child and family functioning fairly similar to those reported by parents during face-to-face interviews. However, the FIATS-AAC does not capture functional ‘depth’ in the way that the parent narratives do. Phase 2 results also confirm that the FIATS-AAC has adequate content validity as reported in an earlier study (Delarosa et al., 2012). To say with certainty that the FIATS-AAC has *strong* evidence of construct validity, the associations between both measures should be evaluated using a larger sample size to allow for potentially other significant associations to emerge. This study could also be repeated using different community participation and HRQOL measures to determine whether the hypothesized levels of association would be achieved. Using additional measures in future research will provide more evidence of the FIATS-AAC as a valid measure that taps into aspects of HRQOL and community participation.

### 3.7 Limitations

There are several limitations of this study. Firstly, since participants were recruited from a hospital-based sample, the findings reported here may not generalize to all children with communication needs. Further, only parents of children who were 6-12 years of age were included in the sample. Further research should also be done to study the construct validity of the FIATS-AAC for both older children (up to 18 years of age) and younger children (3 to 5 year olds) to broaden its utility for research and clinical applications.

The response rate in this study (13%) was low, although the number of responses received still allowed for the study objectives to be met. The sampling pool included parents who were ineligible to participate, so the actual response rate for eligible parents was higher than reported. For example, parents may have been ineligible if their child was not currently using their device and/or the device was only used for reading and writing rather than face-to-face communication. Assessing the proportion of eligible families and their reasons for non-participation was not possible, as the survey was anonymous. This may have affected the external validity of the findings, although the mean scores and the distributions for the three measures administered were comparable to those found in previous research.

Acknowledging different perspectives also highlights the importance of gathering responses from more than one caregiver (i.e. mother and father). However, since the present study used only parent-report questionnaires, one would expect any response bias would be systematic across all measures. In other words, the impact of only receiving parent responses should not impact the validity of the results as the associations found between the questionnaires would not be affected. Mothers of children with AAC needs formed the largest proportion of caregivers who responded. Hence, support for the validity of the FIATS-AAC may not generalize to all caregivers. It is recommended that the perspectives of other caregivers be sought in future validity studies.

Lastly, questionnaires were administered as a single booklet in the same order for consistency. The questionnaires were organized this way since it was hypothesized that the constructs

measured in the PEM-CY and FIATS-AAC would show stronger associations with one another relative to associations between the FIATS-AAC and CHQ-PF28. Placing the CHQ-PF28 in the middle of the survey package was expected to mitigate any effects that responses to the FIATS-AAC would have on subsequent questionnaires. However, this research design choice may have resulted in order effects.

### 3.8 Conclusions

This study demonstrates adequate construct validity of the FIATS-AAC as a measure associated with child-related community participation and HRQOL. The mixed methods approach used in this study provided additional evidence for the construct validity of the FIATS-AAC as a functional status measure for children with communication needs. The content validity of the FIATS-AAC was also adequately supported through the exploratory analysis of parent interviews.

Evaluating the validity of the FIATS-AAC as a measure of ‘real-world’ functioning of children with AAC needs is important if clinicians are to integrate this new tool into their clinical practices. Additional psychometric studies using the FIATS-AAC should be conducted to strengthen evidence of the validity of the FIATS-AAC as a measure of functioning, participation, and HRQOL for children of all ages with communication needs. Access to parent-report measures that reliably detect functional outcomes will assist clinicians in making shared and evidence-informed decisions to improve the everyday lives of children with CCN and their families.

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### 3.10 Declarations of Interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

### 3.11 References

*Please refer to p.61 for reference list.*

## Chapter 4

### General Discussion

The purpose of this chapter is to provide a summary of the findings and introduce topics to consider in the interpretation of the results. The results of this study are applied to the AAC-specific outcomes model and the FIATS-AAC is reviewed within the context of a family systems model. Efforts to involve stakeholders throughout the research process and additional considerations that should be acknowledged in future research endeavors are discussed.

#### 4.1 Summary

It has been well established in the AAC literature that parents and/or family members are key stakeholders in the intervention process (Granlund et al., 2008). For this reason, clinicians strive to integrate the goals and preferences of children and their families when making decisions regarding appropriate intervention strategies. Understanding the outcomes of AAC interventions from the parents' perspective is essential if clinicians are to make decisions that maximize the child's activity and participation across a variety of contexts.

To date, limited research has been conducted on the everyday impact of AAC interventions on the lives of children who need AAC and their families. This is due, in part, to the lack of parent-report AAC outcome measurement tools available with adequate psychometric properties that assess functioning in the child's 'real-world' environment (Fuhrer et al., 2003). A recent systematic review revealed the need for a valid and reliable parent-report AAC outcome measurement tool that is applicable to children of all ages with communication needs (Kron & Ryan, 2016). With adequate levels of content and face validity, test-retest reliability, and internal consistency, the Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication (FIATS-AAC) has the potential to fill this measurement gap (Delarosa et al., 2012). However, more evidence is needed to support the claim that the FIATS-AAC has *strong* evidence of construct validity.



Previous studies suggest that the FIATS-AAC measures family-related factors of functioning, such as the support parents provide to their child in integrating the device into their daily lives. In this present study, evidence has emerged for the FIATS-AAC as a measure that assesses child-related factors of functioning related to community participation and HRQOL. Obtaining further evidence of the construct validity of the FIATS-AAC will allow researchers to know the extent to which the FIATS-AAC can serve as a functional measure that well reflects the domains of functioning outlined in the theoretical framework of the ICF-CY.

## 4.2 AAC outcomes assessment model revisited

The holistic nature and organization of the ICF-CY provides a useful theoretical framework for understanding AAC interventions and outcome assessment. Returning to the proposed AAC outcomes assessment model (Figure 1, p. 7), the components of the *body structures and functions*, and *activity and participation* domains of the ICF-CY, are applicable throughout the following phases: assessment/procurement of the AAC device and/or system and the introductory, short-term, and long-term use and outcomes of AAC device use. The *environmental* and *personal factors* domains of the ICF-CY, which describe the way in which the physical and social environment of the child may influence AAC intervention outcomes, fall within the *moderating co-factors* component of the assessment model.

Now that more is understood about the constructs that relate to child and family functioning as measured by the FIATS-AAC, changes to the AAC outcomes assessment model may be considered. Evidently, the FIATS-AAC is measuring constructs associated with child-related community participation and HRQOL. While the construct of ‘community participation’ maps directly onto the different phases of device use as outlined in the model, HRQOL is a construct that has not yet been considered. With the shift towards incorporating HRQOL as a concept in the ICF-CY that encompasses all aspects of a child’s functioning (McDougall et al., 2010), HRQOL should be added as a distinct concept in the outcomes components of the AAC model.

Although the themes of *communicative partner adaptiveness* and *device practicality* do not add to the dimensionality of the FIATS-AAC, they contribute to the further understanding about the

factors that inform child functioning, and can be considered as moderating co-factors that influence functional performance in the AAC outcomes model. As described in Chapter 3, ‘communicative partner adaptiveness’ and ‘device practicality’ encompass the *environmental factors* domain of the ICF-CY. The specific components addressed within each theme provide additional context to factors that may influence the associated outcomes at different stages of device use. For example, partner training and receptiveness, and device volume and weight, may be added within the *moderating co-factors* component of the AAC model.

### 4.3 Application of the FIATS-AAC within a family systems model

Although health services have begun to take a family-centered approach within the past few decades, recent research suggests that AAC services often lack family-centeredness (Mandak et al., 2017). Mandak and colleagues (2017) report that while AAC clinicians recognize the importance of family-centered AAC services, they often do not engage with the family when delivering AAC services.

Experts suggest a few reasons for this gap, such as professionals lacking interest in involving families in the child’s care, or differing race and/or ethno-cultural backgrounds that make it more difficult to engage with families (Mandak et al., 2017). Another barrier to implementing family-centered AAC services is clinicians lacking the tools that they need to effectively involve families in the AAC assessment and intervention process.

Family systems theory has been proposed as a useful theoretical framework for supporting professionals in delivering family-centered AAC services. It views the family as a combination of interconnected subsystems that represent important relationships in the child’s life, such as siblings, caregivers, and grandparents. The subsystems may vary based on the child’s relationships, but may include family members, peers, educators and/or healthcare professionals. An important point regarding family systems theory is that the family is viewed as a whole (i.e. wholism), rather than individual members that may impact the child.

Understanding the roles that the family plays within the subsystems is essential to improve family-centered AAC services. Examining the functioning of the child from the perspectives of one parent alone is insufficient. AAC clinicians need to have a method to evaluate the individual roles and responsibilities of each family member to understand how they work together to affect the overall functioning of the child and their family.

The FIATS-AAC has many family-related domains such as: caregiver relief, family roles, energy, supervision, and finances that make it well-suited for use within a family systems model of service delivery. Scores on these FIATS-AAC domains can assist clinicians in understanding the strengths and needs of various family members throughout an AAC intervention. The FIATS-AAC can also help determine the goals of each family member prior to the implementation of an AAC intervention. Since the FIATS-AAC assesses functioning within the home, school, and community settings, it can also help professionals determine the barriers associated with the successful adoption of the device within a specific context.

Viewing the application of the FIATS-AAC within a family systems model further highlights the importance of gathering perspectives from different stakeholders during the intervention process. This idea leads to thoughts about future research in which related FIATS-AAC measures could be created for other communication partners (educators, peers) who may play important roles in the life of a child with CCN.

#### 4.4 A novel mixed methods approach

The mixed methods aspect of this study is a new methodological approach that has preliminary support for its use in obtaining support for the validity of outcome measures (Ryan et al., 2013; Stier et al., 2016). A quantitative approach was used to compare scores between the FIATS-AAC and two other measures, while a qualitative approach (i.e., valence analysis) was used to determine the levels of agreement between parents' comments in the interviews as judged by researchers, and FIATS-AAC domain scores as derived from parents' ratings. This approach was initially successfully used in a validity study of items adopted for another measure which assesses the product attitudes of young consumers during the selection of assistive technology

(Ryan et al., 2013). This novel approach to assess the construct validity of a measure was similarly adapted for use in another study that evaluated the validity of the FIATS for adaptive seating applications (Stier et al., 2016).

Although the analytic process in this study was similar to the approach used in earlier studies, the process developed for the present study was novel in a few respects. Firstly, in earlier studies, participants described the rationale for their item (not domain) ratings and a researcher subsequently assigned a valence level based on a blind analysis of this rationale. In the present study, the researcher-assigned valence levels based on a gestalt assessment of narratives assembled into domain-specific passages. In this analysis, both the researcher and parent participant were unaware of the domain scores throughout the interview process. Overall, the valence analysis used to examine the construct validity of the FIATS-AAC provided additional contextual information for the functional domain scores of the FIATS-AAC. This in turn helped to obtain richer support for the validity of the FIATS-AAC and the use of a mixed methods approach in future validity studies.

While one may argue that this mixed methods approach is too subjective for its use in construct validity assessment, it could be adapted to obtain supplementary support for health measurement scales in the future. It is recommended that a protocol be developed and tested to outline the guidelines for using such an approach for future measurement validation. For example, more than one rater should be involved in assigning valences to the parents' responses to help mitigate subjectivity during valence assignments. Interviews should also be conducted within 2 – 4 weeks after questionnaire completion to reduce the influence of change in family life. Categories and their weightings should also be considered and carefully defined prior to conducting interviews to help ensure that meaningful differences between categories are best captured prior to valence assignment. It is also recommended that another check between raters occurs following review of the first two transcripts to confirm domain and valence assignment strategies. Details for assigning weightings to categories are described in the Discussion in Chapter 3 (Section 3.6). Future research should focus on establishing a protocol for using this mixed methods approach to assess the validity of any health measurement scale.

## 4.5 Study Considerations

Several considerations were made throughout this study on a few topics including: child diagnoses, child development, family structure, and sex and gender. These topics were not a threat to the construct validity evaluation of the FIATS-AAC, but are important aspects to consider in the future to learn more about the measure.

Parents were not excluded from the study based on the diagnosis of their child. To participate in this study, the child had to be between 6 to 12 years of age and be currently using an aided AAC device. It should be considered that the levels of functioning may be affected by functional impairments associated with the diagnoses of the child. Developmental delay and autism spectrum disorder were the most common reported diagnoses in this study. Since developmental delay and autism spectrum disorder may vary in severity, it is difficult to conclude how functional status scores in this study may have varied according to diagnosis. This would be an interesting avenue for further research, but was not evaluated in this study due to a sample size too small for a sub-sample analysis.

With respect to child development, the age range of 6 to 12 years was quite broad. Since the study was cross-sectional in nature, it is possible that the level of functioning reported by parents was influenced by the child's developmental age. Although parents may be more involved in the child's life when they are within this age range, it is possible that the parents of older children reported higher overall functioning. One reason this may result is due to older children having a longer period of time to integrate the successful use of their device into their daily activities.

Families structures may differ according to race, ethnicity, religion, education, among other factors (Hanson & Lynch, 2013). For the purposes of this study, it was assumed that parents and/or primary caregivers were those who were primarily responsible for the well-being of the child and whose perspectives would most accurately reflect and report on the child's overall functioning. Since family structures may differ, parents who self-reported as the child's primary caregiver were requested to complete the questionnaires and were approached for participation in the interviews.

The influence that sex and gender may have on the results was not taken into consideration in this study. Although the moderating role of sex and gender may affect functional outcomes of children, this personal information was not collected given the measurement objectives of the present study. Future research may conduct secondary analyses on the data from this study to determine whether: functional levels of children varies by gender, and the types of community activities participated in by the child varies by gender.

## 4.6 Knowledge Translation

There are two approaches to knowledge translation: integrated and end-of-grant. Integrated knowledge translation occurs throughout the research process, while end-of-grant knowledge translation involves the activities that occur following a study to disseminate the research findings (Canadian Institutes of Health Research, 2012). Throughout the research process, several collaborations took place with family leaders, clinicians, and researchers as part of an integrated knowledge translation activity. The goal of these activities was to use participatory approaches to enhance the study design and acceptability to participants.

Meetings with family leaders at the host institution allowed the graduate student researcher to obtain advice on the study protocol, recruitment strategy, as well as strategies for mitigating risk due to sensitive items in the parent-report questionnaires. Study plans were also reviewed by experienced AAC clinicians to gain insight on how to: appropriately conduct interviews, approach participants, and structure the content of the informed consent form for parents. To evaluate and improve the comprehension and flow of the interview guide, the student researcher held individual mock interviews with two family leaders and a research fellow with experience in qualitative methods. The mock interviews assisted in providing strategies to improve the flow of the interview, and how to modify questions to improve clarity.

Emergent opportunities to share the research process and preliminary findings were exploited through presentations at local and international scientific symposia (Kron & Ryan, 2016). A manuscript based largely on the content of Chapter 3 is in preparation for submission to the AAC Journal – the official journal of the International Society for Augmentative and Alternative

Communication. Lay summaries of the research findings will also be shared with all families who were invited to participate in the survey and posted on the AAC Outcomes for Kids Research Alliance website. The AAC Outcomes for Kids Research Alliance is an alliance of AAC clinicians and researchers across Canada, who aim to improve the functional outcomes of children with communication needs.

## 4.7 Clinical Implications

AAC interventionists strive to improve everyday communicative functioning in children with CCN. Outcome assessment measures, such as the FIATS-AAC, are an important component of the interventions process as they provide AAC clinicians with a way to evaluate the effectiveness of AAC interventions. Obtaining empirical support for the validity of the FIATS-AAC adds further evidence for its use as a parent-reported AAC measure that may be used to assess everyday functioning and functional outcomes in the child's natural environment.

Demonstrating further the validity of the FIATS-AAC as a parent-report measure of community participation and HRQOL of children with AAC needs, provides AAC clinicians with a much-needed tool for informing both AAC assessment and intervention processes. This study seeds future research to evaluate the responsiveness of the FIATS-AAC as an outcome measure for routine clinical use. If the FIATS-AAC is responsive it will have the ability to detect functional change within individuals and groups of children following an AAC intervention if change is present. With suitable measurement tools such as the FIATS-AAC, AAC clinicians will have the ability to make shared service decisions and assess the effectiveness of AAC interventions designed to enhance functional communication, which will ultimately improve outcomes for children with CCN.

## References

- Bedell, G. M., Khetani, M. A., Cousins, M. A., Coster, W. J., & Law, M. C. (2011). Parent perspectives to inform development of measures of children's participation and environment. *Archives of Physical Medicine and Rehabilitation, 92*(5), 765-773.
- Branson, D., & Demchak, M. (2009). The use of augmentative and alternative communication methods with infants and toddlers with disabilities: A research review. *Augmentative and Alternative Communication, 25*(4), 274-286.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.
- Canadian Institute's of Health Research. (2015, March 19). Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches. Retrieved from <http://www.cihr-irsc.gc.ca/e/45321.html>.
- Chen, T., Li, L., & Kochen, M. M. (2005). A systematic review: How to choose appropriate health-related quality of life (HRQOL) measures in routine general practice? *Journal of Zhejiang University Science B, 6*(9), 936-940.
- Cohen, J. (1988). *Statistical power analysis for behavioural sciences (2<sup>nd</sup> ed.)*. Hillsdale, NJ: Erlbaum
- Coster, W., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Liljenquist, K., ... Kao, Y. C. (2011). Psychometric evaluation of the Participation and Environment Measure for Children and Youth. *Developmental Medicine & Child Neurology, 53*(11), 1030-1037.
- Delarosa, E., Horner, S., Eisenberg, C., Ball, L., Renzoni, A. M., & Ryan, S. E. (2012). Family Impact of Assistive Technology Scale: Development of a measurement scale for parents of children with complex communication needs. *Augmentative and Alternative Communication, 28*(3), 171-180.
- Dillman, D. A., Smyth, J. D., & Christian, L. M. (2008). *Internet, mail, and mixed-mode surveys: the tailored design method*. United States: John Wiley & Sons, Inc.
- Drager, K., Light, J., & McNaughton, D. (2010). Effects of AAC interventions on communication and language for young children with complex communication needs. *Journal of Pediatric Rehabilitation Medicine, 3*(4), 303-310.
- Dunst, C. J. (2002). Family-centered practices: Birth through high school. *Journal of Special Education, 36*(3), 141-149.
- Eliasson, A. C., Krumlinde-Sundholm, L., Rösblad, B., Beckung, E., Arner, M., Ohrvall, A., M Rosenbaum, P. (2006). The Manual Ability Classification System (MACS) for children



- with cerebral palsy: Scale development and evidence of validity and reliability. *Developmental Medicine and Child Neurology*, 48(7), 549-554.
- Enderby, P. (2014). Introducing the therapy outcome measure for AAC services in the context of a review of other measures. *Disability and Rehabilitation: Assistive Technology*, 9(1), 33–40.
- Fuhrer, M. J., Jutai, J. W., Scherer, M. J., & DeRuyter, F. (2003). A framework for the conceptual modelling of assistive technology device outcomes. *Disability and Rehabilitation*, 25(22), 1243–1251.
- Ganz, J. B., Earles-Vollrath, T. L., Heath, A. K., Parker, R. I., Rispoli, M. J., & Duran, J. B. (2012). A meta-analysis of single case research studies on aided augmentative and alternative communication systems with individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42(1), 60–74.
- Granlund, M., Björck-Åkesson, E., Wilder, J., & Ylvén, R. (2008). AAC interventions for children in a family environment: Implementing evidence in practice. *Augmentative and Alternative Communication*, 24(3), 207–219.
- Hanson, M. J., & Lynch, E. W. (2013). *Understanding families: Supportive approaches to diversity, disability, and risk*. Baltimore, MD: Paul H. Brookes Publishing Co.
- Henderson, S., Skelton, H., & Rosenbaum, P. (2008). Assistive devices for children with functional impairments: Impact on child and caregiver function. *Developmental Medicine & Child Neurology*, 50(2), 89–98.
- Hidecker, M. J., Paneth, N., Rosenbaum, P. L., Kent, R. D., Lillie, J., Eulenberg, J. B., ... Taylor, K. (2011). Developing and validating the Communication Function Classification System for individuals with cerebral palsy. *Developmental Medicine and Child Neurology*, 53(8), 704-710.
- Hulley, S. B., Cummings, S. R., Browner, W. S., Grady, D. G., & Newman, T. B. (2013). *Designing clinical research: Fourth edition*. Philadelphia: Lippincott Williams & Wilkins.
- Kron, A. T., & Ryan, S. E. (2016, August). *Parent-reported effectiveness of AAC interventions for youth: A systematic review of outcome measures*. Paper presented at International Society for Augmentative and Alternative Communication Conference, Toronto, Canada.
- Law, J., Boyle, J., Harris, F., Harkness, A., & Nye C. (2000). Prevalence and natural history of primary speech and language delay: Findings from a recent systematic review of the literature. *International Journal of Language and Communication Disorders*, 35(2), 165-188.
- Light, J., & Drager, K. (2007). AAC technologies for young children with complex communication needs: State of the science and future research directions. *Augmentative and Alternative Communication*, 23(3), 204–216.

- Light, J., & McNaughton, D. (2012). Supporting the communication, language, and literacy development of children with complex communication needs: State of the science and future research priorities. *Assistive Technology*, 24(1), 34–44.
- Lindsay, S., & Tsybina, I. (2011). Predictors of unmet needs for communication and mobility assistive devices among youth with a disability: The role of socio-cultural factors. *Disability and Rehabilitation: Assistive Technology*, 6(1), 10–21.
- Logan, K., Iacono, T., & Trembath, D. (2017). A systematic review of research into aided AAC to increase social-communication functions in children with autism spectrum disorder. *Augmentative and Alternative Communication*, 33(1), 51-64.
- Mandak, K., O'Neill, T., Light, J., & Fosco, G.M. (2017). Briding the gap from values to actions: A family systems framework for family-centered AAC services. *Augmentative and Alternative Communication*, 33(1), 32-41.
- McCullough, N., & Parkes, J. (2008). Use of the child health questionnaire in children with cerebral palsy: A systematic review and evaluation of the psychometric properties. *Journal of Pediatric Psychology*, 33(1), 80–90.
- McDougall, J., Wright, V., & Rosenbaum, P. (2010). The ICF model of functioning and disability, incorporating quality of life and human development. *Developmental Neurorehabilitation*, 13(3), 204-211.
- McNaughton, D., & Light, J. (2015). What we write about when we write about AAC: The past 30 years of research and future directions. *Augmentative and Alternative Communication*, 31(4), 261-270.
- Murdoch, B. E., & Theodoros, D. G. (2001). *Traumatic brain injury: Associated speech, language, and swallowing disorders*. San Diego: Singular/Thomson Learning.
- Patrick, D. L., & Deyo, R. A. (1989). Generic and disease-specific measures in assessing health status and quality of life. *Medical Care Supplement*, 27, S217-S232.
- Raat, H., Botterweck, A., Landgraf, J. M., Hoogeveen, C. W., & Essink-Bot, M. (2005). Reliability and validity of the short form of the child health questionnaire for parents (CHQ-PF28) in large random school based and general population samples. *Journal of Epidemiology and Community Health*, 59(1), 75-82.
- Romski, M., Sevcik, R. A., Adamson, L. B., Smith, A., Cheslock, M., & Bakerman, R. (2011). Parent perceptions of the language development of toddlers with developmental delays before and after participation in parent-coached language interventions. *American Journal of Speech-Language Pathology*, 20, 111-118.
- Ryan, S. E., Campbell, K. A., Rigby, P., Germon, B., Chan, B., & Hubley, D. (2006). Development of the new Family Impact of Assistive Technology Scale. *International Journal of Rehabilitation Research*, 29(3), 195-200.

- Ryan, S. E., Klejman, S., & Gibson, B. E. (2013). Measurement of the product attitudes of children during the selection of assistive technology devices. *Disability and Rehabilitation: Assistive Technology*, 8(1), 21-29.
- Simeonsson, R. J., Björck-Åkesson, E., & Lollar, D. J. (2012). Communication, disability, and the ICF-CY. *Augmentative and Alternative Communication*, 28(1), 3–10.
- Smith, A. L., & Hustad, K. C. (2015). AAC and early intervention for children with cerebral palsy: Parent perceptions and child risk factors. *Augmentative and Alternative Communication*, 31(4), 336-350.
- Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (2005). *Vineland Adaptive Behavior Scales: Survey Interview, 2<sup>nd</sup> edition*. Minneapolis, USA: Pearson Education, Inc.
- Statistics Canada. *Participation and activity limitation survey*. Ottawa: 2006. Retrieved from: <http://www.statcan.gc.ca/pub/89-628-x/2007002/t/4125014-eng.htm>
- Stein, R. E., & Jessop, D. J. (2003). The Impact on Family Scale revisited: Further psychometric data. *Journal of Developmental and Behavioural Pediatrics*, 24(1), 9-16.
- Stier, C. D., Chieu, I. B., Howell, L., & Ryan S. E. (2016). Exploring the functional impact of adaptive seating on the lives of individual children and their families: A collective case study. *Disability and Rehabilitation: Assistive Technology*, 12(5): 450-456.
- Streiner, D. L., & Norman, G. R. (2008). *Health measurement scales: A practical guide to their development and use*. United States: Oxford University Press
- Thomas-Stonell, N. L., Oddson, B., Robertson, B., & Rosenbaum, P. (2010). Development of the FOCUS (Focus on the Outcomes of Communication Under Six), a communication outcome measure for preschool children. *Developmental Medicine & Child Neurology*, 52(1), 47–53.
- Varni, J. W., Burwinkle, T. M., Berrin, S. J., Sherman, S. A., Artavia, K., Malcarne, V. L., & Chambers, H. G. (2006). The PedsQL in pediatric cerebral palsy: Reliability, validity, and sensitivity of the Generic Core Scales and Cerebral Palsy Module. *Developmental Medicine and Child Neurology*, 48(6), 442–449.
- Viera, A. J., & Garrett, J. M. (2005). Understanding interobserver agreement: The Kappa statistic. *Family Medicine*, 37(5), 360-363.
- Washington, K., Thomas-Stonell, N., Oddson, B., McLeod, S., Warr-Leeper, G., Robertson, B., & Rosenbaum, P. (2013). Construct validity of the FOCUS<sup>®</sup> (Focus on the Outcomes of Communication Under Six): A communicative participation outcome measure for preschool children. *Child: Care, Health and Development*, 39(4), 481–489.
- World Health Organization. *International classification of functioning, disability and health*. Switzerland: 2001.

World Health Organization. *International classification of functioning, disability and health for children and youth*. Switzerland: 2007.

Yin, R. (2008). *Case Study Research: Design and Methods*. Fifth Edition: SAGE Publications.

# Appendices

**Appendix A. Sample search strategy using CINAHL database**

S1	(MH “Alternative and Augmentative Communication”) OR (MH “Communication Aids for Disabled”)	Search modes – Boolean/Phrase
S2	Augmentative N3 communicat*	Search modes – Boolean/Phrase
S3	S1 OR S2	Search modes – Boolean/Phrase
S4	Complex communicat*	Search modes – Boolean/Phrase
S5	S3 OR S4	Search modes – Boolean/Phrase
S6	(MH “Communicative Disorders/TH/RH”)	Search modes – Boolean/Phrase
S7	S5 OR S6	Search modes – Boolean/Phrase
S8	(MH “International Classification of Functioning, Disability, and Health”)	Search modes – Boolean/Phrase
S9	S7 AND S8	Search modes – Boolean/Phrase
S10	(MH “Outcomes (Health Care)”) OR (MH “Outcome Assessment”) OR (MH “Treatment Failure”) OR (MH “Treatment Outcomes”)	Search modes – Boolean/Phrase
S11	(MH “Performance Measurement Systems”) OR (MH “Research Instruments”) OR (MH “Clinical Assessment Tools”)	Search modes – Boolean/Phrase
S12	Measurement tool* OR measurement scale*	Search modes – Boolean/Phrase
S13	(MH “Research Measurement”) OR (MH “Questionnaires+)	Search modes – Boolean/Phrase
S14	(MH “Surveys”)	Search modes – Boolean/Phrase
S15	Survey* OR questionnaire* OR interview* OR measure* OR tool* OR assessment* OR scale*	Search modes – Boolean/Phrase
S16	S10 OR S11 OR S12 OR S13 OR S14	Search modes – Boolean/Phrase

S17	S7 AND S16	Search modes – Boolean/Phrase
S18	S7 AND S15	Search modes – Boolean/Phrase
S19	S9 OR S17	Limiters - Published  Date: 20010101-20151231; English Language; Age Groups: All Child  Search modes – Boolean/Phrase
S20	S9 OR S18	Limiters - Published  Date: 20010101-20151231; English Language; Age Groups: All Child  Search modes – Boolean/Phrase

## Appendix B. Family Impact of Assistive Technology Scale for Augmentative and Alternative Communication (FIATS-AAC)

### Family Impact of Assistive Technology Scale for AAC (FIATS-AAC) (Ryan & Renzoni, 2015)

**PLEASE READ:** This questionnaire will help us to learn a bit about you, your child, and your family life as it relates to your child's face-to-face communication. Please complete the questionnaire by saying how much you agree with each statement. For instance, the first item says: '*My child needs help from others when communicating.*' If you strongly agree with this statement because your child always needs help from others when communicating, circle '7'. If you strongly disagree because your child never needs help, then circle '1'. Circle one of the other numbers if you agree or disagree to a lesser amount. Please circle only one rating for each statement.



		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
1	My child needs help from others when communicating.	7	6	5	4	3	2	1
2	My child lets me know if something is wrong.	7	6	5	4	3	2	1
3	I need more support from family members when caring for my child.	7	6	5	4	3	2	1
4	I find it easy to play with my child.	7	6	5	4	3	2	1
5	My child needs a lot of help to be understood.	7	6	5	4	3	2	1
6	Being independent improves my child's self-esteem.	7	6	5	4	3	2	1
7	My child tells me what she/he wants.	7	6	5	4	3	2	1
8	My child has a tough time starting a conversation with people.	7	6	5	4	3	2	1
9	If my child got lost, she/he could ask someone for directions.	7	6	5	4	3	2	1
10	Others share the caregiving responsibilities for my child.	7	6	5	4	3	2	1
11	My child tells me about her/his day.	7	6	5	4	3	2	1



		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
12	My child's communication disability affects my ability to work outside the home.	7	6	5	4	3	2	1
13	It is hard for me to get anything else done when my child is at home.	7	6	5	4	3	2	1
14	My child likes to be independent.	7	6	5	4	3	2	1
15	My child can phone for help in an emergency.	7	6	5	4	3	2	1
16	I need help from professionals to care for my child.	7	6	5	4	3	2	1
17	More than one person is required to help my child communicate.	7	6	5	4	3	2	1
18	My child knows how to take turns during conversations.	7	6	5	4	3	2	1
19	My child is learning to communicate independently.	7	6	5	4	3	2	1
20	My family needs to give up many other luxuries so my child can have the devices she/he needs.	7	6	5	4	3	2	1
21	My child communicates with other people on the phone.	7	6	5	4	3	2	1
22	All family members take turns supporting my child when going out into the neighbourhood.	7	6	5	4	3	2	1
23	My child is very sociable.	7	6	5	4	3	2	1
24	My child communicates with family members.	7	6	5	4	3	2	1
25	I feel my child is safe if I leave her/him with another babysitter/caregiver.	7	6	5	4	3	2	1
26	My child communicates with people with whom she/he is less familiar.	7	6	5	4	3	2	1

		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
27	I find it tiring to help my child communicate.	7	6	5	4	3	2	1
28	My child's communication disability affects family finances.	7	6	5	4	3	2	1
29	I do most of the caregiving for my child at home.	7	6	5	4	3	2	1
30	We watch our finances because of my child's communication disability.	7	6	5	4	3	2	1
31	Other people understand my child.	7	6	5	4	3	2	1
32	It is very demanding saying what my child wants to others.	7	6	5	4	3	2	1
33	My child knows how to keep a conversation going.	7	6	5	4	3	2	1
34	Everyone in my family knows how to communicate with my child.	7	6	5	4	3	2	1
35	My child plays with friends.	7	6	5	4	3	2	1
36	Communication devices for my child make it difficult for my family to afford anything else.	7	6	5	4	3	2	1
37	My child tells me when she/he is afraid.	7	6	5	4	3	2	1
38	My child's independence is increasing.	7	6	5	4	3	2	1
39	My child communicates her/his ideas.	7	6	5	4	3	2	1
40	Much of my time during the day is spent helping my child to communicate.	7	6	5	4	3	2	1
41	My child participates in community activities.	7	6	5	4	3	2	1
42	My child tells me when she/he feels sick.	7	6	5	4	3	2	1

		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
43	My child needs my help to communicate with others.	7	6	5	4	3	2	1
44	My child converses well with friends.	7	6	5	4	3	2	1
45	It is hard work helping my child with homework.	7	6	5	4	3	2	1
46	My child could never go out in the neighbourhood on her/his own.	7	6	5	4	3	2	1
47	My child prefers to communicate with me rather than other family members.	7	6	5	4	3	2	1
48	My child socializes with others at mealtime.	7	6	5	4	3	2	1
49	My child's teacher is satisfied with my child's performance in school.	7	6	5	4	3	2	1
50	Other family members need to help me care for my child.	7	6	5	4	3	2	1
51	My child must be with others to be content.	7	6	5	4	3	2	1
52	I have difficulty managing my child's behaviour.	7	6	5	4	3	2	1
53	My child can spend a long time doing one activity.	7	6	5	4	3	2	1
54	My child can communicate with others.	7	6	5	4	3	2	1
55	My child enjoys school.	7	6	5	4	3	2	1
56	I need longer breaks from watching my child.	7	6	5	4	3	2	1
57	My child gets frustrated easily.	7	6	5	4	3	2	1
58	I have little time to get chores done around the house.	7	6	5	4	3	2	1

		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
59	My child behaves well around me.	7	6	5	4	3	2	1
60	I have trouble coping with the demands of caring for my child.	7	6	5	4	3	2	1
61	My child participates in the classroom.	7	6	5	4	3	2	1
62	My child likes to explore her/his surroundings.	7	6	5	4	3	2	1
63	My child acts appropriately towards other family members.	7	6	5	4	3	2	1
64	My child wants to be with me when I leave the room.	7	6	5	4	3	2	1
65	I would like to get more breaks from caring for my child.	7	6	5	4	3	2	1
66	My child is performing well in school.	7	6	5	4	3	2	1
67	I would like to spend more time with my other family members.	7	6	5	4	3	2	1
68	My child gets bored easily.	7	6	5	4	3	2	1
69	My child can play games.	7	6	5	4	3	2	1
70	My child is well behaved at school.	7	6	5	4	3	2	1
71	I must take my child with me when I go from one room to another.	7	6	5	4	3	2	1
72	I need to get more things done around the house.	7	6	5	4	3	2	1
73	My child can be happy when I am not holding her/him.	7	6	5	4	3	2	1
74	I am concerned about my child's safety when she/he is left alone.	7	6	5	4	3	2	1



		Strongly Agree	Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Disagree	Strongly Disagree
75	My child participates in extra-curricular activities at school.	7	6	5	4	3	2	1
76	My child can use her/his hands to play.	7	6	5	4	3	2	1
77	I need help to take care of my child.	7	6	5	4	3	2	1
78	I am satisfied with my child's achievement of personal goals at school.	7	6	5	4	3	2	1
79	My child feels self-confident.	7	6	5	4	3	2	1
80	A family member needs to be near my child during the day.	7	6	5	4	3	2	1
81	I wish my child could give me a few minutes to myself each day.	7	6	5	4	3	2	1
82	I am concerned about the way my child behaves.	7	6	5	4	3	2	1
83	My child can control toys without help.	7	6	5	4	3	2	1
84	My child is proud of her/his schoolwork.	7	6	5	4	3	2	1
85	My child can be happy when left alone to play.	7	6	5	4	3	2	1
86	My child needs me nearby to do many activities.	7	6	5	4	3	2	1
87	My child disrupts her/his classmates.	7	6	5	4	3	2	1
88	I can manage my child on my own.	7	6	5	4	3	2	1
89	My child likes to be near me.	7	6	5	4	3	2	1



**Appendix C. FIATS-AAC domains and definitions**

<b>Domains</b>	<b>Definition</b>	<b>Item #'s</b>
Behaviour <sup>a</sup>	Degree to which the child engages in appropriate behavior.	52, 59, 63, 70, 82, 87
Contentment <sup>a</sup>	Degree to which the child is content during the day.	51, 53, 57, 68, 73, 79, 85
Doing Activities <sup>a</sup>	Degree to which the child has control over his/her own actions.	54, 62, 69, 76, 83
Education <sup>a</sup>	Degree to which the child is succeeding in school.	49, 55, 61, 66, 75, 78, 84
Face-to-face Communication <sup>a</sup>	Degree to which the child converses with others.	7, 11, 18, 26, 33, 39, 44
Self-Reliance <sup>a</sup>	Degree to which the child performs activities independently.	1, 6, 14, 19, 31, 38, 43
Social Versatility <sup>a</sup>	Degree to which the child interacts with others.	4, 8, 21, 23, 35, 41, 48
Caregiver Relief <sup>b</sup>	Degree to which parent manages caregiving responsibilities.	50, 56, 60, 65, 67, 72, 77, 81, 88
Energy <sup>b</sup>	Degree of energy needed to assist the child.	5, 13, 17, 27, 32, 40, 45
Family Roles <sup>b</sup>	Degree to which family members are involved in caregiving activities	3, 10, 16, 22, 24, 29, 34, 47
Finances <sup>b</sup>	Degree to which the family is free from financial stress	12, 20, 28, 30, 36
Security <sup>b</sup>	Degree to which the parent is free from worry about the child's safety	2, 9, 15, 25, 37, 42, 46
Supervision <sup>b</sup>	Degree to which the child is free from attention from family members.	58, 64, 71, 74, 80, 86, 89

<sup>a</sup> Child-related factors<sup>b</sup> Parent- and family-related factors

## Appendix D. Semi-structured interview guide

### *Semi-structured interview guide*

*Introduction:* My name is Amie Kron and I am the graduate student that is leading this study. Just to recap, the aim of this study is to learn whether we can use a new questionnaire we developed to learn about the everyday lives of children who use AAC devices and their families. You already filled out a few forms to help us with part of this study. By participating in the interview we can learn more about your family life which we hope will give us information about things that may influence your child's functioning. This interview will take approximately 1 hour. Before I go through the details of the interview, I just want to remind you that the interview will be audio recorded. I'll start off the interview with some general questions about you and your child and then I will ask you about your family and child experiences with your child's AAC device. I want to be respectful of your time, so if a question is taking longer than planned, I may just move us along to the next question so we can cover them all. As I go through the interview questions, my goal is to hear about your experiences, so please be aware that there are no right or wrong answers. The interview questions will cover a lot of topic areas so if it seems like we are skipping around a bit, please do not be alarmed. If you do not feel comfortable answering a question, just let me know, and I will move along to the next question. If you need me to clarify any questions I will be happy to do so. I will be using a notepad to track my progress through all the interview questions. Before we get started, I need to get your written consent to participate (summarize consent form, answer questions, and obtain written consent).

*Notes/Observations:* flow of interview (i.e. responsiveness and attentiveness of interviewee, body language, tone, etc.)

### General Questions

Could you please tell me when <name of client> received his/her communication device?

Could you tell me a little about this device? *Probe:* Could you tell me about how <name of child> uses the device?

Do you usually communicate with your child using this device? Are there other ways your child communicates with you?

Does your child also communicate in these same ways with people at home and out in their community? *Probe:* Could you tell me a little more about that?

### Family Experiences

Now that I have asked you some general questions about your child's communication device, I will ask you some questions about your family experiences. This will help me understand more about how the device may affect you and your family.

Have you and your family changed your everyday routines in any way to accommodate your child's communication device? *Probe: You can consider how the device may impact your family's participation in community and school events and time spent doing other activities at home. Probe: Can you tell me a little bit more about that? What does all this mean to you and your family?*

The next questions relate to your role as a parent.

Thinking of yourself as <child's name> <mother, father, guardian>, does your child's level of communication affect the time you spend supporting your child? *Probe: You can think of activities you would perform on a typical day to support your child.*

What types of support do you get from family members? *Probe: You can think about how involved your family is in caring for your child* **(FAMILY ROLES)**

How much energy/time does it take to communicate with your child. Does the amount of effort change if/when you support your child's communication with others? *Probe: You can think about how supporting for your child affects the time you have for yourself/others. What makes you answer this way?* **(ENERGY)**

Do you feel that you would benefit from occasional relief from the support you provide your child whether this is from friends or other family members or others (e.g, paid babysitter)? *Probe: If you had help from others would you be able to better manage your child and other tasks you need to complete?* **(CAREGIVER RELIEF)**

The next question is about the financial influence of your child's communication needs. Have been any financial pros or cons related to getting or using this device? *Probe: What makes you say yes/no? You can think about how your child's communication needs affect your ability to pay for other expenses.* **(FINANCES)**.

I just have one last question about your family experiences before we move on. Are you and your family ever worried about how safe your child may be? *Probe: You can think about how you feel when you or another family member is not with your child at different times. What makes you answer this way? Probe different environments and communication partners – home, school, community and familiar/unfamiliar communication partners.* **(SECURITY)**

### **Child Experiences**

Thank you for giving me some information about your family experiences. The rest of this interview will focus on questions related to your view of your child's experiences using his/her AAC device.

Before I get into specific questions, I just want to learn more about your child and their use of their device. Do you get a general sense from your child whether they like/dislike their device? *Probe: Are there any aspects of using the device that you feel your child really enjoys, and others that make it more difficult? What are you seeing that makes you think this?*



I also want to get to know a bit more about your child's communication experiences. How would you describe your child's communication style and abilities? *Probe: I want you to consider whether your child can tell you/others if they want something, keep themselves engaged in a discussion, and just tell you about their day* (**FACE-TO-FACE COMMUNICATION**)

Now I am going to ask you more specific questions about your child's experiences across the home, school, and community. Could you tell me about school experiences so far – what are the things he/she enjoys most – are there things that have been challenging because of your child's communication abilities? *Probe: Are they enjoying any particular aspects and having difficulty with others?* (**EDUCATION**)

The next few questions focus on your child's experiences in other social situations.

Does your child's device allow them to participate in the activities they enjoy? What are these activities? *Probe: What makes you say yes/no? Can you give some examples?*

(If child seems to participate in activities)...When your child is participating in these activities, do you feel that they have control over how they are involved in these activities? *Probe: Control can mean whether they can communicate well during the activity, and if toys or games are involved, whether they can handle them well* (**DOING ACTIVITIES**)

Does your child need any assistance when participating in these activities or would you describe them as independent? (**SELF-RELIANCE**)

How does your child interact with peers, teachers, family members? *Probe: You can think about how your child plays with others and how they build relationships with them. Can you give examples?* (**SOCIAL VERSATILITY**)

(If child seems like they are interacting with others)... Now we will focus on the communication part of your child's involvement in social situations. When your child is in social situations, can they communicate on their own or do they require help from others? *Probe: Does this depend on who the communication partner is? Can you explain this further?* (**SELF-RELIANCE**)

Would you describe your child as having appropriate behaviour in different social settings? *Probe: You can think about whether you ever are concerned about your child's behaviour? Can tell me about a recent time you were concerned about your child's behaviour?* (**BEHAVIOUR**)

Please think about a typical day that your child has. Would you say that your child appears happy or content or is there a better way to describe your child's mood at different times during the day? *Probe: How does your child communicate that she is happy or content? Does this change based on who your child is with? Please tell me more.* (**CONTENTMENT**)

I would now like to discuss the forms that you filled out earlier for a brief moment. How similar or different do you think that your experiences and views of your child and family compared to

your responses on these forms? *Probe: Were the issues you brought up in this interview similar the issues you may have been in 'agreement' with on the forms?* Do you think the forms missed anything important when asking about areas that might influence or be influenced by your child's ability to communicate using an AAC device?

That brings us to the end of the interview. Did I miss anything that you would like to explain or discuss with me?

Thank you so much for your time. The responses you provided to me are very valuable. If you have any questions after the interview do not hesitate to contact me. My phone number is XXX-XXX-XXXX or you can send me an e-mail at [akron@hollandbloorview.ca](mailto:akron@hollandbloorview.ca).

**Appendix E. SPSS syntax for FIATS-AAC total score, domain scores, and related statistics***SPSS Syntax*

\*FIATS-AAC Basic Analysis

\*FIATS-AAC (89 items) variable assignment for domains.

\*Behaviour variables (6) = fiats52\_t1\_Rev, fiats59\_t1, fiats63\_t1, fiats70\_t1, fiats82\_t1\_Rev, fiats87\_t1\_Rev.

\*Caregiver Relief variables (9) = fiats50\_t1\_Rev, fiats56\_t1\_Rev, fiats60\_t1\_Rev, fiats65\_t1\_Rev, fiats67\_t1\_Rev, fiats72\_t1\_Rev, fiats77\_t1\_Rev, fiats81\_t1\_Rev, fiats88\_t1.

\*Contentment variables (7) = fiats51\_t1\_Rev, fiats53\_t1, fiats57\_t1\_Rev, fiats68\_t1\_Rev, fiats73\_t1, fiats79\_t1, fiats85\_t1.

\*Doing Activities variables (5) = fiats54\_t1, fiats\_62\_t1, fiats69\_t1, fiats76\_t1, fiats83\_t1.

\*Education variables (7) = fiats49\_t1, fiats55\_t1, fiats61\_t1, fiats66\_t1, fiats75\_t1, fiats78\_t1, fiats84\_t1.

\*Energy variables (7) = fiats5\_t1\_Rev, fiats13\_t1\_Rev, fiats17\_t1\_Rev, fiats27\_t1\_Rev, fiats32\_t1\_Rev, fiats40\_t1\_Rev, fiats45\_t1\_Rev.

\*Face-to-face communication variables (8) = fiats7\_t1, fiats\_11\_t1, fiats18\_t1, fiats24\_t1, fiats\_26\_t1, fiats33\_t1, fiats\_39\_t1, fiats44\_t1.

\*Family Roles variables (7) = fiats3\_t1\_Rev, fiats10\_t1, fiats16\_t1\_Rev, fiats22\_t1, fiats29\_t1\_Rev, fiats34\_t1, fiats47\_t1\_Rev.

\*Finances variables (5) = fiats12\_t1\_Rev, fiats20\_t1\_Rev, fiats28\_t1\_Rev, fiats30\_t1\_Rev, fiats36\_t1\_Rev.

\*Security variables (7) = fiats2\_t1, fiats9\_t1, fiats15\_t1, fiats25\_t1, fiats37\_t1, fiats42\_t1, fiats46\_t1\_Rev.

\*Self Reliance variables (7) = fiats1\_t1\_Rev, fiats6\_t1, fiats14\_t1, fiats19\_t1, fiats31\_t1, fiats38\_t1, fiats43\_t1\_Rev.

\*Social Versatility variables (7) = fiats4\_t1, fiats8\_t1\_Rev, fiats21\_t1, fiats23\_t1, fiats35\_t1, fiats41\_t1, fiats48\_t1.

\*Supervision variables (7) = fiats58\_t1\_Rev, fiats64\_t1\_Rev, fiats71\_t1\_Rev, fiats74\_t1\_Rev, fiats80\_t1\_Rev, fiats86\_t1\_Rev, fiats89\_t1\_Rev.

\*Need to reverse score items.

\*Items that have been reversed are called x\_Rev

recode fiats1\_t1, fiats3\_t1, fiats5\_t1, fiats8\_t1, fiats12\_t1, fiats13\_t1, fiats16\_t1, fiats17\_t1, fiats20\_t1, fiats27\_t1, fiats28\_t1, fiats29\_t1, fiats30\_t1, fiats32\_t1, fiats36\_t1, fiats40\_t1, fiats43\_t1, fiats45\_t1, fiats46\_t1,

fiats47\_t1, fiats50\_t1, fiats51\_t1, fiats52\_t1, fiats56\_t1, fiats57\_t1, fiats58\_t1, fiats60\_t1, fiats64\_t1, fiats65\_t1, fiats67\_t1, fiats68\_t1, fiats71\_t1, fiats72\_t1, fiats74\_t1, fiats77\_t1, fiats80\_t1, fiats81\_t1, fiats82\_t1, fiats86\_t1, fiats87\_t1, fiats89\_t1

(1=7) (2=6) (3=5) (4=4) (5=3) (6=2) (7=1) into

fiats1\_t1\_Rev, fiats3\_t1\_Rev, fiats5\_t1\_Rev, fiats8\_t1\_Rev, fiats12\_t1\_Rev, fiats13\_t1\_Rev, fiats16\_t1\_Rev, fiats17\_t1\_Rev, fiats20\_t1\_Rev,

fiats27\_t1\_Rev, fiats28\_t1\_Rev, fiats29\_t1\_Rev, fiats30\_t1\_Rev, fiats32\_t1\_Rev,  
 fiats36\_t1\_Rev, fiats40\_t1\_Rev, fiats43\_t1\_Rev, fiats45\_t1\_Rev, fiats46\_t1\_Rev,  
 fiats47\_t1\_Rev, fiats50\_t1\_Rev, fiats51\_t1\_Rev, fiats52\_t1\_Rev, fiats56\_t1\_Rev,  
 fiats57\_t1\_Rev, fiats58\_t1\_Rev, fiats60\_t1\_Rev, fiats64\_t1\_Rev, fiats65\_t1\_Rev,  
 fiats67\_t1\_Rev, fiats68\_t1\_Rev,  
 fiats71\_t1\_Rev, fiats72\_t1\_Rev, fiats74\_t1\_Rev, fiats77\_t1\_Rev, fiats80\_t1\_Rev,  
 fiats81\_t1\_Rev, fiats82\_t1\_Rev, fiats86\_t1\_Rev,  
 fiats87\_t1\_Rev, fiats89\_t1\_Rev.

\*Calculate domains as mean of relevant items.

```
compute behaviour_t1 = mean (fiats52_t1_Rev, fiats59_t1, fiats63_t1, fiats70_t1,
fiats82_t1_Rev, fiats87_t1_Rev).
compute caregiver_relief_t1 = mean (fiats50_t1_Rev, fiats56_t1_Rev, fiats60_t1_Rev,
fiats65_t1_Rev, fiats67_t1_Rev, fiats72_t1_Rev, fiats77_t1_Rev, fiats81_t1_Rev, fiats88_t1).
compute contentment_t1 = mean (fiats51_t1_Rev, fiats53_t1, fiats57_t1_Rev, fiats68_t1_Rev,
fiats73_t1, fiats79_t1, fiats85_t1).
compute doing_activities_t1 = mean (fiats54_t1, fiats62_t1, fiats69_t1, fiats76_t1, fiats83_t1).
compute education_t1 = mean (fiats49_t1, fiats55_t1, fiats61_t1, fiats66_t1, fiats75_t1,
fiats78_t1, fiats84_t1).
compute energy_t1 = mean (fiats5_t1_Rev, fiats13_t1_Rev, fiats17_t1_Rev, fiats27_t1_Rev,
fiats32_t1_Rev, fiats40_t1_Rev, fiats45_t1_Rev).
compute face_to_face_communication_t1 = mean (fiats7_t1, fiats11_t1, fiats18_t1, fiats24_t1,
fiats26_t1, fiats33_t1, fiats39_t1, fiats44_t1).
compute family_roles_t1 = mean(fiats3_t1_Rev, fiats10_t1, fiats16_t1_Rev, fiats22_t1,
fiats29_t1_Rev, fiats34_t1, fiats47_t1_Rev).
compute finances_t1 = mean (fiats12_t1_Rev, fiats20_t1_Rev, fiats28_t1_Rev, fiats30_t1_Rev,
fiats36_t1_Rev).
compute security_t1 = mean (fiats2_t1, fiats9_t1, fiats15_t1, fiats25_t1, fiats37_t1, fiats42_t1,
fiats46_t1_Rev).
compute self_reliance_t1 = mean ( fiats1_t1_Rev, fiats6_t1, fiats14_t1, fiats19_t1, fiats31_t1,
fiats38_t1, fiats43_t1_Rev).
compute social_versatility_t1 = mean (fiats4_t1, fiats8_t1_Rev, fiats21_t1, fiats23_t1, fiats35_t1,
fiats41_t1, fiats48_t1).
compute supervision_t1 = mean (fiats58_t1_Rev, fiats64_t1_Rev, fiats71_t1_Rev,
fiats74_t1_Rev, fiats80_t1_Rev, fiats86_t1_Rev, fiats89_t1_Rev).
```

variable labels behaviour\_t1 'Behaviour' caregiver\_relief\_t1 'Caregiver Relief' contentment\_t1  
 'Contentment' doing\_activities\_t1 'Doing Activities' education\_t1 'Education' energy\_t1 'Energy'  
 face\_to\_face\_communication\_t1 'Face-to-face Communication' family\_roles\_t1 'Family Roles'  
 finances\_t1 'Finances' security\_t1 'Security' self\_reliance\_t1 'Self-Reliance' social\_versatility\_t1  
 'Social Versatility' supervision\_t1 'Supervision' fiats\_sum\_t1 'Sum of FIATS Domains'

## EXAMINE

VARIABLES= behaviour\_t1, caregiver\_relief\_t1, contentment\_t1, doing\_activities\_t1, education\_t1, energy\_t1, face\_to\_face\_communication\_t1, family\_roles\_t1, finances\_t1, security\_t1, self\_reliance\_t1, social\_versatility\_t1, supervision\_t1,

fiats\_sum\_t1

/PLOT BOXPLOT STEMLEAF HISTOGRAM  
/COMPARE GROUP  
/STATISTICS DESCRIPTIVES  
/CINTERVAL 95  
/MISSING PAIRWISE  
/NOTOTAL.

\*Parametric Correlations

\*Correlations between the PEM-CY (how often) and FIATS-AAC total and domain scores

## CORRELATIONS

/VARIABLES=pemcy\_often\_mean WITH fiats\_sum\_t1 behaviour\_t1  
caregiver\_relief\_t1 contentment\_t1 doing\_activities\_t1 education\_t1 energy\_t1  
face\_to\_face\_communication\_t1 family\_roles\_t1 security\_t1  
finances\_t1 self\_reliance\_t1 social\_versatility\_t1 supervision\_t1  
/PRINT=TWOTAIL NOSIG  
/MISSING=PAIRWISE.

\*Correlations between the PEM-CY (how involved) and FIATS-AAC total and domain scores

## CORRELATIONS

/VARIABLES=pemcy\_involved\_mean WITH fiats\_sum\_t1 behaviour\_t1  
caregiver\_relief\_t1 contentment\_t1 doing\_activities\_t1 education\_t1 energy\_t1  
face\_to\_face\_communication\_t1 family\_roles\_t1 security\_t1  
finances\_t1 self\_reliance\_t1 social\_versatility\_t1 supervision\_t1  
/PRINT=TWOTAIL NOSIG  
/MISSING=PAIRWISE.

\*Correlations between the CHQ-PF28 (Physical Summary Score) and the FIATS-AAC total and domain scores

## CORRELATIONS

/VARIABLES=PhSRAW\_transformed WITH fiats\_sum\_t1 behaviour\_t1  
caregiver\_relief\_t1 contentment\_t1 doing\_activities\_t1 education\_t1 energy\_t1  
face\_to\_face\_communication\_t1 family\_roles\_t1 security\_t1  
finances\_t1 self\_reliance\_t1 social\_versatility\_t1 supervision\_t1  
/PRINT=TWOTAIL NOSIG  
/MISSING=PAIRWISE.

\*Correlations between the CHQ-PF28 (Psychosocial Summary Score) and the FIATS-AAC total and domain scores

#### CORRELATIONS

```

/VARIABLES=PsSRAW_transformed WITH fiats_sum_t1 behaviour_t1
caregiver_relief_t1 contentment_t1 doing_activities_t1 education_t1 energy_t1
face_to_face_communication_t1 family_roles_t1 security_t1
finances_t1 self_reliance_t1 social_versatility_t1 supervision_t1
/PRINT=TWOTAIL NOSIG
/MISSING=PAIRWISE.

```

*Syntax for the scoring for the PEM-CY and CHQ-PF28 has not been provided due to proprietary concerns.*

#### *Variable Label Descriptions*

<b>Variable</b>	<b>Description</b>
<b>fiatsx_t1</b>	Item on the FIATS-AAC (i.e. fiats1_t1 corresponds to the score for the 1 <sup>st</sup> FIATS-AAC item)
<b>fiatsx_t1_Rev</b>	Reversed score for item on the FIATS-AAC (i.e. fiats1_t1_Rev corresponds to the reversed score for the 1 <sup>st</sup> FIATS-AAC item)
<b>behaviour_t1</b>	Mean FIATS-AAC score for ‘behaviour’ domain
<b>caregiver_relief_t1</b>	Mean FIATS-AAC score for ‘caregiver relief’ domain
<b>contentment_t1</b>	Mean FIATS-AAC score for ‘contentment’ domain
<b>doing_activities_t1</b>	Mean FIATS-AAC score for ‘doing activities’ domain
<b>education_t1</b>	Mean FIATS-AAC score for ‘education’ domain
<b>energy_t1</b>	Mean FIATS-AAC score for ‘energy’ domain
<b>face_to_face_communication_t1</b>	Mean FIATS-AAC score for ‘face-to-face communication’ domain
<b>family_roles_t1</b>	Mean FIATS-AAC score for ‘family roles’ domain
<b>security_t1</b>	Mean FIATS-AAC score for ‘security’ domain
<b>finances_t1</b>	Mean FIATS-AAC score for ‘finances’ domain
<b>self_reliance_t1</b>	Mean FIATS-AAC score for ‘self-reliance’ domain
<b>social_versatility_t1</b>	Mean FIATS-AAC score for ‘social versatility’ domain
<b>supervision_t1</b>	Mean FIATS-AAC score for ‘supervision’ domain

<b>fiats_sum_t1</b>	Total FIATS-AAC score (sum of thirteen domain means)
<b>pemcy_often_mean</b>	PEM-CY - Average Frequency (Individual Setting Score)
<b>pemcy_involvement_mean</b>	PEM-CY – Average Involvement (Individual Setting Score)
<b>PhSRAW_transformed</b>	CHQ-PH28 – Physical Summary Score
<b>PsSRAW_transformed</b>	CHQ-PF28 – Psychosocial Summary Score

**Appendix F.** Descriptive statistics and Cronbach's alphas for FIATS-AAC total and domain scores

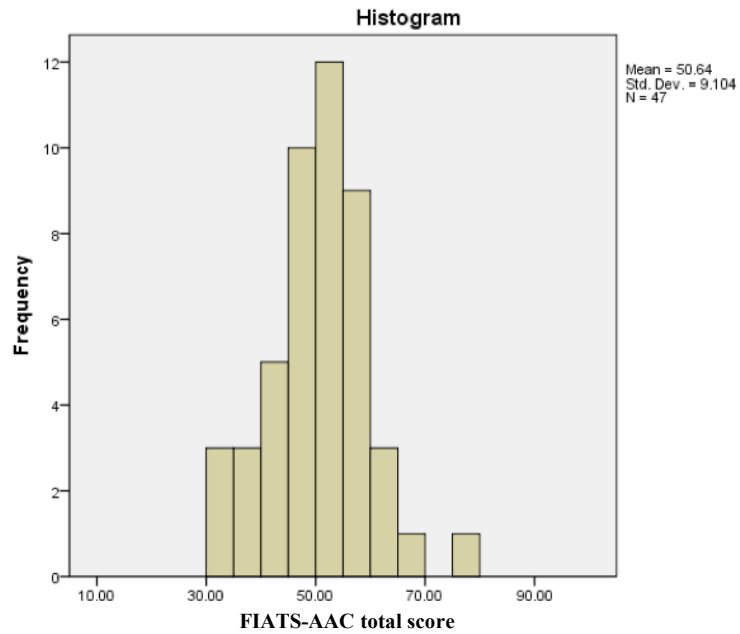
<b>Domain(# of items)</b>	<b>Minimum</b>	<b>Maximum</b>	<b>SD</b>	<b>Mean</b>	<b>n*</b>	<b>Alpha</b>
Behaviour (6)	2.2	7.0	1.2	4.9	45	0.83
Caregiver Relief (9)	1.0	6.7	1.3	3.5	45	0.90
Contentment (7)	1.9	6.3	1.0	4.3	44	0.68
Doing Activities (5)	2.4	6.6	1.0	4.6	46	0.46
Education (7)	1.0	6.1	1.1	4.6	43	0.73
Energy (7)	1.7	5.7	1.1	3.5	41	0.76
Face-to-face communication (8)	1.6	5.6	1.0	3.6	44	0.75
Family Roles (7)	1.3	5.3	1.0	3.6	44	0.58
Finances (5)	1.0	6.8	1.5	3.9	47	0.82
Security (7)	1.6	5.1	0.7	3.0	47	0.48
Self-reliance (7)	1.7	5.9	1.0	4.0	46	0.72
Social Versatility (7)	1.4	5.4	0.9	3.7	46	0.54
Supervision (7)	1.0	6.3	1.2	3.4	45	0.80

\*Participants with any missing item ratings were not included in the calculation of alpha



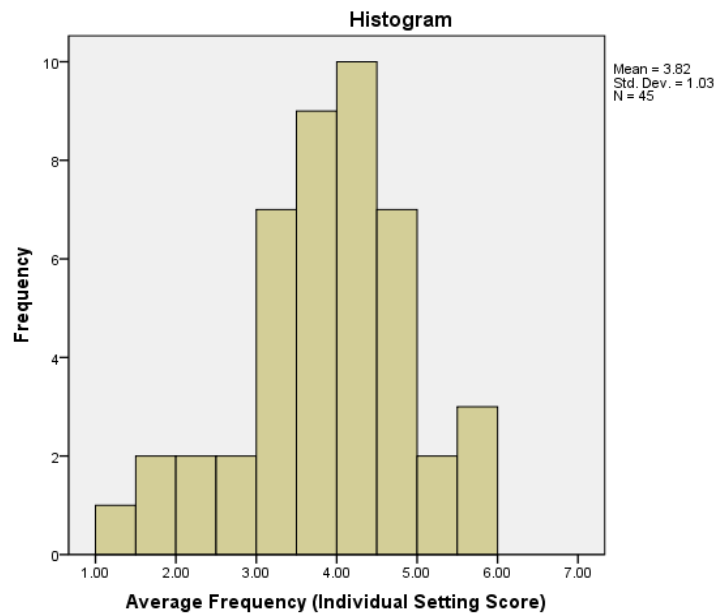
**Appendix G. Histograms for total scores of participant questionnaires**

*FIATS-AAC*

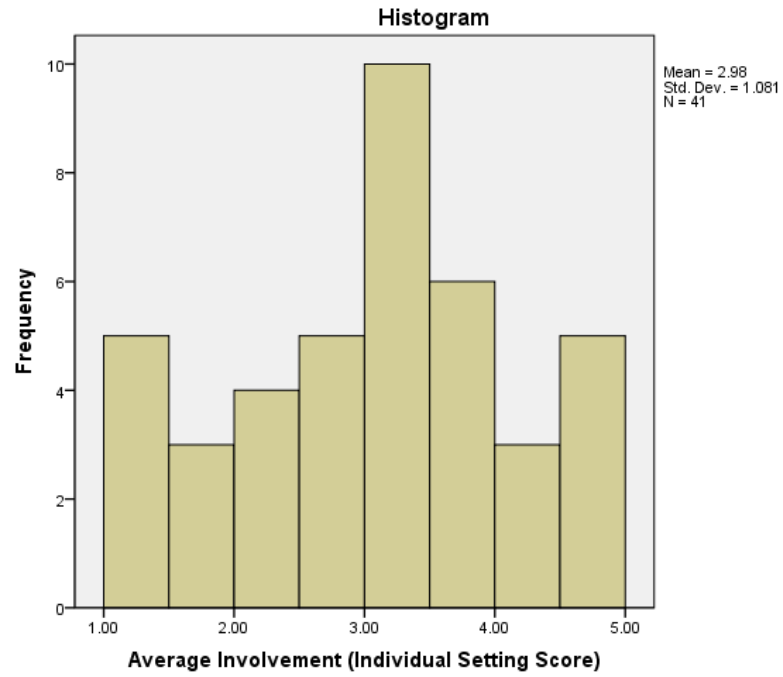


*PEM-CY*

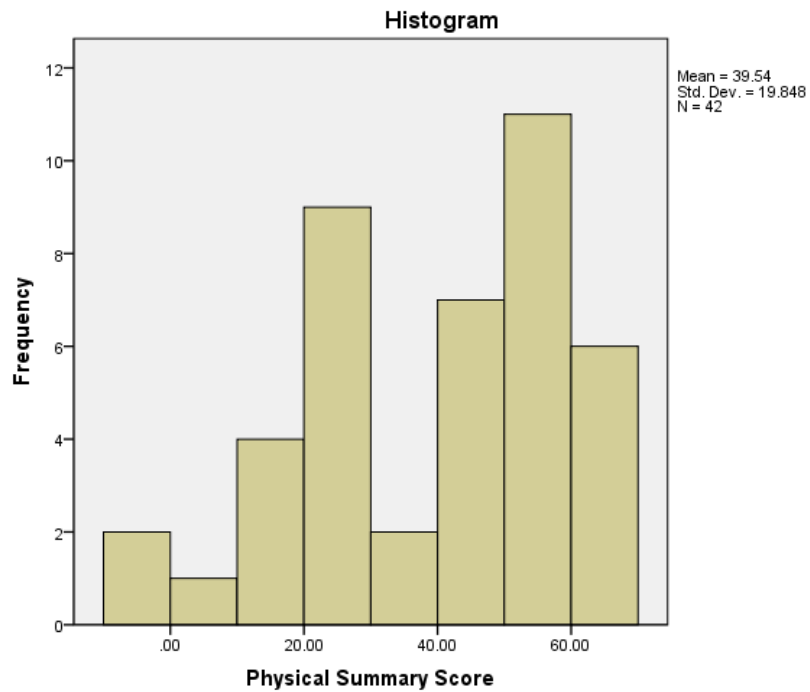
*Average Frequency - (community setting)*



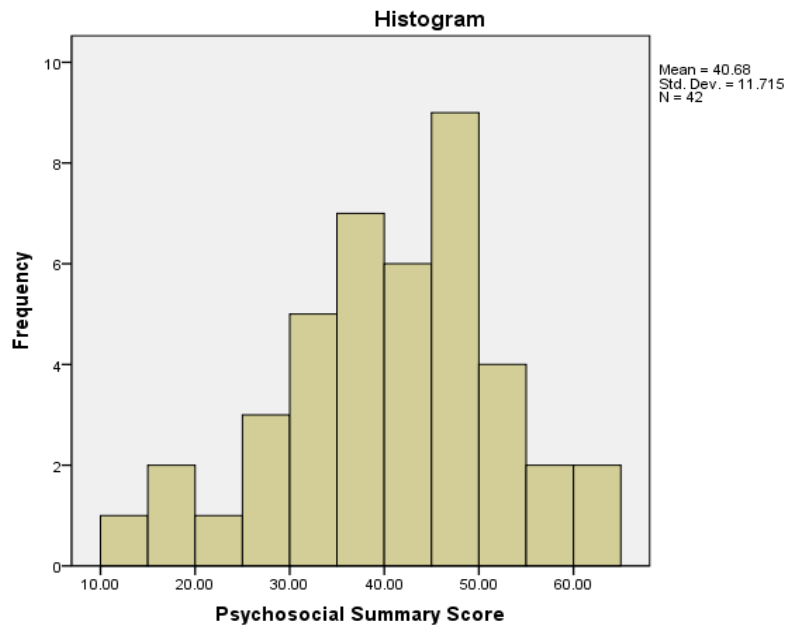
*PEM-CY*  
*Average Involvement – (community setting)*

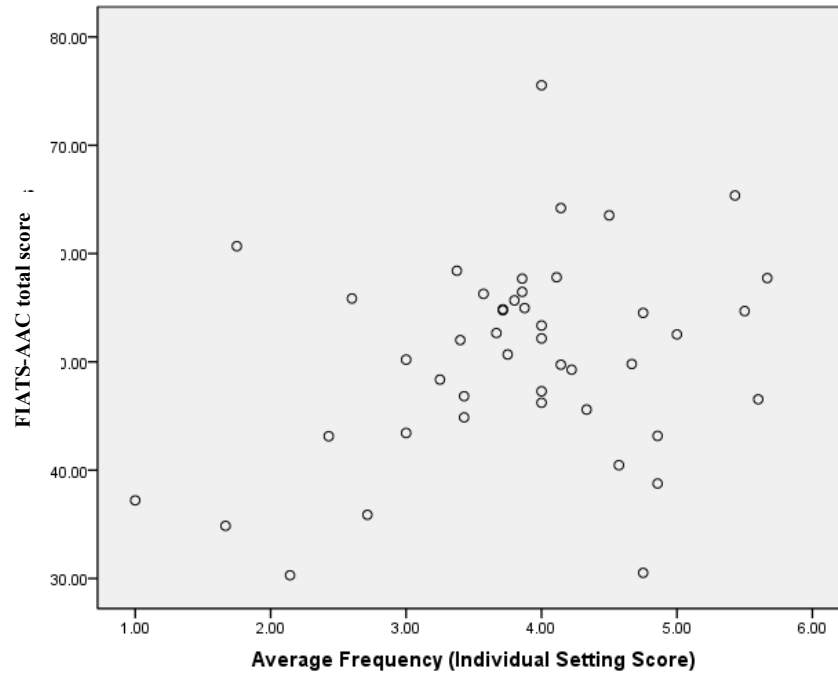
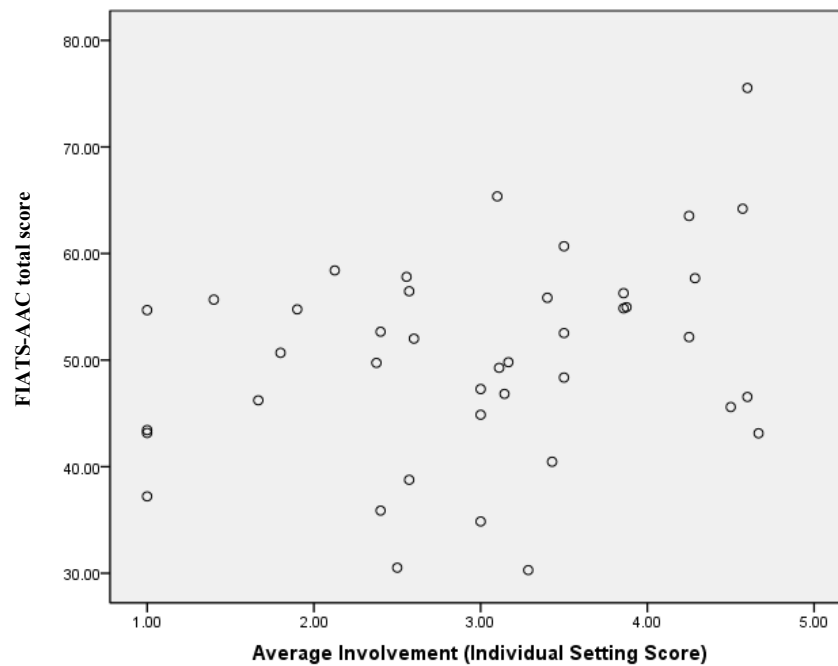


*CHQ-PF28*  
*Physical Summary Score*

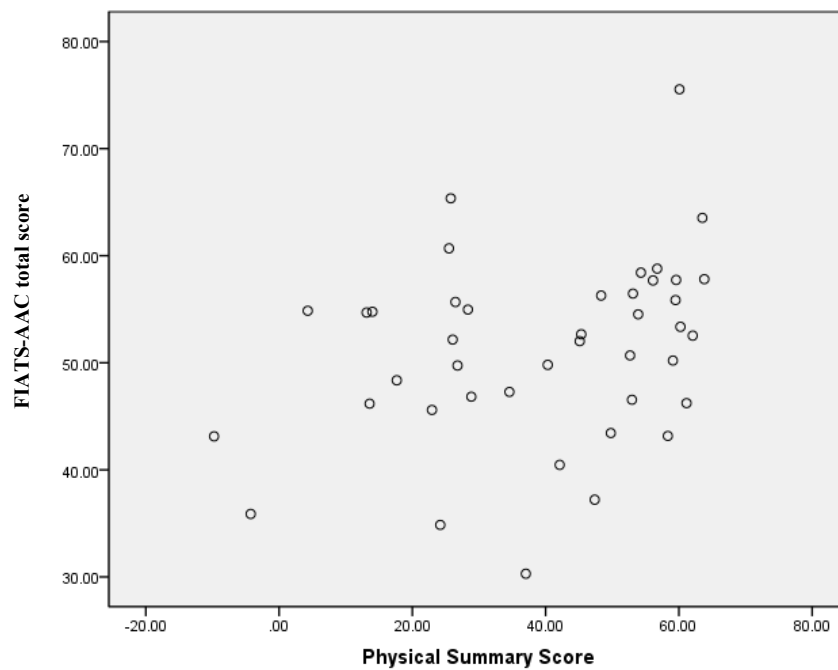


*CHQ-PF28*  
*Psychosocial Summary Score*

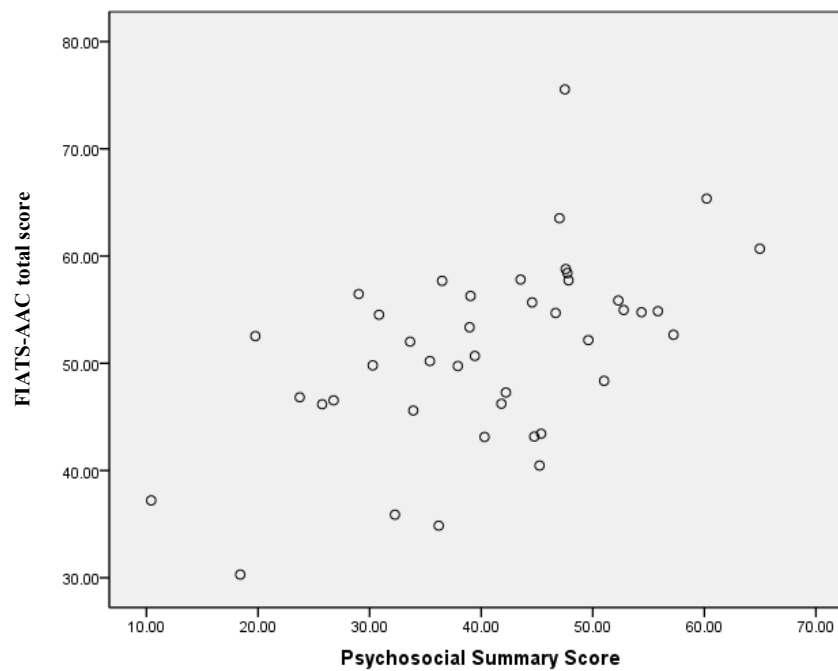


**Appendix H.** Scatterplots for FIATS-AAC total correlations with PEM-CY and CHQ-PF28*FIATS-AAC total and PEM-CY (how often)**FIATS-AAC total and PEM-CY (how involved)*

*FIATS-AAC total and CHQ-PF28 (Physical Summary Score)*



*FIATS-AAC total and CHQ-PF28 (Psychosocial Summary Score)*



**Appendix I.** Observed and assigned valence ratings for semi-structured interviews

<b>1</b>					<b>5</b>				
<b>Questionnaire</b>					<b>Questionnaire</b>				
<b>Interview</b>	Positive	Neutral	Negative	<b>Sum</b>	<b>Interview</b>	Positive	Neutral	Negative	<b>Sum</b>
Positive	0	0	1	1	Positive	1	2	0	3
Neutral	0	1	1	2	Neutral	0	4	0	4
Negative	0	2	8	10	Negative	0	5	1	6
<b>Sum</b>	0	3	10	<b>13</b>	<b>Sum</b>	1	11	1	<b>13</b>
<b>2</b>					<b>6</b>				
<b>Questionnaire</b>					<b>Questionnaire</b>				
<b>Interview</b>	Positive	Neutral	Negative	<b>Sum</b>	<b>Interview</b>	Positive	Neutral	Negative	<b>Sum</b>
Positive	2	5	0	7	Positive	1	1	0	2
Neutral	1	2	1	4	Neutral	0	1	0	1
Negative	0	2	0	2	Negative	0	7	3	10
<b>Sum</b>	3	9	1	<b>13</b>	<b>Sum</b>	1	9	3	<b>13</b>
<b>3</b>					<b>TOTAL</b>				
<b>Questionnaire</b>					<b>Questionnaire</b>				
<b>Interview</b>	Positive	Neutral	Negative	<b>Sum</b>	<b>Interview</b>	Positive	Neutral	Negative	<b>Sum</b>
Positive	2	4	0	6	Positive	9	12	1	22
Neutral	1	1	0	2	Neutral	2	9	2	13
Negative	0	5	0	5	Negative	2	28	13	43
<b>Sum</b>	3	10	0	<b>13</b>	<b>Sum</b>	13	49	16	<b>78</b>
<b>4</b>									
<b>Questionnaire</b>									
<b>Interview</b>	Positive	Neutral	Negative	<b>Sum</b>					
Positive	3	0	0	3					
Neutral	0	0	0	0					
Negative	2	7	1	10					
<b>Sum</b>	5	7	1	<b>13</b>					

**Appendix J.** Distribution of researcher-assigned valences

<b>Valence rating</b>	<b>Valence distribution by interview (%)</b>					
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
Positive	8	54	46	23	23	15
Neutral	15	31	15	0	31	8
Negative	77	15	39	77	46	77