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Assessing communicative participation in preschool children with the Focus on the Outcomes of Communication Under Six: a scoping review

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ABBREVIATIONS

CFCS	Communication Function Classification System
FOCUS	Focus on the Outcomes of Communication Under Six
ICF	International Classification of Functioning, Disability and Health

AIM To describe uses of the Focus on the Outcomes of Communication Under Six (FOCUS) in research with children with and without various communication disorders since its publication in 2010.

METHOD Six databases were searched for the term 'Focus on the Outcomes of Communication Under Six'. With additional searches we ascertained 70 articles, of which 25 met inclusion criteria for full review and data extraction.

RESULTS The FOCUS has been used in research across multiple countries, purposes, populations, contexts, and versions. Evaluative studies have described: the development of children's communicative participation skills and factors that impact the development of communicative participation; the impact of specific interventions on communicative participation; how FOCUS captures change relative to measures of impairment; and how FOCUS performs when used at different intervals. Adaptations have included: use of the FOCUS as a descriptive or discriminative tool; use with children outside the validated age range; use of select items; and use with typically developing children.

INTERPRETATION The FOCUS is used worldwide in research and practice, and much has been learned about children's communicative participation. Future research is needed to explore the relationship between children's impairments and their communicative participation, develop a FOCUS App, and develop and validate a FOCUS for school-age children.

Clinical measures are tools. They need to be carefully designed and validated to fulfill one or more of the following purposes: (1) to describe a clinical issue or situation (e.g. the MacArthur-Bates Communicative Development Inventories provide a summative description of a child's vocabulary);¹ (2) to assess the presence or absence of a problem (e.g. the Goldman-Fristoe Test of Articulation confirms an articulation impairment),² or level of function (e.g. the Communication Function Classification System [CFCS] classifies children's functional abilities into one of five levels);³ (3) to predict some concurrent or future issue (e.g. the Communication Symbolic Behaviour Scales surveys, which act as indicators of symbolic development);⁴ or (4) to evaluate change over time (e.g. the Focus on the Outcomes of Communication Under Six [FOCUS] measures growth in communicative participation).⁵ Two key properties of any clinical measure must be established before it can be applied with confidence in practice and research. First, a measure must be shown to be valid for the purpose(s) for which it is being used, with credible

evidence that it provides useful information about what is being measured. Second, a measure must be shown to be reliable, that is, to provide consistent answers when used repeatedly when nothing has changed, when different people use the measure with the same person, or when someone self-reports on more than one occasion under a steady-state circumstance. In the absence of good reliability, it is hard to be confident that the findings are 'valid'.

A modern approach to the concept of health has been captured by the World Health Organization's 2001 framework for health in its International Classification of Functioning, Disability and Health (ICF).⁶ Health has been described as 'the ability to adapt and self-manage in the face of social, physical, and emotional challenges'.⁷ The ICF framework (Fig. 1) presents a useful integrated biopsychosocial approach to health for everyone. The framework offers a dynamic system of interconnected components, all of which contribute to a person's health and health outcomes. An adaptation of the ICF concepts in the field of childhood disability are the 'F-words': function, family,

fitness, fun, friends, and future.⁸ These ideas, grafted onto the ICF framework to operationalize it, have had considerable impact and uptake around the world with more than 20 000 downloads, more than 240 citations, and at least 35 translations of the paper to date.

All components of the ICF framework are important in pediatric speech-language pathology, and there are many tools to support clinicians and researchers wanting to measure skills and outcomes within the Body Function and Structure and Activity components. Despite evidence that children with communication impairments experience a multitude of participation restrictions,^{9,10} and despite the studies that demonstrate that children and parents are most interested in addressing participation restrictions in therapy,¹¹ there are few tools to measure children's success within the Participation component.¹²

Conceptually grounded in the ICF framework, the FOCUS is a criterion-referenced, participation-focused outcome measurement tool.⁵ It was codesigned with input from parents to assess outcomes that are relevant and meaningful to them. The FOCUS takes a broad approach to evaluating outcomes by asking parents to rate items on 7-point Likert scales about how children use their communication to participate in everyday settings.⁵ The original FOCUS had 50 items,⁵ and there is now a validated 34-item version.¹³ The outcome of interest is the amount of change between assessments, and children are said to have made clinically meaningful change in their communicative participation if they meet a criterion (16 points on the FOCUS and 11 points on the FOCUS-34).^{5,13}

The FOCUS was first published in 2010. Informally, we know that it has been accessed by individuals and organizations in over 50 countries, has been widely used in both practice and research, and has been translated into more

What this paper adds

- Growth in communicative participation is reported across impairments, functional levels, and contexts.
- Outcomes vary based on child, environmental, and intervention factors.
- Weak to no correlation between changes in impairment and participation are reported.
- Adaptations of scoring, population, age, and the measure are reported.

than 20 languages. The shortened version was officially published in 2019,¹³ and it has already been used in two studies.^{14,15} Given this widespread adoption of the FOCUS, a scoping review of the literature was undertaken to document how it has been used. A scoping review was chosen because of the broad research aims of the review.¹⁴ Specific aims were to: (1) describe how the FOCUS has been reported in the literature, (2) describe the literature on children's communicative participation as measured using the FOCUS, and (3) identify adaptations of the FOCUS that differ from the developers' intended application.

METHOD

Six databases (CINAHL, Embase, ERIC, Psych Info, Medline, and Web of Science) were searched for the term 'Focus on the Outcomes of Communication Under Six' and 67 articles were identified (March 2020). After removing duplicates and the original development paper,⁵ 26 articles remained. Subsequently, three reference searches were run in Web of Science. The first was for articles that referenced the original FOCUS development paper⁵ ($n=30$ additional articles). The second was for articles that cited the FOCUS validation paper¹⁵ ($n=6$ additional articles). The third was for articles that cited the paper describing the measurement of communicative participation¹⁶ ($n=8$ additional articles). Seventy articles were included for review.

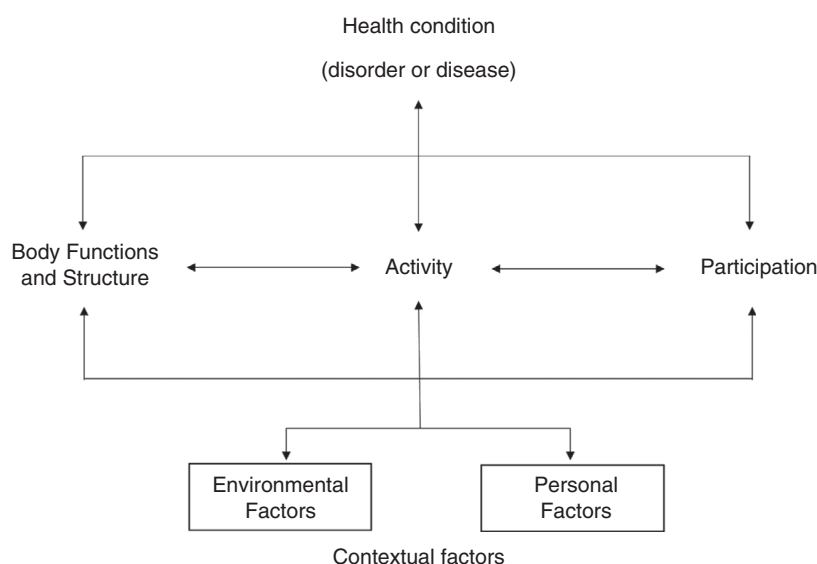


Figure 1: The International Classification of Functioning, Disability and Health framework.⁶

Each article was screened to determine whether it met three inclusion criteria, that the article: (1) reported FOCUS data, (2) was a peer-reviewed publication, and (3) was available in English. Screening was done by BJC and confirmed by NT-S (100% agreement). One article was excluded because it was only available in Russian, and three conference proceedings were excluded. Other articles were excluded because: the FOCUS was referenced, identified, or recommended, but no data were reported ($n=38$); the FOCUS was used in a knowledge translation study but data were not reported ($n=2$); or the article referenced ‘communicative participation’ but not the FOCUS ($n=1$). After screening, 25 articles remained and data were extracted into Excel spreadsheets for the following variables: country, impairment category, version, purpose, time between administration, CFCS levels, age range, context, intended use, and communicative participation outcomes. Data were extracted by BJC, who reviewed each article and categorized it for each variable. Data extractions were confirmed by NT-S (100% agreement) and data were then summarized descriptively. The articles identified as intervention studies were also assessed using the Oxford Centre for Evidence-Based Medicine levels of evidence.¹⁷ Assessment was completed by BJC and confirmed by NT-S (100% agreement).

RESULTS

Aim 1: how has the FOCUS been reported in the literature?

The FOCUS was most often used in the Canadian context, and for evaluative purposes. Clinical populations varied, but most often included children with general speech, language, and communication impairments. Use of the original 50-item FOCUS was most common, and studies were most often conducted in community clinics (Table 1).

Aim 2: what have we learned about children’s communicative participation?

To summarize findings on children’s communicative participation, we reviewed and extracted data from the 13 identified intervention studies. Articles were assessed for quality using the Oxford Centre for Evidence-Based Medicine levels of evidence¹⁷ (Table 2). Most were case series ($n=8$), but other designs included cohort studies ($n=4$) and a randomized trial ($n=1$). Intervention studies have reported on the development of children’s communicative participation, factors impacting development, and how development is associated with children’s impairments. Researchers have also reported administering the FOCUS at various assessment intervals.

Charting communicative development over time

Cunningham et al.¹⁸ reported FOCUS scores and rates of growth on the FOCUS for children with various communication impairments aged between 18 and 67 months. Notably, both scores and development varied in relation to a child’s level of communicative function as classified using

Table 1: Use of the FOCUS across countries, purposes, populations, contexts, and versions

Variable	Items assessed
Country	Australia ($n=2$) ^{28,33} Canada ($n=17$) ^{13,15,16,18-26,29,37-39,42} Germany ($n=1$) ⁴¹ Italy ($n=1$) ⁴⁰ Jamaica ($n=1$) ³² UK ($n=1$) ²⁷ USA ($n=1$) ³⁴ Vietnam ($n=1$) ³⁵
Purpose	Descriptive or discriminative ($n=4$) ³²⁻³⁵ Evaluative ($n=13$) ^{16,19-29} Reliability and validity testing ($n=8$) ^{13,15,37-42}
Population	General speech, language, and communication impairments ($n=13$) ^{13,15,16,18,19,22-25,37-39,42} Autism spectrum disorder ($n=1$) ³² Developmental language disorder ($n=1$) ³⁵ Speech sound disorder ($n=7$) ^{26-29,33-34,41} Late talkers ($n=2$) ^{20,21} Typically developing ($n=1$) ⁴⁰
Context	Community speech-language pathology clinics ($n=16$) ^{13,15,16,18-26,29,37-39} Kindergarten classrooms ($n=3$) ^{35,40,41} Early childhood education centers ($n=3$) ^{28,33,42} Developmental-behavioral pediatric clinic ($n=1$) ³² Community SLPs ($n=2$) ^{27,34}
Version used	Original 50-item FOCUS ($n=20$) ^{13,15,16,18-20,22-29,32-35,37-39} FOCUS-F ($n=1$) ⁴² FOCUS-G ($n=1$) ⁴¹ FOCUS-I ($n=1$) ⁴⁰ FOCUS-34 ($n=2$) ^{20,21}

FOCUS, Focus on the Outcomes of Communication Under Six; SLP, speech-language pathology; FOCUS-F, French translation of the FOCUS; FOCUS-G, German translation of the FOCUS; FOCUS-I, Italian translation of the FOCUS; FOCUS-34, 34-item version of the FOCUS.

Table 2: Oxford Centre for Evidence-Based Medicine (CEMB) levels of evidence for 13 identified intervention studies

Study	Research design	CEMB level
Thomas-Stonell et al. ¹⁵	Case series	4
Thomas-Stonell et al. ¹⁶	Case series	4
Hidecker et al. ¹⁹	Case series	4
Kwok et al. ²⁰	Case series	4
Cunningham et al. ²¹	Case series	4
Thomas-Stonell et al. ²²	Case series	4
Washington et al. ²³	Cohort	3
Washington et al. ²⁴	Cohort	3
Namasivayam et al. ²⁶	Cohort	3
Pennington et al. ²⁷	Case series	4
McLeod et al. ²⁸	Randomized trial	2
Namasivayam et al. ²⁹	Cohort	3
Washington et al. ³⁸	Case series	4

the CFCS.³ Generally, children who had better functional communication had more rapid development and higher FOCUS scores, a finding also documented by Hidecker et al.¹⁹ Importantly, however, children in the lowest levels of function (CFCS levels IV and V) still developed, although at a slower rate.¹⁸ Based on the data, children in CFCS levels I to III were predicted to make clinically meaningful change in under 4 months, while children in

CFCS levels IV and V were predicted to take longer (4.2 and 9.7 months respectively).¹⁸ Seven other studies also reported FOCUS scores together with CFCS classifications, included children who were lower-functioning, and documented meaningful change across all CFCS levels.^{19–25}

Factors impacting development

Factors related to children, their environments, and their intervention services have all been investigated as being associated with the development of children’s communicative participation. One study identified environmental and intervention factors associated with development.²⁵ Cunningham et al.²⁵ reported that children had higher FOCUS scores and more linear growth when they were: (1) participating in an early learning environment, (2) receiving intervention, and (3) spending more time in intervention, but the impact of each factor varied by a child’s CFCS level. For example, children in CFCS levels IV and V made change on the FOCUS with each additional month spent in intervention, while children in CFCS levels I to III demonstrated this benefit at younger (18–40mo), but not older (40–78mo), ages.²⁵ Thomas-Stonell et al. also identified intervention as an important factor, noting clinically meaningful change on the FOCUS during an intervention, but not a waitlist period, for three groups of children.¹⁶

Type of communication impairment may also be associated with children’s communicative participation.¹⁶ Clinically meaningful gains in communicative participation have been documented for children with a variety of speech, language, and communication needs.^{16,19–24,26–27} These included targeted interventions for children with childhood apraxia of speech,²⁶ dysarthria,²⁷ and children who were late-to-talk.^{20,21} Three-quarters of late talkers made meaningful gains on the FOCUS during a parent-implemented intervention,^{20,21} but change was also observed during a baseline period, suggesting that the FOCUS may capture change during non-treatment periods for some groups.²¹ Thomas-Stonell et al.¹⁶ reported that the FOCUS captured meaningful change for children with speech, language, and speech-language impairments, but the amount of change varied across groups. Children with speech-only impairments had the highest scores and made the most change. Cunningham et al. reported a similar observation for children with speech versus language impairments.²⁵

Assessing outcomes in the context of the ICF

Two intervention studies targeted children’s impairments.^{28,29} One evaluated intervention frequency for children with motor-based speech sound disorders and the other evaluated a computer-based intervention. Both found no significant differences in children’s speech production or communicative participation, but treatment and comparison groups both made clinically meaningful change on the FOCUS, suggesting that the FOCUS can capture real-world changes in communicative participation even when no statistically significant differences are observed between

groups. The relationship between change on the FOCUS and change on measures of impairment (speech intelligibility, consonant inventory, or expressive vocabulary) was assessed in two studies.^{21,27} Both reported weak to no correlation between changes in impairment and participation.

Administration frequency and intervention dose

In the 13 identified intervention studies, the FOCUS was administered at intervals ranging from every 6 months^{18,22} to every 9 to 12 weeks.^{21,28,29} Several studies reported delivering ‘intensive’ interventions and described changes on the FOCUS that were in excess of the criterion for clinically meaningful change due to intensity of treatment. Both groups theorized that the magnitude of change was due to intervention dose.²⁹

Aim 3: in what ways has the FOCUS been adapted?

We were motivated to investigate whether and in which ways the FOCUS had been adapted, based on the results of a study by Towns et al.³⁰ that identified multiple adaptations of the Gross Motor Function Classification System.³¹ Most studies included in this review reported the intended application of the FOCUS, that is, it was used with preschool children as an evaluative tool, or applied in a validity or reliability study. However, some identified studies used the FOCUS for purposes other than those for which it was developed (Table 3).

Adaptions of scoring

Three studies reported using the FOCUS as a descriptive tool,^{32–34} and one used it both descriptively and discriminatively.³⁵ One study calculated and reported averages for total and profile scores to quantify communicative participation.³² It is not incorrect to present average total FOCUS scores for groups of children (e.g. to show equality between treatment and comparison groups), but FOCUS profile scores should be included as a clinical tool to determine where change occurred; they were not developed or validated to detect change. Additional work is needed to confirm whether it is valid to use them this way. Pham et al.³⁵ included the FOCUS in a battery of tests with the intended purpose of discriminating between children with and without developmental language disorder. The authors reported large effect sizes between groups based on three criteria, one of which was parent reporting

Table 3: Adaptations of the Focus on the Outcomes of Communication Under Six (FOCUS)

Type	Adaptations
Adaptations of scoring	Use as a descriptive tool ($n=3$) ^{32–34} Use as a discriminative tool ($n=1$) ³⁵
Use outside the validated age range	Use with children >5y11mo ($n=3$) ^{24,27,34} Use with children <18mo ($n=4$) ^{19–22}
Other adaptations	Using only some FOCUS questions ($n=1$) ³⁴ Use with typically developing children ($n=1$) ⁴⁰

on the FOCUS.³⁵ Although the FOCUS has not been validated for this purpose, it may be useful for documenting the functional impact of a child's language impairment, a requirement for diagnosing developmental language disorder.³⁶

Using the FOCUS outside the validated age range

The FOCUS was validated for use with children aged between 18 months and 5 years 11 months, but several studies used the FOCUS with children outside this age range. Some were validation or reliability studies conducted by the developers ($n=6$),^{13,15,16,37-39} but six others reported FOCUS data for children outside the validated age range. Three studies included children older than 5 years 11 months (range 6-16y),^{24,27,34} and four included children younger than 18 months (range 13-17mo).¹⁹⁻²² Studies that included younger children all reported clinically meaningful change in average total FOCUS scores during intervention. Two reported meaningful change during a baseline period before intervention, but this was only observed for some of the children who were under 18 months of age.^{20,21} All children were 18 months or older at the start of treatment when communicative participation change was assessed. Studies that included children older than 5 years 11 months also reported clinically meaningful changes in children's communicative participation. Pennington et al.²⁷ reported meaningful change for children with cerebral palsy who were up to 11 years of age when the FOCUS was completed, and Washington et al.²⁴ reported clinically meaningful change during intervention for groups that included children who were age 6 years at baseline, suggesting that it may be possible to use the FOCUS with children outside the original validated age range.

Other adaptations

Two additional adaptations were identified. In one study, the FOCUS was modified by administering only questions specific to speech, with the goal of describing communicative participation in a group of children with childhood apraxia of speech.³⁴ Those authors then reported average scores for individual FOCUS items. A second study validated the Italian version of the FOCUS with a group of kindergarten children.⁴⁰ Most did not have communication impairments and were not in speech-language therapy, two criteria used to develop the original FOCUS. Interestingly, the FOCUS was still strongly correlated with scores on other related measures, suggesting that further investigation with typically developing children is warranted.

DISCUSSION

The FOCUS is used worldwide in research^{27,41} and clinical practice, and is currently being used in large health systems to evaluate the real-world impact of speech-language interventions.^{21,22} In the past 2 years, 15 organizations and 60 individual speech-language pathologists from 13 countries have purchased the measure. It has been translated

into more than 20 languages, and all published studies of FOCUS translations (Italian, German, and French) have been valid and culturally appropriate.⁴⁰⁻⁴² This widespread adoption is in part reflected by our initial search of the literature, which identified 38 articles that cited and/or recommended the FOCUS as an outcome measure. Most identified articles had enrolled Canadian families. The FOCUS has been used in several different provinces in Canada with different intervention models, and has been found to be appropriate and valid throughout. It has also been found to be valid in Germany and Italy, and has been used in studies in five other countries (Table 1). It remains to be seen if cultural differences in diverse countries affect the validity of the FOCUS.

Multiple adaptations to the FOCUS were identified in this review, including use with children who were typically developing and those outside the validated age range, as well as the use of the FOCUS as a descriptive and discriminative tool. As an evaluative tool, the FOCUS was designed and validated to measure changes in communicative participation skills associated with intervention. Validation studies should use the appropriate population and assess how well the measure captures change associated with interventions. For findings to be valid, the FOCUS must be given in its entirety. If it is given to populations other than those with which it was developed and validated, or with children outside the validated age range, it may capture change, but interpreting this change may be difficult.^{34,40}

The FOCUS was not designed as a descriptive or a discriminative measure, nor was it designed for use with children with typically developing communication skills. That is why, despite numerous requests, FOCUS norms were not developed. We believe that identified adaptations are the result of a lack of participation-based measures of children's communication.^{34,43} In 2010, the FOCUS was the sole clinical measure of communicative participation for children with communication disorders, and in 2020 this is still the case. The adaptations observed indicate an unmet need in the field and suggest that additional measures are necessary to support clinicians and researchers interested in children's communicative participation.

One important finding for both research and practice is that change on the FOCUS varies according to children's CFCS levels. The evidence shows that the FOCUS captures clinically important changes across CFCS levels; however, it is likely to take longer for children in CFCS levels IV and V to show this change.²⁵ For researchers, this finding shows the value of interpreting outcomes according to CFCS classification strata. For clinicians, it shows the importance of setting expectations and goals that are reflective of a child's functional communication ability. The CFCS functional communication levels are one of several important 'sources of variation' that may influence observed changes. Other documented factors include age, participation in an early learning environment, communication impairment, and receipt of intervention services.

These factors should also be considered when interpreting change on the FOCUS.

Another relevant finding is that change on the FOCUS was only weakly associated with change assessed with 'impairment-based' measures. It may be that impairment- and participation-based skills develop in parallel, but are unrelated,²¹ or that the available studies lacked the power to document an effect.²⁵ It may also be that gains in multiple components of the ICF framework (e.g. Body Function and Structure, Activity, and Environmental/Personal Factors) combined are associated with the development of communicative participation. FOCUS users should be aware that change captured using the tool may be different from other changes children make in intervention.

This review highlights the need for additional research related to both the FOCUS and children's communicative participation. Most of the identified intervention studies were observational, and were categorized at level 4 of the Oxford Centre for Evidence-Based Medicine levels of evidence, so work incorporating higher-level study designs would be a welcome contribution and, in some cases, may permit greater confidence in research results. However, it should be noted that well-designed observational studies are sometimes the most appropriate way to answer a research question and can yield results similar to randomized controlled trials.⁴⁴ Our current research plans include the development of an application to make online completion and scoring of the FOCUS easier for parents, and to

allow for automatic calculation of change and profile scores. Discussions are also underway about developing a school-age version of the FOCUS for children who are 6 to 9 years of age. More research is needed to see how well the FOCUS works as a discriminative (and possibly predictive) measure, and to investigate the association between children's impairments, activity limitations, personal and environmental factors, and their communicative participation.⁴⁵ The FOCUS may also be useful for supporting the triangulation and interpretation of data for qualitative studies of children's functional outcomes.

Limitations associated with this review are the inclusion of only articles available in English and the date of searches. Since the review was completed in early 2020, it is possible that not all articles reporting FOCUS data published in 2020 have been included. It should also be noted that many of the 25 studies included were published by the authors of this review.

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