



# Inclusion Through Participation: Understanding Participation in the International Classification of Functioning, Disability, and Health as a Methodological Research Tool for Investigating Inclusion

Gregor R. Maxwell 1,2\*, Mats Granlund 3,4 and Lilly Augustine 2,5

<sup>1</sup> Inclusive and Special Education Section, Department of Education, UIT Norway's Arctic University, Tromsø, Norway, <sup>2</sup> Child Health Intervention Learning and Development, Swedish Institute for Disability Research, School of Education and Communication, Jönköping University, Jönköping, Sweden, <sup>3</sup> Child Health Intervention Learning and Development, Swedish Institute for Disability Research, School of Health Sciences, Jönköping University, Jönköping, Sweden, <sup>4</sup> Department of Special Education, Oslo University, Oslo, Norway, <sup>5</sup> Department of Psychology, Faculty of Education, Kristianstad University, Jönköping, Sweden

**OPEN ACCESS** 

#### Edited by:

Brahm Norwich, University of Exeter, United Kingdom

#### Reviewed by:

Matthew J. Schuelka, University of Birmingham, United Kingdom Caroline Bond, University of Manchester, United Kingdom

#### \*Correspondence:

Gregor R. Maxwell gregor.maxwell@uit.no

#### Specialty section:

This article was submitted to Special Educational Needs, a section of the journal Frontiers in Education

Received: 12 January 2018 Accepted: 22 May 2018 Published: 12 June 2018

#### Citation:

Maxwell GR, Granlund M and
Augustine L (2018) Inclusion Through
Participation: Understanding
Participation in the International
Classification of Functioning, Disability,
and Health as a Methodological
Research Tool for Investigating
Inclusion. Front. Educ. 3:41.
doi: 10.3389/feduc.2018.00041

This paper investigates the use and validity of the International Classification of Functioning disability and health (ICF) as a common language for describing inclusive educational settings. There is a specific focus on investigating participation through the ICF as one aspect of inclusion as an improved understanding of participation as a measure of inclusion will greatly benefit children with additional support needs. In addition there will be a better understanding of the operationalization of participation, in terms of both policy and practice, and improved applications of the ICF. The study uses a narrative summary review to analyse the findings from a selection of studies where the ICF has been used as a methodological tool in the field of education. In the 16 included studies the ICF is either used to present a new theoretical position, synthesize a new research approach or tool, or is integrated into the framework of an existing research method. Findings also show that the ICF is used in a number of different ways and that when it is used directly, variation is found in the type of information that was linked to ICF codes or categories. In conclusion further clarity on defining and measuring participation with the ICF framework is required in order to create a more consistent tool for investigating inclusive education. One way to improve the construct of participation is to take a bi-dimensional approach. It is the authors' belief that this newer approach to modeling participation will be considered in any future revisions of the ICF/ICF-CY-a so-called "ICF-2". This would thus create a more accountable classification framework that succeeds in capturing the involvement experience of the individual and in doing so achieves a more effective and useful classification framework for the field of inclusive education.

Keywords: ICF-CY, methodology, education, participation, inclusion

1

#### INTRODUCTION

A number of challenges are often encountered by children with additional support needs when they attend school, these can range from logistical access-related issues to the school itself to a lack of technical or human support services. In order to overcome these issues and reduce social exclusion we need to furnish education with effective policy that enhances inclusive education (Grammenos, 2003). The World Health Organization's International Classification of Functioning, Disability and Health—in both the original adult-focused version (the ICF, World Health Organization, 2001), and the child and youth version (the ICF-CY, World Health Organization, 2007)—has been suggested as suitable and appropriate for use in the field of education (Florian et al., 2006) and can provide common terminology for practitioners, policy makers, and researchers (Simeonsson et al., 2008). Hollenweger has also expanded the basic ICF model for application in education and recognizes that a definition of disability used for eligibility purposes is required within the general curriculum for all children (Hollenweger, 2011).

A short note on the terminology and the ICF, as the theoretical underpinnings of the ICF and ICF-CY are identical (the differences lie in the execution of the coding framework), in this paper we will refer to the ICF when referring generally to the framework and to the ICF-CY when referring to specific agerelevant applications of the ICF or when studies have explicitly used the ICF-CY.

Awareness of the context is of great importance when assessing functioning and the ICF can be useful as the framework provides the opportunity to capture functional information about not just the individual, but also the way they interact with their environment and which personal factors they bring to the situation. Participation is also a key component of inclusion though challenges remain in conceptualizing, measuring, and providing interventions (Granlund, 2013). Involvement is of particular importance in an inclusive education setting where democratic values play an important role (Nilholm, 2006). Similarly, of Nilholm's (2007) three perspectives on special education—the Compensation-, the Critical-, and the Dilemma perspective—the Dilemma combines individual and social perspectives and could potentially be practically put into operation by the ICF.

A previous review of the ICF in the field of education has found that the framework is currently used as a research tool, theoretical framework, and tool for implementing educational processes (Moretti et al., 2012, p. S103). Similarly, while operationalizations of participation are not always consistent with definitions used, when focussing on participation within inclusive education aspects relating to adaptations made and making support available are most prevalent (Maxwell et al., 2012a). More recently, Norwich (2016) has explored the usefulness of using the bio-psycho-social approach in special education in England and compares how the ICF-CY fits in with current and previous terminology and conceptualizing of "special educational needs." As a result of Norwich's paper, and an everincreasing collection of other works investigating the application

of the ICF in an education context, we believe a more focussed review of the current state of knowledge is merited.

The presented paper intends to explore the use and validity of the ICF as a common language for describing inclusive educational settings with a focus on investigating participation through the ICF as one aspect of inclusion. The paper is specifically focused by the following research questions:

- How does the participation component of the ICF provide a valid and consistent approach to investigating aspects of inclusion?
- In what way can the participation component of the ICF be practically improved as a tool for investigating inclusion?

#### **BACKGROUND**

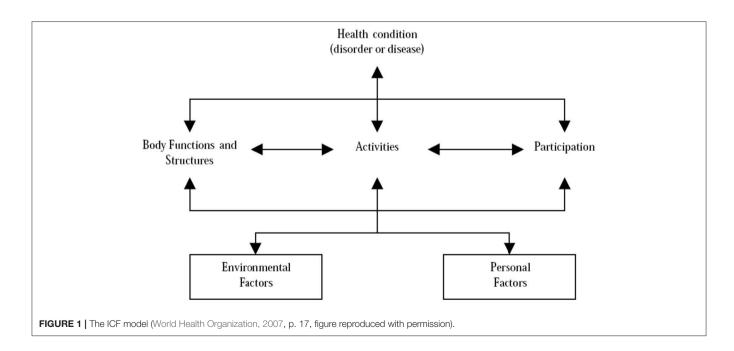
The United Nations' (UN) Convention on the Rights of the Child requires respect for the diversity of learning conditions for all students in order to uphold inclusive values, practices, and principles within education (United Nations, 1989). These points have been further built upon by preceding international conventions and documents, such as the Salamanca statement (UNESCO, 1994), the Dakar framework (UNESCO, 2000), the UN's Convention on the Rights of Persons with Disabilities (United Nations, 2006), and most recently the ICF (World Health Organization, 2001), and the Child and youth version, the ICF-CY (World Health Organization, 2007). In parallel with these major international developments in the course of the last 20-30 years Ainscow et al. (2006) have developed an approach to education and society based on "inclusive values" such as equity, participation, community, compassion, and respect for diversity. This approach, also referred to as the "Index for Inclusion" (Booth and Ainscow, 2011) is principally focussed on increasing participation and as such shares strong theoretical links with the ICF and additionally encourages the user to build their own view of inclusion based on their own experiences and values, much in the same way the ICF encourages the user to bring their own theoretical ideas to the framework.

However, how to build on this approach and the international steering documents and practically and reliably investigate inclusive education is challenging with considerations relating to, for example, methodological issues including terminology, the nature of interventions, and research methods (Lindsay, 2007); difficulty is also seen when applying inclusion in practice (cf. Göransson et al., 2010). Special education is intrinsically linked with inclusion, and three specific perspectives are described by Nilholm (2007), these are: the Compensation perspective, the Critical perspective, and the Dilemma perspective. By often using medical and psychological groups and diagnoses to categorically provide support the compensation perspective locates the problem and cause of any difficulties in the individual child. Working more democratically, the critical perspective relocates the problem from within the child to the context whereupon it becomes the responsibility of the school or education system. The critical perspective abandons categorical groupings and diagnoses and employs more subjective descriptors and can be seen as a direct response to the compensation perspective (Skrtic, 1991). By comparison, the dilemma perspective is a critique of both of the compensation and critical perspectives and takes a pragmatic approach by recognizing the shortcomings of the two other perspectives while simultaneously acknowledging that there is no ultimate solution to an educational situation since each one is very much shaped by the context and time in which they occur. One means to operationalize inclusion for individual students, which would be in-line with the dilemma perspective, is to define it as participation. As participation contains two dimensions; the frequency with which a student attends the same educational activities as other students combined with the intensity of involvement the student perceives in the attended activities.

The ICF (World Health Organization, 2001) uses a person-based bio-psycho-social approach to classify aspects of functioning of persons in their environments. As such it is as a member of the WHO family of classifications and was introduced as a context-based international standard for human functioning intended to complement the non-contextfocussed International Classification of Disease (World Health Organization, 1992). Both the ICF and the ICF-CY can be considered to be conceptually identical since they use the same model to construct their frameworks; the only difference is to be found in the expansion of the chapters within the domains and an associated increase in the number of codes. The ICF framework is organized into two main parts: Part one is concerned with components relating to functioning and disability where body functions and structures interact with activities and participation. Part two is concerned with contextual factors and contains components related to environmental and personal factors as external and internal influences on functioning and disability. It should be stressed that the ICF treats disability is a normal occurrence and experience of living and not comparable to an illness, although there is a requirement for the presence of

a health condition (see Figure 1). The framework uses codes to describe aspects of functioning and there are four components of classification: activities and participation, environmental and contextual factors, body functions, and body structures (World Health Organization, 2007). Within each of these four components sub-chapters are hierarchically arranged that correspond horizontally across body functions, body structures, and activities and participation. For example relating to thinking and learning, there is a logical connection across each of the firstlevel sub-chapters with: b1 Mental functions in body functions, s1 Structures of the nervous system in body structures, and d1 Learning and applying knowledge in activities and participation. Coding rules (Cieza et al., 2005) have been produced to provided constancy and clarity for researchers, however difficulties are being reported when coding large sections of free text (Klang Ibragimova et al., 2011) and when coding items from questionnaires (Augustine et al., 2017).

While the ICF is intended for use by all, it can be especially useful in providing a context-based profile of functioning for individuals in need of additional support. Bringing in the context makes the ICF relatively unique and allows the framework to capture environmental factors, which are all aspects of the external setting, and provides the theoretical basis to develop ways to capture personal factors—which are things related to the individual, suggested by the ICF itself as factors such as age, gender, social status, life experience, etc. (World Health Organization, 2007, p. 229). Personal factors are, however, not yet classified in the ICF although it is hope to bring them into operation in any future iterations of the framework after further standardization and defining (Geyh et al., 2011). Despite various shortcomings the ICF nevertheless provides a noncategorical approach to disability and is therefore suitable for a cross-national classification system (Hollenweger, 2008) and has already been integrated into a proposed matrix for inclusive



education systems (Hollenweger, 2010). It is therefore valid to propose the ICF as the methodological bridge to provide consistency when investigating inclusive education.

## The ICF-CY as a Framework to Operationalize and Measure Participation

The ICF's bio-psycho-social approach has its roots in both an individual-focussed *medical model* of human functioning, and a socially-constructed participation-restriction-based *social model* of functioning. The two constructs are bridged by activity. Participation restrictions can be considered socially constructed phenomena when availability and access to everyday activities is in focus; participation is thus considered as being given the same opportunities or equivalent to frequency of taking part in the same situations as others.

#### Participation as a Construct

There is a great deal of discussion surrounding participation as a construct in the literature with focus often being on clarity and definition (cf. McConachie et al., 2006; Badley, 2008; Coster and Khetani, 2008; Whiteneck and Dijkers, 2009; Granlund, 2013; Imms et al., 2016). Specifically there have been recent calls to ensure that participation measures capture the whole life space of the child (King, 2013), that a measure includes the environment as a facilitator or barrier to participation (Coster et al., 2012), that it is age-relevant (McConachie et al., 2006), and that attendance and involvement are central aspects of the concept (Imms et al., 2016). There is unfortunately ambiguity within the ICF where activity and participation are presented as two distinct entities in the model (World Health Organization, 2007, p. 17 Figure 1 and Figure 1 in this paper), however, in the ICF's framework itself they are combined to form one of the main components, needing other information in order to separate activity and aspects of participation, such as qualifiers. This has led to empirical investigations to present them as distinct (Jette et al., 2003) and theoretical musings to improve matters (Badley, 2008).

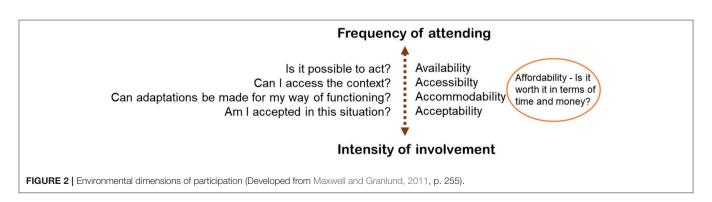
One way to consider participation is to look at both the right to take part and the level of engagement or involvement when taking part (Granlund et al., 2012); these two perspectives are both related to functioning in a context and were initially outlined by Granlund (2006) and have conceptual roots in sociology and developmental psychology respectively. The

sociological root focuses on the availability of and access to everyday activities while describing participation as frequency of attending the same activities as others. Participation based on the psychological root focuses on whether the environment is accommodated to and accepted by the child while describing the intensity of involvement or engagement in an activity. A viable way of assessing the involvement of a person in their environment is to measure either the frequency of attendance or the intensity of engagement in a life situation (Maxwell, 2012). Participating in an activity can therefore be seen from two perspectives: the individual, and the society; the ICF framework does not make this distinction with activity (individual) and participation (society) being operationalized as one domain, despite being conceived as two constructs (see Figure 1). Since the ICF does not take this bi-dimensional approach in its representation and operationalization of participation it is currently problematic to use. Therefore changes are required to effectively operationalize participation within the ICF, particularly when contextualizing functioning such as is required in education.

Figure 2 shows the conceptual re-working of participation initially used by Simeonsson et al. (2001) and expanded upon by Maxwell and Granlund (2011) where frequency of attending and intensity of involvement are outlined as two aspects of participation. These aspects exist in a spectrum of five environmental dimensions of conditions for participation (Simeonsson et al., 1999) and have their origins in a model of access to health (Penchansky and Thomas, 1981) with considerable development to better suit education.

The five central dimensions concerning the environment have been developed by Granlund and colleagues (Maxwell et al., 2012b; Granlund, 2013) while calling for operations of participation that include both frequency and intensity dimension. The five environmental dimensions are:

- Availability describes the objective possibility to engage in a situation.
- Accessibility describes whether you can, or perceive that you can, access the context for the situation.
- Affordability covers not only financial constraints but also whether the amount of effort in both time and energy expenditure is worth the return to engage in the situation.
- Accommodability/Adaptability describes whether a situation can be adapted.



 Acceptability covers people's acceptance of a person's presence in a situation. When values are expressed, or common beliefs are held which are of a subjective nature then this can be considered acceptability.

The environment needs to be considered as a pre-requisite as it is an intrinsic part of the involvement part of the participation experience and acts as a "scene-setter" (Badley, 2008) by facilitating or hindering participation. Here, it has to be emphasized that although involvement is being referred to in a psychological manner, it is not related to a medical approach as it is considered from a subjective experience of participation from the individual's perspective. By representing participation from both a frequency of attending and an intensity of involvement perspective it is proposed that reductionist issues will be avoided as the focus will not be on only one of the dimensions (Maxwell, 2012). This bi-dimensional construction of participation provides a more balanced way of representing the construct and brings in involvement to provide a more stringent and balanced construction of participation that will enable better and more effective measures to be developed (Granlund, 2013). The involvement component of participation is also of particular importance in an inclusive education setting where democratic values play an important role (Nilholm, 2006).

### Practical Approaches: Bio-Psycho-Social and Inclusive- and Special Education

Theoretical perspectives require practical approaches to realize their full potential. The WHO's ICF with its bio-psycho-social approach to classifying aspects of functioning and disability within a defined context offers one potentially useful way to operationalize the dilemma perspective. The ICF intends to capture data concerning functioning and can be used to describe human functioning and disability for clinical, research, and policy development purposes (Üstün et al., 2003). The ICF does not however offer any theory in its own right, but merely a framework and language for health and health-related states that can be mapped with different constructs and domains around which existing theoretical approaches can be applied (World Health Organization, 2007, p. 17). In relation to inclusive education this also indicates that the ICF offers a more pragmatic approach to classifying additional support needs than either the compensation or critical perspectives offer. The ICF is therefore particularly useful when operationalizing Nilholm's dilemma perspective (Nilholm, 2007) within inclusive- and special education.

From its inception, the ICF and ICF-CY were seen as useful frameworks for the field of education, particularly when requiring the classification of individuals with additional support needs (Florian et al., 2006). In terms of the ICF's use in education Moretti et al. (2012) found that while there is still a low prevalence of its use the ICF/ICF-CY is currently being used as a research tool, theoretical framework, and tool for implementing educational processes. Specific uses of the ICF in education systems have been seen in Portugal, Italy, and Switzerland. In Portugal in 2008 the country introduced a national ICF-based eligibility assessments for specialized. In Italy the ICF was used at

local levels in schools to design individual education plans (IEPs). In Switzerland the ICF has been integrated into the education system of the canton of Zürich.

As there is currently a great deal of variety and discrepancy in theory, praxis, and research within the field of education, the ICF can be considered as able to provide the field with a useful and unifying language (Moretti et al., 2012). In terms of specifically adapting the ICF to education, while the WHO specifically intends the ICF to exclusively concerned with health domains of well-being (World Health Organization, 2007, p. 228), the ICF also allows domains of life which contribute to health-related well-being to be considered; thus education can be included (Hollenweger, 2014).

#### **METHOD**

#### Study Design

This study uses qualitative evidence synthesis (Hannes and Lockwood, 2011) in the form of a narrative summary (Dixon-Woods et al., 2005) to review the participation-related findings from studies which all use the ICF framework as either a theoretical basis or a methodological tool to analyse education and inclusion-related data. Studies were selected from refined keyword searches online and in a number of academic databases, along with an ecological search-approach based on a snowball method starting with known researchers in the field. Inclusion criteria included that studies explored the relationship between education, the ICF, and participation. Information about how the concept participation was applied was extracted using an extraction protocol based on the research questions.

#### Material

Data were sourced by executing keyword searches initially in Google scholar, and then with more focus within the following databases: ERIC (Educational Resources Information Centre), PsychINFO, PsychNET, Sociological Abstracts (ProQuest). Search terms were chosen based on the study's focus and their suitability was discussed among the authors, experts in the field, and research librarians in order to judge the search sources, preliminary results, and the theoretical and practical relevance. Specifically, keywords were selected based on their relevance to the ICF (e.g., ICF, International Classification of functioning, ICF-CY, etc.), and to education (school, education\*, inclusion/inclusive, eligibility, goals, identification) and various abbreviations/ combinations of the word participation (participate, take part, involved, etc.)

The search was limited to English-language publications and included academic works in the form of journal articles, conference proceedings/papers, books and book chapters, and reports. The time period of 2001 to the present day was chosen as the ICF was published in 2001. The results had to be available on the 30th November 2017. From an initial search pool of several thousand publications, 16 were included in the presented study (**Table 1**).

In all of the studies information has been compared or contrasted with ICF or ICF-CY components or translated into

TABLE 1 | Included studies.

| Study                                 | Title  | Туре                      | Context/Country             | Details  |
|---------------------------------------|--|---------------------------|-----------------------------|--|
| Castro et al.,<br>2011                | Linking the Carolina curriculum for pre-schoolers with special needs to the ICF-CY.  | Empirical                 | Portugal                    | Data are linked to ICF-CY codes and categories in order to use the ICF-CY framework to analyse 33 Individualized Education Programmes for pre-schoolers with autism attending inclusive special education services in Northern Portugal.   |
| Castro et al.,<br>2014                | Content analysis of Portuguese individualized education programmes for young children with autism using the ICF-CY framework.  | Empirical                 | Portugal                    | A Portuguese study that links a curriculum-based developmental measure, designed for the assessment of pre-schoolers with mild to severe special needs, to the codes of the ICF.   |
| Coster et al.,<br>2012                | Development of the participation and environment measure for children and youth: conceptual basis.   | Empirical                 | North America               | Presents the Participation and Environment Measure for Children and Youth (PEM-CY), which is a parent-report questionnaire-based tool intended for a broad range of children with and without disability. PEM-CY includes questions on participation frequency (how often) and quality (how involved) on 0–7 and 1–5 point scales respectively.  |
| Hollenweger,<br>2011                  | Development of an ICF-based eligibility procedure for education in Switzerland.  | Theoretical               | Switzerland                 | Proposes a model to integrate and use the ICF-CY in educational systems by using eligibility procedures based on the ICF.  |
| Hollenweger<br>and Moretti,<br>2012   | Using the International Classification of Functioning, Disability and Health Children and Youth version in education systems: a new approach to eligibility.   | Theoretical               | Switzerland                 | Proposes practical ways to integrate and use the ICF-CY in educational systems by using eligibility procedures based on the ICF.   |
| Klang et al.,<br>2016                 | The content of goals in individual educational programs for students with complex communication needs.   | Empirical                 | United States of<br>America | The study investigates communication-related goals in Individual Education Plans (IEPs) by using the ICF to explore the contents of the plans.   |
| Klein and<br>Camargo,<br>2018         | A Proposed Functional Abilities<br>Classification Tool (FACT) For<br>Developmental Disorders<br>Affecting Learning and Behavior.   | Theoretical and empirical | North<br>America/Canada     | Presents the Functional Abilities Classification Tool (FACT) for developmental disorders affecting learning and behavior (DDALB). The FACT tool is based on the concepts of the ICF and is intended to provide ability and participation classification that is complementary to medical diagnosis. The authors attempt to propose a comprehensive tool for widespread usage in schools that measures both abilities and participation in the population of children with DDALB. |
| Koutsogeorgou<br>et al., 2013         | Associations of social capital and inclusive education policies: the usefulness of the biopsychosocial model.  | Empirical                 | Europe                      | A policy review where the ICF-CY categories are used as reference-points to compare international data on inclusive policy provision.  |
| Maxwell and<br>Granlund,<br>2011      | How are conditions for participation expressed in education policy documents? A review of documents in Scotland and Sweden.  | Empirical                 | Sweden and<br>Scotland      | Presents a practical application of the ICF within research and uses the ICF-CY's categories to review how inclusion is expressed by the participation content of policy documents from Scotland and Sweden when related to special education/additional support needs. A framework based on the five environmental dimensions of participation is used.   |
| Maxwell and<br>Koutsogeorgou,<br>2012 | Using social capital to construct a conceptual International Classification of Functioning, Disability, and Health Children and Youth Version–Based framework for stronger inclusive education policies in Europe. | Theoretical               | Europe                      | Proposes linking the ICF with social capital to develop a measure for inclusive policy provisions.   |

(Continued)

TABLE 1 | Continued

| Study                                | Title   | Туре                                       | Context/Country | Details   |
|--------------------------------------|---|--|-----------------|---|
| Maxwell et al.,<br>2012a             | Participation and environmental aspects in education and the ICF and the ICF-CY: Findings from a systematic literature review.  | Empirical, systematic literature review    | International   | A review of the use of the ICF-CY in education with a specific focus on methodological consistency between researchers' theoretical descriptions and practical applications of participation constructs.  |
| Maxwell et al.,<br>2012b             | Does thinking and doing the same thing amount to involved participation? Empirical explorations for finding a measure of intensity for a third ICF-CY qualifier.  | Empirical                                  | Sweden          | The ICF-CY's categories are used in a Swedish context to directly code data relating to individual students' self-reported expressions of participation. ICF-CY categories are used as reference-points to compare expressions with an index of intensity/engagement being developed from ratings of thinking and doing the same thing.           |
| Moretti et al.,<br>2012              | A Systematic Literature Review of the Situation of the International Classification of Functioning, Disability, and Health and the International Classification of Functioning, Disability, and Health–Children and Youth Version in Education: A Useful Tool or a Flight of Fancy? | Empirical, systematic<br>literature review | International   | Presents the use of the ICF-CY in education.  |
| Raggi et al.,<br>2014                | The development of a structured schedule for collecting ICF-CY-based information on disability in school and preschool children: an action research from Italy.   | Empirical                                  | Italy           | Outlines the development of an instrument to collect disability information in school settings based on the ICF-CY. This is done through an action-research process 67 ICF-CY categories were included and deemed useful and 62 were developed into the developed ICF-CY-PEI schedule (ICF-CY-based schedule for Individualized Education Plans). |
| Sanches-<br>Ferreira et al.,<br>2013 | Portugal's special education law: implementing the International Classification of Functioning, Disability and Health in policy and practice.   | Empirical                                  | Portugal        | The paper describes the implementation of the ICF under Decree-Law 3/2008 and its utility in the assessment process and eligibility determination of students for special education. This is done through a document analysis of the assessment and eligibility processes from a nationally representative sample of school students.             |
| Sanches-<br>Ferreira et al.,<br>2015 | Evaluating implementation of the International Classification of Functioning, Disability and Health in Portugal's special education law.  | Empirical                                  | Portugal        | A followed-up to Portugal's introduction in 2008 of an ICF-based eligibility assessments for specialized education services, Decree-Law 3/2008. The paper reports the results of a two-year project commissioned by the Portuguese Ministry of Education to investigate the implementation of the law.  |

ICF or ICF-CY codes or categories as a common language for health-related information. The studies that directly used the ICF framework within an existing research methodological framework (Castro et al., 2011, 2014; Maxwell and Granlund, 2011; Maxwell and Koutsogeorgou, 2012; Maxwell et al., 2012a,b; Moretti et al., 2012; Koutsogeorgou et al., 2013; Raggi et al., 2014; Klang et al., 2016) all used the *Linking rules* developed by Cieza et al. (2005) and the *Guidelines for coding ICF* presented in the ICF-CY, annex 2 (World Health Organization, 2007, p. 234). For the document analyses practices for qualitative content analysis were also taken into consideration (Krippendorff, 2004). The presented studies exhibit a number of theoretical and practical problems being experienced during the linking process with differences also being seen in the type of information that was connected to the ICF-CY.

#### **RESULTS**

In the 16 included studies the ICF is either used to present a new theoretical position, synthesize a new research approach or tool, or is integrated into the framework of an existing research method. Results are presented here under the two research questions.

#### How Does the Participation Component of the ICF Provide a Valid and Consistent Approach to Investigating Aspects of Inclusion?

The most comprehensive review of the literature regarding the use of the ICF in education is provided by Moretti et al. (2012)

who give a general overview of how the ICF/ICF-CY is currently situated in education, Special Educational Needs and with children requiring additional support in school. In their study 23 publications met inclusion criteria from an initial 421 and results showed a predominance of studies from Europe and North America, and from English-speaking countries. The articles were mainly published in non-educational journals, and the most used ICF components were activity and participation, participation, and environmental factors. From the analysis of the included papers, the ICF is currently used as a research tool, theoretical framework, and tool for implementing educational processes (Moretti et al., 2012). From the same dataset Maxwell et al. (2012a) expanded the review by focusing on how participation was described theoretically and used practically in educational research; this paper explicitly used the bi-dimensional model for participation (Granlund, 2013) and found that availability and accommodations were the most investigated environmental dimensions. Coincidentally in Maxwell et al. (2012a) 23 publications also met inclusion criteria from the 421 works initially found with results showing that the operationalization of participation was not always consistent with definitions used, however all papers reviewed referenced at least one of the environmental dimensions of participation which further validates the bi-dimensional approach to participation.

A policy review study comparing Scotland and Sweden (Maxwell and Granlund, 2011) reviewed 41 educational policy documents in order to investigated how conditions for participation are expressed for pupils with additional support needs. The study analyzed and compared documents that had a direct bearing on classroom practices from the two countries at national, regional, and local-levels. Results indicate that expressing conditions for participation as available and accessible opportunities, or as factors relating to affordability can be readily done. However, expressing conditions for participation as accommodation- and acceptability-related experiences within a context was less apparent. There were also differing foci regarding how conditions for participation are expressed: In Scotland there is a focus on availability of participation opportunities, whereas in Sweden there is a focus on acceptable use and implementation.

As support for the ICF offering a common and consistent language for professionals, Castro et al. (2011) found that the ICF-CY along with a biopsychosocial model of development provided a theoretical framework, as well as a classification system, that enabled the documentation of functionality profiles of children using a common language across settings and disciplines.

When investigating communication-related IEP goals Klang et al. (2016) found that they contain information on multiple domains of functioning in the ICF-CY. The results show that IEP goals specifically focus on ICF-CY components Activities and Participation and Environmental Factors as well as Body Functions. However, although the IEP goals contain information related to several components of the ICF-CY, few goals are formulated in terms of participation.

Three ICF-based measurement tools are presented in the results. The first from Klein and Camargo (2018) propose a Functional Abilities Classification Tool (FACT) based on the

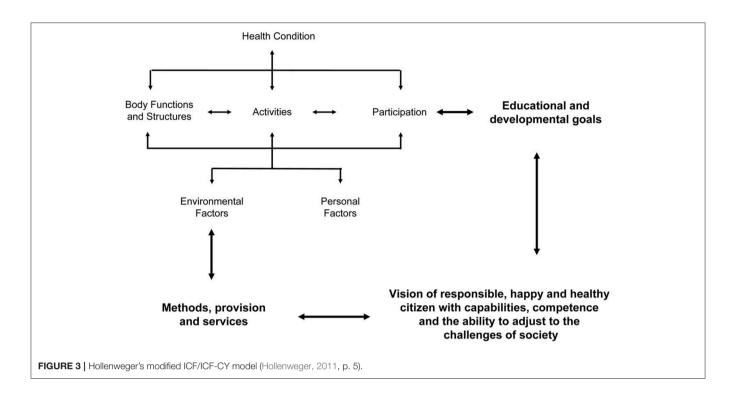
concepts of the ICF. The second tool is the Participation and Environment Measure for Children and Youth (PEM-CY) and has a model for participation that uses three perspectives: frequency, extent of involvement, and desire for change, (Coster et al., 2012). The PEM-CY also uses parents as proxy-measures for an assessment of the children's participation. The third tool that used the ICF to develop measuring instruments was developed in Italy by Raggi et al. (2014). Their study aimed to develop an instrument to collect disability information in school settings, based on the ICF-CY. The ICF-PEI Schedule is presented as a feasible instrument for school settings to collect and exploit functioning and disability data. The authors suggest "Teachers can fruitfully employ it to assist in the definition of educational objectives and verify them longitudinally" (Raggi et al., 2014, p. 86).

In terms of national studies there is a prevalence of articles reporting studies from Portugal, which is to be expected as the country adopted an ICF-based special education/inclusion law in 2008. As a consequence of introducing this ICF-based eligibility assessments for specialized education, there are studies reported here indicating that the ICF framework was effective at determining eligibility for special education services based on student functioning rather than medical or psychological diagnoses (Sanches-Ferreira et al., 2013, 2015).

## In What Way Can the Participation Component of the ICF Be Practically Improved as a Tool for Investigating Inclusion?

Relating to practical issues when analysing the functioning of inclusive education policies and systems, Maxwell and Koutsogeorgou (2012) proposed linking social capital to inclusive education policy and practice by mapping the participation and trust indicators of social capital to the ICF-CY and by using the Matrix to Analyse Functioning in Education Systems (MAFES, Hollenweger, 2010). Maxwell and Koutsogeorgou (2012) also proposed that the theoretical structuring of social capital—from the two dimensions of structural and cognitive corresponds with the current theorizing of participation from two dimensions—the frequency of attending and the intensity of the involvement experience; this has however been difficult to realize in practice (Koutsogeorgou et al., 2013). Results from Koutsogeorgou et al. (2013) showed that more than half of the meaningful concepts found were linked to the ICF-CY's Environmental Factors component. Almost one quarter of the meaningful concepts were not covered or definable within the ICF/ICF-CY framework, with Body Structures being the least linked component.

It is fairly well-documented that the ICF poorly operationalizes participation as the model has the components activity and participation as distinct entities whereas they are combined as one component within the coding framework itself (Badley, 2008). In pursuit of further clarity, Klang et al. (2016) use an activity-focussed interpretation of activity-participation divide as outlined by Whiteneck and Dijkers (2009) while Coster et al. (2012) reformulated their own interpretation of



participation and the environment—also based on Whiteneck and Dijkers (2009)—likely for the same reason. Similarly, a bi-dimensional conceptualizing of participation is used in three of the studies (Maxwell and Granlund, 2011; Maxwell et al., 2012a,b) in order to address the same issue.

There are issues relating to the reliability of coding using the ICF. Results from Castro et al. (2011) showed only a moderate level of reliability based on inter-rater agreement between the coders who developed the linkage process. In addition, they found that the curriculum they were analysing-the Carolina curriculum for pre-schoolers with special needs-covers body functions as well as activities and participation considered in the ICF-CY, but does not cover the environmental factors or body structures domains. Another study from Castro et al. (2014) found that when linking IEPs to the ICF-CY the majority of the functionality domains addressed in the analyzed IEPs mapped to the Activities and Participation component of the ICF-CY. Very few mapped to the Environmental Factors component. Similarly, when developing a set of structured, easy to use, and feasible questions for the school context Raggi et al. (2014) found that a group of 14 teachers who identified 118 ICF-CY categories that were relevant to a school context, however only 62 were ultimately included in the ICF-CY-PEI schedule that the researchers have developed.

It would appear that there are practical issues relating the using the ICF as there are studies calling for the integrating of alternative theoretical approaches, e.g., social capital, studies working to either re-conceptualize participation, or to divide the constructs of activity and participation in the coding framework, and reliability issues when coding or mapping existing constructs across to the framework. It can therefore be

useful to investigate how the ICF can be practically improved as a tool for investigating inclusion.

In terms of adapting the ICF for educational purposes, Judith Hollenweger and colleagues have developed an eligibility procedure for specialized education services (Hollenweger and Moretti, 2012) based on the ICF-CY (World Health Organization, 2007) and the UN convention on the Rights of Persons with Disabilities (United Nations, 2006). Hollenweger has expanded the basic ICF model (Hollenweger, 2011, see Figure 3) and recognizes that a definition of disability used for eligibility purposes is required within the general curriculum for all children. Here Hollenweger recognizes that inclusive education often has to provide specialized measures to some children in order to ensure participation. Eligibility decisions, along with eligibility thresholds, thus become necessary when reasonable accommodations are made based on additional resources. In order to realize this Hollenweger has expanded the basic ICF model to better represent how the context interacts with the participation experience (see Figure 3).

The ICF measures doing using the capacity and performance qualifiers as a way to capture a measure of experience. The study by Maxwell et al. (2012b) constructed an index of the subjective experience of involvement by hypothesizing that the experienced involvement of pupils in school activities was higher when thinking and doing coincided. Data, which compared pupils' self-reported experiences of involvement by recording what children were thinking and doing, were gathered in real-time using experience sampling method (Csikszentmihalyi and Larson, 1987). Importantly, the study reliably brings in the child's perspective with high ecological validity (Napa Scollon et al., 2003). The results indicate a strong relation between an index

of the subjective experience of involvement (based on measures of concentration, control, involvement, and motivation) and whether children were thinking and doing the same thing, with an increased subjective experience of involvement also giving better psychological health and well-being. Additionally, as prior knowledge on why an activity is being carried out affects involvement, aspects of choice were also found to be influential.

As a result of the poor connection between the theoretical formulation and practical execution of activity and participation, and the construction of environmental factors most researchers are forced to choose either an existing suggested distinction—such as Klang et al. (2016) and Coster et al. (2012) using Whiteneck and Dijkers (2009) or to formulate their own (Maxwell et al., 2012b). Raggi et al. (2014) also encountered difficulties with the understanding of environmental factors when teachers were required to rate performance; this was solved through direct observation, in order to simplify environmental factor rating.

Although yet to be empirically tested, Klein and Camargo (2018) propose a tool to make the ICF more useable in school systems by suggesting the ICF is used as the basis for a universal classification system for children with developmental disorders affecting learning and behavior (DDALB).

Here in the included studies in this review we see firm calls to adapt the ICF to fit educational purposes either with a modification of the existing model (Hollenweger, 2011; Hollenweger and Moretti, 2012), by developing an entirely new approach to participation (Maxwell et al., 2012b), or by integrating it into a practical tool (Klein and Camargo, 2018).

#### DISCUSSION

When looking at ways of defining and implementing participation in an inclusive school setting using the ICF we found that 11 of the 16 papers used a bi-dimensional approach by looking at activity/participation together with the environmental dimension (Coster and Khetani, 2008; Hollenweger, 2011; Maxwell and Granlund, 2011; Hollenweger and Moretti, 2012; Maxwell and Koutsogeorgou, 2012; Maxwell et al., 2012a,b; Koutsogeorgou et al., 2013; Raggi et al., 2014; Klang et al., 2016; Klein and Camargo, 2018). This encouraging number would indicate that participation is beginning to be more consistently used, however it is useful to consider how the participation component of the ICF is of use when investigating aspects of inclusion.

#### How Does the Participation Component of the ICF Provide a Valid and Consistent Approach to Investigating Aspects of Inclusion?

Using a dilemma perspective (Nilholm, 2006, 2007) when operationalizing participation as an aspect of inclusion, requires that a bi-directional approach is necessary in order to accommodate the more nuanced approach that this perspective requires. The fact that this bi-dimensional approach is absent

or lacking in some representations is problematic in terms of developing a cohesive way to move forward.

The studies presented here have aspects relating to a sociological approach to participation. Here we see parallels with the critical perspective as outlined by Nilholm (2007) where availability and accommodations made are the most investigated dimensions (Maxwell et al., 2012b). Additionally, from the analysis presented in Moretti et al. (2012), results show that the ICF is currently used as a research tool, theoretical framework, and tool for implementing educational processes. Here it is also shown that the ICF can bring a unifying and common language to the field of education as there is currently significant discrepancy in theoretical, praxis, and research issues—see for example Clark et al. (1998). However, while a low incidence of the use of the ICF in education is reported in the systematic literature review, results indicate that there is potential for the ICF model and framework to be used in education systems to describe general conditions of inclusion (Moretti et al., 2012). It is, however, probably not suitable for describing content or achievement in specific academic subjects.

The way in which participation is operationalized does not always necessarily align with the definitions used, however, based on Granlund's bi-dimensional definition (Granlund, 2013), most empirical studies analyzed here apply the participation concept in educational research do use a balanced bi-dimensional approach when measuring participation (Coster and Khetani, 2008; Hollenweger, 2011; Maxwell and Granlund, 2011; Hollenweger and Moretti, 2012; Maxwell and Koutsogeorgou, 2012; Maxwell et al., 2012a,b; Koutsogeorgou et al., 2013; Raggi et al., 2014; Klang et al., 2016; Klein and Camargo, 2018). The various definitions of participation are also distinct from the way in which it is put into operation suggesting that those who use the concept are still in the process of developing approaches to investigating the participation of children with additional support needs (Maxwell et al., 2012b).

From the studies analyzed in this paper it can be seen that there is more often a focus on providing equal opportunities to participate, rather than taking heed to the participation experience itself and is particularly apparent in inclusive education policy (see for example: Maxwell and Granlund, 2011). This tendency demonstrates that the frequency dimensions are simpler to construct and put into operation—as also seen in Maxwell et al. (2012b) where the authors are working to improve conceptual understanding of the intensity dimensions. One strong influencing factor is likely to be the significant impact that the social approach to disability has had in the recent years—see for example the social theory of disability (Gustavsson and Söder, 1990; Gustavsson, 2004) or the social theory of embodiment (Shakespeare, 2004).

Similarly, Klang et al. (2016) find that the communication-related IEP goals of pupils contain information on multiple domains of functioning in the ICF-CY, indicating evidence of the paradigm shift from focusing on the individual level of functioning to the societal level. The FACT tool (Klein and Camargo, 2018) provides a classification tool that can complement medical diagnoses by capturing ability- and participation-related information—also bringing it in-line with

the ICF's own intentions and ethos. The FACT does this by including classifications for participation over several different environmental settings, through this information functional abilities, personal factors, and environmental aspects can be considered. Another finding from Klang et al. (2016) is that a relatively small number of the IEP goals contain information on interaction with others and participation in school and leisure activities. Here the researchers suggests an individual-focus in terms of intervention outcomes rather than a societal-focus. While this would indicate the child's participation in activities that are meaningful and that involve interaction with other people—which are worthy of inclusion—it would still indicate the lack of a broader societal-perspective within the ICF-CY framework.

Moving from a sociological to a psychological approach draws on the compensation perspective (Nilholm, 2007) and while, like the medical approach to disability, has fallen out of favor in recent years, it should not be neglected in the rush to shift problems over to the social context. The absence of a nuanced or fully developed understanding of the intensity side of participation can be directly connected to the overbearance of the social approach to disability that has been predominant in recent decades. This neglect of interest in individual factors has also led to calls for a re-introduction of biomedical factors in models of disability in order to provide a more balanced representation of the phenomena (Williams, 1999). Furthermore, the results from Maxwell and Granlund (2011) and Koutsogeorgou et al. (2013)—which show that policy documents have difficulty expressing acceptability, and to some extend accommodability are potentially attributable to human rights advocacy where being forced into a rigid definition of what is and is not acceptable as a way to define involvement could violate human rights. This might also explain the low prevalence of an interest in the individual child's involvement experience in the inclusive education literature (where any focus on involvement tends to feature only the parents/family). Challenges reported in Koutsogeorgou et al. (2013) and Maxwell and Koutsogeorgou (2012) also suggest that the theoretical construction and practical operation of the frequency-intensity spectrum requires further development, particularly when using them for analyses of textual sources.

Strong evidence is provided in Maxwell et al. (2012b) for adding a third involvement qualifier to the activities and participation component of the ICF-CY—the addition and creation of qualifiers is permitted and outlined in the appendices of the ICF. Additionally, along with choice, increased subjective experience of involvement leads to better psychological health and well-being; factors that positively affect the individual's experience of inclusion (Maxwell et al., 2012b).

Klein and Camargo (2018) implore that in order to give us a more child-focussed approach to functional assessment, the current assessment paradigm needs to shift its emphasis to functional abilities and participation. This will in turn give us enough assessment to define goals and inform plans in a more succinct manner, and move us away from system-centered exhaustive qualification assessments with cut-off criteria that have limited meaning to the individuals involved in them

along with restricted practical implications. Similarly, when assessing the mapping of IEPs to the ICF, Castro et al. (2014) showed that very few functionality domains were mapped to the Environmental Factors component. This would suggest that IEPs in Portugal are still taking an individual perspective when assessing adaptations required for children with additional support needs.

By starting with both sociological and psychological approaches to participation it is interesting to note how and where affordability fits in to the spectrum. During the analysis of the various reviewed studies it would appear that the construct of affordability does not adhere completely to either a social or psychological understanding of participation and nor does it fit comfortably on the spectrum between the two as previously reported by Maxwell and Granlund (2011). It would therefore appear that affordability is an outlier in the proposed model (see **Figure 2**) and while still an environmental dimension of participation, it is more intrinsically related to all aspects of participation rather than being directly relatable in a spectrum.

#### In What Way Can the Participation Component of the ICF Be Practically Improved as a Tool for Investigating Inclusion?

Practically, as the ICF does not currently provide a consistent approach to constructing and operationalizing participation, and is inconsistent as a tool for investigating inclusion for children with disabilities, significant development is required in order to effectively use it for inclusive education. The exhaustiveness of the ICF/ICF-CY's coding framework can also make it seem a little overwhelming to the unfamiliar. Maxwell et al. (2012a) and Moretti et al. (2012) also outlined various issues when using the ICF/ICF-CY in education, such as the framework being criticized for still being overtly medical. One of the reviewed papers from Maxwell et al. (2012a) and Moretti et al. (2012) specifically criticizes the ICF for still taking an individualistic view of disability based on functional normality that focusses on deviance from a standardized human condition where the "medical model" is still dominant, thus perpetuating existing power relations (D'alessio, 2008) and not contributing positively to inclusive education practices. D'alessio (2008) also concedes that not regarding disability as a disease is an important developmental advance made by the ICF. However, a multi-categorical or multidimensional approach still needs to be developed to conceptualize "workable" contextually-aware disability descriptions for education. These descriptions need to be able to capture the context and be based on mapped-out patterns of functioning rather than prescribed categories base on single conditions (Florian et al., 2006); in order to support this need Simeonsson et al. (2008) report that:

"Within the ICF-CY framework, the focus of classification is on the child's response to the demands of schooling in terms of activity limitations and participation restrictions experienced by a child rather than the diagnosed condition" (Simeonsson et al., 2008, p. 218). It is also argued that the participation construct needs further expansion as it misses the individual's experience by centering attention merely on the observation of a person's performance of an activity (Asbjørnslett and Hemmingsson, 2008); this is also emphasized by Daley et al. (2009) who find that the ICF-CY lacks clear codes for overall health conditions. Granlund et al. (2004) similarly, report that additional item-analysis and more expansive investigations are needed in order to more effectively assign ICF participation codes to items from instruments used when assessing the functioning of pupils with disabilities in schools.

Similarly, the ambiguous connection of the two dimensions of social capital and the two dimensions of participation (as originally proposed by, Maxwell and Koutsogeorgou, 2012) indicates that the construction of participation within the ICF is both unclear and currently not representative of the bidimensional approach to participation. How to distinguish between activity and participation in the ICF framework has long been a cause of disagreement amongst researchers and practitioners. As a result, Klang et al. (2016) had to make a conscious decision to choose and elected an activity-focussed approach as outlined by Whiteneck and Dijkers (2009) where the first six chapters are viewed as activity and the remaining three as participation. This approach will no doubt have affected their results (although the authors do acknowledge this in their discussion) and is a significant shortcoming of the theoretical underpinnings of the ICF. Similarly, conceptualization of participation itself and environmental factors have also been difficult to construct (Whiteneck and Dijkers, 2009) with Coster et al. (2012) acknowledging that with the complexity and multifaceted nature of the two constructs, no single measure is likely to capture all aspects. As a result they propose that developing and identifying specific dimensions that are relevant in a particular measurement context would be a more fruitful direction to take research (Coster et al., 2012, p. 244).

Similar limitations are found with the other ICF components with results from Castro et al. (2011) showing that the curriculum they were analysing—the Carolina curriculum for pre-schoolers with special needs—omitted the environmental factors and body structures domains showing a lack of alignment between the ICF and existing tools. Raggi et al. (2014) also encountered alignment difficulties as when developing their ICF-CY-PEI schedule the teachers included in the action research process initially identified 118 ICF-CY categories that were relevant to a school context. However, only 67 were taken further into the development of the schedule with 62 being included in the finished product. This near 50% drop-out rate suggests that there was a high level of disagreement amongst the teachers and by assertion an implication that the ICF-CY presents as complex and difficult to understand for teachers.

Another criticism of the ICF comes from the lack of classification categories for personal factors (Granlund et al., 2004), and how to operationalize these is a current matter of debate (Geyh et al., 2011; Simeonsson et al., 2014). Hollenweger (2008) however, points out that while the ICF does not currently fully address our understanding of disability in light of the present ways in which it is conceptualized and classified within

education systems, the framework is an on-going project likely to run over many years. As a result an approach that is more analytical, instead of attempting to be comprehensive, is called for so that a more nuanced understanding of the embedded nature of the multi-level processes by which disability can be experienced and classified within special educational needs (Hollenweger, 2008)

Although the general theoretical consistency that the ICF brings to the inclusive education arena—by giving a strong biological, psychological, and social insight into any investigations—will provide more consistent results and conclusions to be formed, there are still inconsistencies in the construction and operation of major components of the framework: specifically, participation, and personal factors. However, there are ways that the ICF can be practically improved as a tool for investigating inclusion, such as use of a bi-dimensional approach to participation (Granlund, 2013); this will alleviate inconsistencies with the construct of participation and provide a consistent representation of the involved experience, and further developments with respect to personal factors will likely glean international consensus.

In order to provide a more meaningful way to classify children who experience difficulties in a school environment we need to move away from the reliance on labels and specific groupings in order to assign resources due to associated stigma and exclusion possibilities (McDowell and O'Keeffe, 2012). The FACT tool (Klein and Camargo, 2018) attempts to fill this current gap by offering an ICF-based functional assessment tool and as such can be considered an improved practical implementation of the ICF framework itself. Whether aspects proposed by Klein and Camargo (2018) get included in future revisions of the ICF remains to be seen.

Despite proposing a fairly robust measure of participation and the environment, in the form of the PEM-CY, that also includes the parental and children and youth perspectives, Coster et al. (2012) find that there is still a need for more conceptual expansion of participation and the environment. The hypothesized relationships between person, activity, participation, and the environment need to be improved in order to aid the development of measures that can be adapted to fit the needs of these investigations and as a result are more likely to yield informative results (Coster et al., 2012). Klang et al. (2016) also had to choose how to practically implement the constructs of activity and participation when they undertook their study, and as a result choose an approach that was ultimately a compromise, it is proposed here that a clearer position is stated within the ICF itself. Raggi et al. (2014) were similarly required to make modifications by simplifying environmental factor rating, by asking teachers to rate performance through direct observation. This would imply that the teachers had, or it was anticipated that they would have, difficulty with rating environmental factors; suggesting that the environmental factors component of the ICF presents as complex and relatively incompatible with education and requires further development both theoretically and practically. All these apparent challenges would imply support for the various calls to change and improve the ICF's theoretical underpinnings, such as participation (Granlund et al., 2012; Granlund, 2013), participation and the environment (Whiteneck and Dijkers, 2009), and personal factors (Geyh et al., 2011; Simeonsson et al., 2014).

In terms of practically addressing these shortcomings, Hollenweger (2011) provides the modifications to the ICF's model which allow it to better fit into the education field (see Figure 3). Maxwell et al. (2012b) provides empirical evidence for how to construct a third involvement qualifier for the ICF-CY's activities and participation component which would capture the subjective experience of involvement relating to acceptance, adaptations and accommodations, as originally called for by Granlund et al. (2012), based on measures of concentration, control, involvement, and motivation (Maxwell et al., 2012b). Klein and Camargo (2018) provide a new and interesting sounding tool in the form of the FACT. Further empirical investigation is required to further validate these new possibilities.

The presented review in this paper is naturally limited by the scope of this study. The review is not systematic, however a pragmatic decision was made to focus on qualitatively synthesizing the content of the found works, rather than attempting to compile an exhaustive list of studies. Another limitation is related to the privileged position we occupy by being based in the wealthier in the part of the world (Northern Europe specifically). This privilege is borne out by the finding that all of the studies reported in this, and previous reviews on a similar theme, originate from the Global North and report findings predominantly from the Global North. A general low degree of access to and presence of resources in the Global South means that this situation is inevitable given the current global situation. Action is therefore needed to equalize the situation and redistribute resources so that a more balanced global representation can be provided.

#### **ETHICAL CONSIDERATIONS**

The studies presented in this paper use data from studies that have previously been vetted for ethical appropriateness and use data that have been gathered from credible sources. While it is potentially a big assumption to take by assuming that these previous studies have passed through suitable ethical approval systems, integrity, and confidentiality will be upheld since all data have already been de-personalized and will be handled following national Swedish and Norwegian research guidelines. Consequently there should not be any problems with using these data. Additionally, using the data for this study places it under the same overarching aims of the original studies that have already been granted ethical approval.

#### CONCLUSION

This paper set out to investigate how suitable the operationlization of participation through the ICF is as a way for investigating inclusion. In short summary further clarity on defining and measuring participation with the ICF framework is required in order to create a more consistent tool

for investigating inclusive education. More detailed conclusions can be drawn from the two research questions.

#### How Does the Participation Component of the ICF Provide a Valid and Consistent Approach to Investigating Aspects of Inclusion?

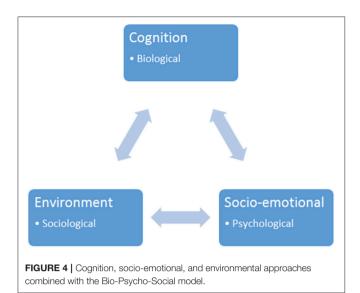
In order to effectively use the ICF as a tool for inclusive education, modifications are required: Specifically to the participation component. The ICF is currently used in three main ways: as a theoretical framework, as a tool for research, and as a tool for educational processes (Moretti et al., 2012). In this paper a broad selection of evidence from a selection of different ecological levels has been presented for the construction and operation of participation from two perspectives: the frequency of attendance (sociological), and the intensity of involvement (psychological), and how this could be incorporated into future iterations of the ICF to make it a suitable tool for inclusive education. The presented results also reinforce the dilemma perspective to special education (Nilholm, 2007) where a balanced approach combining individual and social approaches to inclusion is called for. The new and arguably more balanced approach to participation proposed here reflects this by using five environmental dimensions of availability, accessibility, affordability, accommodability, and acceptability. It is proposed here and previously (Maxwell, 2012), that this can contribute to the development of a new theory related to the subjective experience of involvement (Maxwell et al., 2012b). This theoretical development will take measures of concentration, involvement, motivation, and control will further aid the discussion about the differentiation between activities and participation in the ICF (see Whiteneck, 2005, for a review). A major improvement that this approach brings is increased validity for the participation construct by the inclusion of children's own personal subjective experiences of involvement.

# In What Way Can the Participation Component of the ICF Be Practically Improved as a Tool for Investigating Inclusion?

The authors concur that there is still much to be done regarding further conceptual expansion of the constructs of activity, participation and the environment, as seen from the number of included articles in this paper discussing these themes, such as calls for refinements in participation (Granlund et al., 2012; Granlund, 2013), participation and the environment (Whiteneck and Dijkers, 2009), and personal factors (Geyh et al., 2011; Simeonsson et al., 2014). Specifically there is also a need for a theory of environments (Whiteneck and Dijkers, 2009) and its effects on participation; this theory could then be used to formulate and test hypotheses about relationships across a number of children with or without additional support needs.

#### **Recent Developments in the Field**

Similar to the ideas outlined in this paper, Norwich (2016) explores the usefulness of using the bio-psycho-social approach



in special education in England and compares how the ICF-CY fits in with current and previous terminology and conceptualizing of "special educational needs." Norwich proposes that the ICF-CY offers one way to realize current measurement and assessment issues, and concludes that the ICF-CY can provide an informed approach to assessing additional educational needs by providing norms about functioning and the environment for eligibility decision-making.

The bio-psycho-social approach—as seen in the ICF/ICF-CY—can offer one potential solution to bridging approaches traditionally seen in special and inclusive education based on cognition, socio-emotional variance/deviance, and contextual-based interventions (Struyf, 2016). These two approaches are strikingly similar and can be combined into the model presented in **Figure 4**.

By bringing the bi-dimensional approach to participation as a way to more accurately represent the construct, it is the authors' belief that a more valid approach to participation has been formed. Previous approaches have neglected the involvement component and can thus be considered to be lacking as tools for inclusive education. Similarly, given that current inclusion legislation and policies focus more on making situations more

available, accessible, and affordable, there is also a need to bring in and focus more on accommodations and acceptability. Despite various positive suggestions the ICF is still found to be lacking both theoretically and practically as a tool for education. Specifically, regarding the operationalization of a bi-dimensional approach to participation the ICF does permit modifications to the coding framework under the guidelines found in the appendices (World Health Organization, 2007, p. 244) and one potential way to implement the intensity of involvement would be to make use of an additional qualifier in the activities and participation component to represent the subjective experience of involvement (Granlund et al., 2012). Alternatives would be to construct a new measure based on the ICF-CY, such as Klein and Camargo (2018) with their FACT tool, or Coster et al. (2012) with the PEM-CY. These solutions are however ultimately a compromise as the underlying theoretical modeling of the ICF does not align with the intended practical operation. Therefore, it is better to propose revisions to the ICF itself and it is the authors' hopes and intentions that aspects of the proposed bi-dimensional approach to participation are included in future revisions of the ICF/ICF-CY—the so-called "ICF-2," which is somewhat overdue. By making changes to the underlying construction of the classification's model we would thus create a more accountable classification of the involvement experience and more effectively meet the requirements of the inclusive education field.

#### **AUTHOR CONTRIBUTIONS**

All authors listed have made a substantial, direct and intellectual contribution to the work, and approved it for publication.

#### **ACKNOWLEDGMENTS**

This study was supported by Sunnerdalhs Handikappfond project 20/11, *The ICF-CY as a methodological research tool for education and inclusion*. Studies 1–3 were financially supported by the EU project MURINET (MRTN-CT-2006-035794, see www.murinet.eu) and study four was supported by Sunnerdahls Handikappfond project 17/09, *The usefulness of the ICF-CY for measuring participation in educational activities-clarifying the difference between activity and participation*. The publication charges for this article have been funded by a grant from the publication fund of UiT The Arctic University of Norway.

#### REFERENCES

Ainscow, M., Booth, T., Dyson, A., Farrell, P., Frankham, J., Gallannaugh, F., et al. (2006). *Improving Schools, Developing Inclusion*. New York, NY: Routledge.

Asbjørnslett, M., and Hemmingsson, H. (2008). Participation at school as experienced by teenagers with physical disabilities. Scand. J. Occup. Ther. 15, 153–161. doi: 10.1080/11038120802022045

Augustine, L., Lygnegård, F., Granlund, M., and Adolfsson, M. (2017). Linking youths' mental, psychosocial, and emotional functioning to ICF-CY: lessons learned. *Disabil. Rehabil.* doi: 10.1080/09638288.2017.1334238. [Epub ahead of print].

Badley, E. M. (2008). Enhancing the conceptual clarity of the activity and participation components of the International Classification of

Functioning, Disability, and Health. Soc. Sci. Med. 66, 2335–2345. doi: 10.1016/j.socscimed.2008.01.026

Booth, T., and Ainscow, M. (2011). *Index for Inclusion: Developing Learning and Participation in Schools*. Britsol: Centre for Studies on Inclusive Education.

Castro, S., Pinto, A., and Simeonsson, R. J. (2014). Content analysis of Portuguese individualized education programmes for young children with autism using the ICF-CY framework. Eur. Early Childhood Educ. Res. J. 22, 91–104. doi: 10.1080/1350293X.2012. 704303

Castro, S., Pinto, A. I., and Maia, M. (2011). Linking the Carolina curriculum for preschoolers with special needs to the ICF-CY. Br. J. Dev. Disabil. 57, 133–146. doi: 10.1179/096979511798967043

- Cieza, A., Geyh, S., Chatterji, S., Kostanjsek, N., Üstün, B., and Stucki, G. (2005).
  ICF linking rules: an update based on lessons learned. J. Rehabil. Med. 37, 212–218. doi: 10.1080/16501970510040263
- Clark, C., Dyson, A., and Millward, A. (1998). Theorising Special Education. London: Routledge.
- Coster, W., and Khetani, M. A. (2008). Measuring participation of children with disabilities: Issues and challenges. *Disabil. Rehabil.* 30, 639–648. doi: 10.1080/09638280701400375
- Coster, W., Law, M., Bedell, G., Khetani, M., Cousins, M., and Teplicky, R. (2012). Development of the participation and environment measure for children and youth: conceptual basis. *Disabil. Rehabil.* 34, 238–246. doi:10.3109/09638288.2011.603017
- Csikszentmihalyi, M., and Larson, R. (1987). Validity and reliability of the experience-sampling method. *J. Nerv. Ment. Dis.* 175, 526–536.
- D'alessio, S. (2008). "'Made in Italy': integrazione scolastica and the new vision of inclusive education," in *Policy, Experience and Change: Cross-Cultural Reflections on Inclusive Education*, eds L. Barton and F. Armstrong (New York, NY: Springer Science & Business Media), 53–72.
- Daley, T. C., Simeonsson, R. J., and Carlson, E. (2009). Constructing and testing a disability index in a US sample of preschoolers with disabilities. *Disabil. Rehabil.* 31, 538–552. doi: 10.1080/09638280802214352
- Dixon-Woods, M., Agarwal, S., Jones, D., Young, B., and Sutton, A. (2005). Synthesising qualitative and quantitative evidence: a review of possible methods. J. Health Serv. Res. Policy 10, 45–53B. doi:10.1177/135581960501000110
- Florian, L., Hollenweger, J., Simeonsson, R. J., Wedell, K., Riddell, S., Terzi, L., et al. (2006). Cross-cultural perspectives on the classification of children with disabilities: Part, I. Issues in the classification of children with disabilities. *J. Spec. Educ.* 40, 36–45. doi: 10.1177/00224669060400010401
- Geyh, S., Peter, C., Müller, R., Bickenbach, J. E., Kostanjsek, N., Üstün, B. T., et al. (2011). The personal factors of the international classification of functioning, disability and health in the literature-a systematic review and content analysis. *Disabil. Rehabil.* 33, 1089–1102. doi: 10.3109/09638288.2010.523104
- Grammenos, S. (2003). *Illness, Disability and Social Inclusion*. Dublin: European Foundation for the Improvement of Living and Working Conditions. Available online at: http://www.eurofound.europa.eu/pubdocs/2003/35/en/1/ef0335en.pdf
- Granlund, M. (2006). "Studies of participation related to ICF-CY," in *Paper Presented at the Invited Presentation MHADIE Meeting* (Prague). Available online at: http://urn.kb.se/resolve?urn=urn:nbn:se:hj:diva-5082
- Granlund, M. (2013). Participation–challenges in conceptualization, measurement and intervention. Child Care Health Dev. 39, 470–473. doi: 10.1111/cch.12080
- Granlund, M., Arvidsson, P., Niia, A., Bjorck-Akesson, E., Simeonsson, R. J., Maxwell, G., et al. (2012). Differentiating activity and participation of children and youth with disability in Sweden: a third qualifier in the international classification of functioning, disability, and health for children and youth? Am. J. Phys. Med. Rehabil. 91(13 Suppl. 1), S84–S96. doi: 10.1097/PHM.0b013e31823d5376
- Granlund, M., Eriksson, L., and Ylven, R. (2004). Utility of International Classification of Functioning, Disability and Health's participation dimension in assigning ICF codes to items from extant rating instruments. *J. Rehabil. Med.* 36, 130–137. doi: 10.1080/16501970310021707
- Gustavsson, A. (2004). The role of theory in disability research-springboard or strait-jacket? Scand. J. Disabil. Res. 6, 55–70. doi: 10.1080/15017410409512639
- Gustavsson, A., and Söder, M. (1990). Social Forskning om Människor Med Psykisk Utvecklingsstörning: En Bibliograferad Kommentar: Rektorsämbetet. Stockholm: Utbildningsförvaltningen.
- Göransson, K., Nilholm, C., and Karlsson, K. (2010). Inclusive education in Sweden? A critical analysis. *Int. J. Inc. Educ.* 15, 541–555. doi:10.1080/13603110903165141
- Hannes, K., and Lockwood, C. (2011). Synthesizing Qualitative Research: Choosing the Right Approach. Hoboken: Wiley.
- Hollenweger, J. (2008). "Cross-national comparison of special education classification system," in *Disability Classification in Education. Issue and Perspective*, eds L. Florian and M. J. McLaughlin (Thousand Oaks, CA: Corwin Press), 11–30.
- Hollenweger, J. (2010). MHADIE's matrix to analyse the functioning of education systems. *Disabil. Rehabil.* 32, S116–S124. doi: 10.3109/09638288.2010.520809

- Hollenweger, J. (2011). Development of an ICF-based eligibility procedure for education in Switzerland. BMC Public Health 11, 1–8. doi: 10.1186/1471-2458-11-s4-s7
- Hollenweger, J. (2014). Definition and Classification of Disability: Webinar Booklet. New York, NY. Available online at: http://www.inclusive-education.org/sites/default/files/uploads/booklets/IE Webinar Booklet 2.pdf
- Hollenweger, J., and Moretti, M. (2012). Using the International Classification of Functioning, Disability and Health Children and Youth version in education systems: a new approach to eligibility. Am. J. Phys. Med. Rehabil. 91, S97–S102. doi: 10.1097/PHM.0b013e31823d5501
- Imms, C., Adair, B., Keen, D., Ullenhag, A., Rosenbaum, P., and Granlund, M. (2016). 'Participation': a systematic review of language, definitions, and constructs used in intervention research with children with disabilities. *Dev. Med. Child Neurol.* 58, 29–38. doi: 10.1111/dmcn.12932
- Jette, A. M., Haley, S. M., and Kooyoomjian, J. T. (2003). Are the ICF activity and participation dimensions distinct? J. Rehabil. Med. 35, 145–149. doi: 10.1080/16501970310010501
- King, G. (2013). Perspectives on measuring participation: going forward. Child Care Health Dev. 39, 466–469. doi: 10.1111/cch.12083
- Klang Ibragimova, N., Pless, M., Adolfsson, M., Granlund, M., and Björck-Åkesson, E. (2011). Using content analysis to link texts on assessment and intervention to the International Classification of Functioning, Disability and Health-version for Children and Youth (ICF-CY). J. Rehabil. Med. 43, 728–733. doi: 10.2340/16501977-0831
- Klang, N., Rowland, C., Fried-Oken, M., Steiner, S., Granlund, M., and Adolfsson, M. (2016). The content of goals in individual educational programs for students with complex communication needs. *Augment. Altern. Commun.* 32, 41–48. doi: 10.3109/07434618.2015.1134654
- Klein, B., and Camargo, O. K. (2018). A Proposed Functional Abilities Classification Tool (FACT) For developmental disorders affecting learning and behaviour. Front. Educ. 3:2. doi: 10.3389/feduc.2018.00002
- Koutsogeorgou, E., Maxwell, G., Moretti, M., Aluas, M., and Quintas, R. (2013). "Associations of social capital and inclusive education policies: the usefulness of the biopsychosocial model," in *Paper Presented at the 11th European Sociological Association conference* (Torino).
- Krippendorff, K. (2004). Content Analysis: An Introduction to Its Methodology. Thousand Oaks, CA: SAGE.
- Lindsay, G. (2007). Educational psychology and the effectiveness of inclusive education/mainstreaming. Br. J. Educ. Psychol. 77, 1–24. doi: 10.1348/000709906x156881
- Maxwell, G. (2012). Bringing More to Participation: Participation in School Activities of Persons with Disability Within the Framework of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY). 16 Doctoral thesis, Comprehensive summary, School of Education and Communication, Jönköping. Available online at: http://urn.kb.se/resolve?urn=urn:nbn:se:hj:diva-18079DiVAdatabase
- Maxwell, G., Alves, I., and Granlund, M. (2012a). Participation and environmental aspects in education and the ICF and the ICF-CY: findings from a systematic literature review. *Dev. Neurorehabil.* 15, 63–78. doi: 10.3109/17518423.2011.633108
- Maxwell, G., Augustine, L., and Granlund, M. (2012b). Does thinking and doing the same thing amount to involved participation? Empirical explorations for finding a measure of intensity for a third ICF-CY qualifier. *Dev. Neurorehabil.*15, 274–283. doi: 10.3109/17518423.2012. 689780
- Maxwell, G., and Granlund, M. (2011). How are conditions for participation expressed in education policy documents? A review of documents in Scotland and Sweden. Eur. J. Spec. Needs Educ. 26, 251–272. doi:10.1080/08856257.2011.563610
- Maxwell, G., and Koutsogeorgou, E. (2012). Using social capital to construct a conceptual International Classification of Functioning, Disability, and Health Children and Youth Version–Based framework for stronger inclusive education policies in Europe. *Am. J. Phys. Med. Rehabil.* 91:S118. doi: 10.1097/PHM.0b013e31823d4b92
- McConachie, H., Colver, A. F., Forsyth, R. J., Jarvis, S. N., and Parkinson, K. N. (2006). Participation of disabled children: how should it be characterised and measured? *Disabil. Rehabil.* 28, 1157–1164. doi: 10.1080/09638280500 534507

- McDowell, M., and O'Keeffe, M. (2012). Public services for children with special needs: discrimination by diagnosis? J. Paediatr. Child Health 48, 2–5. doi: 10.1111/j.1440-1754.2011.02394.x
- Moretti, M., Alves, I., and Maxwell, G. (2012). A systematic literature review of the situation of the international classification of functioning, disability, and health and the international classification of functioning, disability, and health—children and youth version in education: a useful tool or a flight of fancy? *Am. J. Phys. Med. Rehab.* 91:S103. doi: 10.1097/PHM.0b013e31823d53b2
- Napa Scollon, C., Kim-Prieto, C., and Diener, E. (2003). Experience sampling: promises and pitfalls, strengths and weaknesses. J. Happiness Stud. 4, 5–34. doi: 10.1023/A:1023605205115
- Nilholm, C. (2006). Special education, inclusion and democracy. Eur. J. Spec. Needs Educ. 21, 431–445. doi: 10.1080/08856250600957905
- Nilholm, C. (2007). Perspektiv på Specialpedagogik. Lund: Studentlitteratur.
- Norwich, B. (2016). Conceptualizing special educational needs using a biopsychosocial model in england: the prospects and challenges of using the international classification of functioning framework. Front. Educ. 1:5. doi:10.3389/feduc.2016.00005
- Penchansky, R., and Thomas, J. W. (1981). The concept of access: definition and relationship to consumer satisfaction. *Med. Care* 19, 127–140.
- Raggi, A., Meucci, P., Leonardi, M., Barbera, T., Villano, A., Caputo, M. R., et al. (2014). The development of a structured schedule for collecting ICF-CY-based information on disability in school and preschool children: an action research from Italy. Int. J. Rehabil. Res. 37, 86–96. doi: 10.1097/mrr.000000000000000042
- Sanches-Ferreira, M., Simeonsson, R. J., Silveira-Maia, M., and Alves, S. (2015). Evaluating implementation of the International Classification of Functioning, Disability and Health in Portugal's special education law. *Int. J. Inc. Educ.* 19, 457–468. doi: 10.1080/13603116.2014.940067
- Sanches-Ferreira, M., Simeonsson, R. J., Silveira-Maia, M., Alves, S., Tavares, A., and Pinheiro, S. (2013). Portugal's special education law: implementing the International Classification of Functioning, Disability and Health in policy and practice. *Disabil. Rehabil.* 35, 868–873. doi: 10.3109/09638288.2012.708816
- Shakespeare, T. (2004). Social models of disability and other life strategies. *Scand. J. Disabil. Res.* 6, 8–21. doi: 10.1080/15017410409512636
- Simeonsson, R. J., Bailey, D. D., Scandlin, D., Huntington, G. S., and Roth, M. (1999). "Disability, health, secondary conditions and quality of life: emerging issues in public health," in *Issues in Disability & Health: The Role of Secondary Conditions in Quality of Life*, eds R. J. Simeonsson and L. N. McDevitt (Chapel Hill, NC: University of North Carolina), 51–72.
- Simeonsson, R. J., Carlson, D., Huntington, G. S., McMillen, J. S., and Brent, J. L. (2001). Students with disabilities: a national survey of participation in school activities. *Disabil. Rehabil.* 23, 49–63. doi: 10.1080/096382801750058134
- Simeonsson, R. J., Lollar, D., Björck-Åkesson, E., Granlund, M., Brown, S. C., Zhuoying, Q., et al. (2014). ICF and ICF-CY lessons learned: pandora's box of personal factors. *Disabil. Rehabil.* 36, 2187–2194. doi:10.3109/09638288.2014.892638
- Simeonsson, R. J., Simeonsson, N., and Hollenweger, J. (2008). "The International Classification of Functioning, Disability and Health for Children and Youth:

- a common language for special education,". in *Disability Classification in Education, Issues, and Perspectives*,eds L. Florian and M. McLaughlin (Thousand Oaks, CA: Corwin Press), 207–226.
- Skrtic, T. M. (1991). Behind Special Education: A Critical Analysis of Professional Culture and School Organization. Denver, CO: Love Publishing Company.
- Struyf, E. (2016). "Bridging the divide: What can we learn from what really works in special and inclusive education?," in *Paper Presented at the Biennial Meeting of EARLI SIG15* (Leuven).
- UNESCO (1994). The Salamanca Statement and Framework for Action on Special Needs Education. Paris.
- UNESCO (2000). The Dakar Framework for Action. Education for All: Meeting our Collective Commitments. Dakar.
- United Nations (1989). Convention on the Rights of the Child, 44/25 CFR.
- United Nations (2006). Convention on the Rights of Persons with Disabilities, 44/25 CFR.
- Üstün, T. B., Chatterji, S., Bickenbach, J., Kostanjsek, N., and Schneider, M. (2003). The International Classification of Functioning, Disability and Health: a new tool for understanding disability and health. *Disabil. Rehabil.* 25, 565–571. doi: 10.1080/0963828031000137063
- Whiteneck, G. (2005). "Conceptual models of disability: past, present, and future," in Workshop on Disability in America: A New Look, eds M. J. Fields, A. M. Jette, and L. Martin (Washington, DC: National Academies Press).
- Whiteneck, G., and Dijkers, M. P. (2009). Difficult to measure constructs: conceptual and methodological issues concerning participation and environmental factors. Arch. Phys. Med. Rehab. 90(11 Suppl.), S22–S35. doi:10.1016/j.apmr.2009.06.009
- Williams, S. J. (1999). Is anybody there? Critical realism, chronic illness and the disability debate. Soc. Health Illness 21, 797–819.
- World Health Organization (1992). The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines. Geneva: World Health Organization.
- World Health Organization (2001). *International Classification of Functioning, Disability and Health: ICF.* Geneva: World Health Organization.
- World Health Organization (2007). International Classification of Functioning, Disability, and Health: Children & Youth Version: ICF-CY. Geneva: World Health Organization.

**Conflict of Interest Statement:** The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Copyright © 2018 Maxwell, Granlund and Augustine. This is an open-access article distributed under the terms of the Creative Commons Attribution License (CC BY). The use, distribution or reproduction in other forums is permitted, provided the original author(s) and the copyright owner are credited and that the original publication in this journal is cited, in accordance with accepted academic practice. No use, distribution or reproduction is permitted which does not comply with these terms.