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Person-centered Outcomes in Culturally and Diverse Contexts: International Application of the ICF

Karla Washington  
*University of Cincinnati*

Jane McCormack  
*Charles Sturt University*

A. Lynn Williams  
*East Tennessee State University,* williamsl@etsu.edu

Brenda Louw  
*East Tennessee State University,* louwb1@etsu.edu

Nancy Thomas-Stonell  
*Bloorview Research Institute*

*See next page for additional authors*

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Person-centered Outcomes in Culturally and Diverse Contexts: International Application of the ICF

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Creator(s)
Karla Washington, Jane McCormack, A. Lynn Williams, Brenda Louw, Nancy Thomas-Stonell, and Tammy Hopper

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Person-centered Outcomes in Culturally and Diverse Contexts: International application of the ICF

Karla Washington
Jane McCormack
Lynn Williams
Brenda Louw
Nancy Thomas-Stonell
Tammy Hopper
Disclosure Statement

- Financial Disclosures:
  - The presenters are employed by different universities or research institutes
  - Each presenter received complimentary ASHA registration

- Non-Financial Disclosures: Presenters have no relevant non-financial disclosures
International Application of the ICF

1. Application of ICF – Overview

2. Considerations for children within the Australian context
   – Jane McCormack

3. Considerations for Brazil and the United States
   – Lynn Williams and Brenda Louw

4. Considerations for Jamaican-Creole speaking preschoolers
   – Karla Washington

5. Considerations for Canadian preschoolers
   – Nancy Thomas-Stonell

6. Considerations for Dementia within the Canadian context
   – Tammy Hopper
1. Application of the ICF in speech-language pathology: An introduction and overview

Karla Washington, Ph.D., CCC-SLP, S-LP(C)
University of Cincinnati
Cincinnati, Ohio, USA
Background

“health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”

(WHO, 1946)
ICF-CY

Part 1: Functioning and Disability

Body Functions & Structures <-> Activities

Part 2: Contextual Factors

Environmental Factors <-> Personal

Health Condition (Disease or disorder)

WHO (2007)
Each presenter will describe

• **Context and population**
  - countries/languages/population/age-group

• **Rationale for using the ICF**
  - why use it/benefits/theoretical strengths

• **Application of the ICF**
  - How it has been applied/ Research and practice

• **Resources**
  - for SLPs to support application (e.g., access to tools/publications/guides/websites)
2. Research and clinical application of the ICF in pediatric speech-language pathology contexts in Australia

Jane McCormack, Ph.D., CPSLP
University of Sheffield, UK
Charles Sturt University, Australia
Disclosure Statement

- The presenter acknowledges that she is an author of one of the clinical tools outlined in this presentation
- There are no financial disclosures
Context and population: Australia

- 23,896,623 (population)
- National language is English; 23.2% speak a language other than English at home
  - Mandarin (1.6%), Italian (1.4%), Arabic (1.3%), Greek (1.2%), and Cantonese (1.2%)
- Aboriginal and Torres Strait Islander people comprise approx. 3% of the Australian population; approx. 12% of Indigenous people speak an Indigenous language at home
- Children aged 0-4 years comprise approx. 6% of the population
  - Approx. 25% of parents have concerns about how their 4-5 year old children “talk and make speech sounds” (McLeod & Harrison, 2009)
Rationale

• “The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), provides a conceptual framework for speech pathologists within which individual functioning and health are paramount...Applying the ICF to the clinical practice of speech pathology, practitioners can incorporate both the diagnosis of impairment (body function and structure) and the activity and participation of the individual to assess the impact of the communication and/or swallowing disorder on quality of life.

• …including the contextual factors (environmental and personal) and activity and participation levels, allows speech pathologists to collaboratively set goals with an individual and their caregivers.

• It is expected that an entry-level speech pathologist in Australia will be familiar with the ICF framework and competently apply the social health principles of individual functioning and well-being to their speech pathology practice” (Speech Pathology Australia, 2011, p.6).
Clinical applications of the ICF

<table>
<thead>
<tr>
<th>Individual Level</th>
<th>Institutional Level</th>
<th>Social Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Assessment</td>
<td>• Education and training</td>
<td>• Eligibility criteria</td>
</tr>
<tr>
<td>(e.g., Intelligibility in Context Scale)</td>
<td>(e.g., embedding of the Professional Framework and Range of Practice Principles into SLP training programs).</td>
<td>(e.g., National Disability Insurance Scheme)</td>
</tr>
<tr>
<td>• Intervention planning</td>
<td>• Resource planning and development</td>
<td>• Social policy development</td>
</tr>
<tr>
<td>(e.g., Communication Support Inventory – Children and Youth)</td>
<td>• Quality improvement</td>
<td>• Needs assessments</td>
</tr>
<tr>
<td>• Progress monitoring</td>
<td>• Outcome evaluation</td>
<td>• Environmental assessments</td>
</tr>
<tr>
<td>(e.g., Focus on Outcomes of Children Under Six; AusTOMs)</td>
<td>• Service delivery planning</td>
<td></td>
</tr>
<tr>
<td>• Self evaluation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Research applications of the ICF

<table>
<thead>
<tr>
<th></th>
<th><strong>Project 1 (McCormack et al., 2009)</strong></th>
<th><strong>Project 2 (McCormack et al., 2011)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aims</strong></td>
<td>To systematically review research that identified an association between speech impairment and Activity Limitations and/or Participation Restrictions, in order to better understand the social dimensions of childhood speech impairment.</td>
<td>To investigate the association between communication (speech and language) impairment in early childhood and Activities and Participation at school-age using parent-, teacher- and child-report, and direct assessment.</td>
</tr>
<tr>
<td><strong>Research Design</strong></td>
<td>Systematic (narrative) Review</td>
<td>Longitudinal Study</td>
</tr>
<tr>
<td><strong>Data</strong></td>
<td>57 papers</td>
<td>4,329 children (7-9 years)</td>
</tr>
<tr>
<td><strong>Application of the ICF (ICF-CY)</strong></td>
<td>ICF used to determine key words and synthesise results</td>
<td>ICF used to identify 18 outcome measures across 5 domains</td>
</tr>
<tr>
<td><strong>Results</strong></td>
<td>Activity Limitations / Participation restrictions across 6 ICF components (Learning and applying knowledge; Communication; Mobility; Self-care; Interpersonal interactions &amp; relationships; Major life areas)</td>
<td>Children identified with communication impairment at 4-5 years performed significantly less well at 7-9 years on <strong>all outcomes</strong> (Learning and applying knowledge; General tasks and demands; Communication; Interpersonal interactions &amp; relationships; Major life areas)</td>
</tr>
</tbody>
</table>
## Resources

<table>
<thead>
<tr>
<th>Clinical Tool</th>
<th>Author(s)</th>
<th>Weblink</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus on Outcomes on Communication Under Six (FOCUS)</td>
<td>Thomas-Stonnell, Oddson, Robertson &amp; Rosenbaum (2010)</td>
<td><a href="http://research.hollandbloorview.ca/Outcomemeasures/FOCUS">http://research.hollandbloorview.ca/Outcomemeasures/FOCUS</a></td>
</tr>
</tbody>
</table>
3. Application of the ICF in Brazil and the United States

Lynn Williams, PhD, CCC-SLP
Brenda Louw, PhD
East Tennessee State University
Disclosure Statement

• The information presented in this session was jointly funded by the U.S. Department of Education Fund for the Improvement of Post-Secondary Education (FIPSE) and the Brazilian Ministry of Education (Fundacao Coordenacao de Aperfeicoamento de Pessoal de Nivel Superior; CAPES). Neither author received compensation as members of the project staff.

• Convention registration fee waivers were provided for our participation on this invited panel.
• East Tennessee State University (lead US institution)
  • Brenda Louw (Project Co-Director)
  • Lynn Williams (Project Co-Director)
  • Nancy Scherer (Senior Project Staff)
• University of Northern Iowa
  • Ken Bleile (Project Co-Director)
• Universidade Federal de Santa Maria (lead Brazil institution)
  • Marcia Keske-Soares (Project Director)
  • Themis Kessler
• Universidade de São Paulo-Baurú
  • Inge Trindade
Context and Population

- Brazil is the largest country in South America and the 5th most populated country in the world
- Portuguese is the national language of Brazil
- Brazil has the 2nd largest population of SLPs
  - Brazilian Society of Speech-Language Pathology and Audiology (http://www.sbfa.org.br/portal)
Portuguese Speakers in the U.S.  
(Shin & Kominski, 2010)

- 687,126 Portuguese speakers in the U.S.
- #5 most common Indo-European language spoken in the U.S.
  - Portuguese speakers represent 1.2 percent of speakers of non-English language in the U.S.
- Brazilian Portuguese (BP) differs from the Portuguese spoken in Europe (EP) in terms of pronunciation, spelling and vocabulary
Brazilian Context Relative to the ICF
(Fernanda Dreux M. Fernandes & Mara Behlau, 2013)

• Movement in the Brazilian government towards improved access and quality of services to persons with disabilities
  • Professional and scientific associations participated in implementation of these changes
  • Complexity of identification of under-served populations and specific barriers to access to services and resources for a nation of 200 million people living in a vast country

• Brazilian SLP/A associations aim to increase the use of ICF with a larger number of students and professionals
  • Important outcome for SLP/A is to guarantee adequate communication between PWCD and health/education service providers to ensure the best quality of care
Rationale for Using the ICF

VISION
Making effective communication, a human right, accessible and achievable for all.

MISSION
Empowering and supporting audiologists, speech-language pathologists, and speech, language, and hearing scientists through advancing science, setting standards, fostering excellence in professional practice, and advocating for members and those they serve.

STRATEGIC OBJECTIVES
1. Expand data available for quality improvement and demonstration of value
2. Advance interprofessional Education and Interprofessional Collaborative Practice (IPE/IPP)
3. Enhance the generation, publication, knowledge translation, and implementation of clinical research
4. Enhance service delivery across the continuum of care to increase value and access to services
5. Increase influence and demonstrated value of audiology and speech-language pathology services
6. Increase the diversity of the membership
7. Enhance international engagement
8. Increase members’ cultural competence

TRANSFORM
Revolutionary change within the professions and/or the association

GROW
Expanded, recast, expanded and/or innovate within association programs, operations, and functions

RUN
Ongoing operations, including evaluation and process improvement in association programs and functions

OPERATIONAL PRIORITIES
- Enhance membership value and satisfaction
- Maintain an effective technology infrastructure
- Maximize non-dues revenue
- Facilitate staff engagement, inclusion, and a culture of learning
- Ensure effective project and process management and execution
- Ensure effective management and utilization of resources and data

VALUES: EXCELLENCE • INTEGRITY • DIVERSITY • COMMITMENT • RESEARCH-BASED • MEMBER-CENTRIC • RESPONSIVE
ASHA’s Strategic Pathway: Transforming Clinical Practice

SO4: Enhance Service Delivery across the Continuum of Care to Increase Value and Access to Services

Transforming clinical practice so that clinicians make effective clinical decisions that enhance patient’s outcomes using ICF

SO8: Increase Members’ Cultural Competence

Enhanced ability to help clients/students/patients achieve their desired clinical outcomes
Cross-Linguistic Consortium (FIPSE) Goals Linked to Strategic Pathway

SO4
Increase Value and Access to Services

• Promote a general understanding of the relatedness of the professions in Brazil and the US within a global context.
• Apply ICF framework in assessment and intervention with children who have a communication disorder.

SO8
Enhanced clients achieve their desired clinical outcomes

• Promote language and cultural skills
• Promote cultural and research competence in SLP/A students
Objective 1
To investigate the association between communication disorders in children and limitations to life activities within the theoretical framework of the ICF-CY.
- Families
- Social
- Educational
- Cultural differences

Objective 2
To understand the social and cultural aspects of assessment and intervention for children with communication disorders across different etiologies (e.g., cleft lip/palate, SSD, HI)
- Models of intervention
- Barriers to access or implementation

Objective 3
To explore and identify resilience and risk factors in the different social and cultural contexts across different subgroups of communication disorders from a strength-based approach.
FIPSE Research Teams

- Cleft Lip/Palate Team 1
  - ICF-CY in CLP (Objective 1 and 2)

- Cleft Lip/Palate Team 2
  - Nasometry in US and Brazil (Objective 2)

- Speech Sound Disorders Team
  - Prevalence of SSD in English-speaking countries and Brazil (Objective 1 and 3)

- Hearing Impairment Team
  - Prevalence of HI in English-speaking countries and Brazil (Objective 1 and 3)
# FIPSE Research Application of the ICF

<table>
<thead>
<tr>
<th>Focus</th>
<th>Design</th>
<th>Description</th>
<th>ICF-CY</th>
<th>Language</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Children</strong></td>
<td>Descriptive Synthesis</td>
<td>a. Prevalence of SSD in US/Brazil</td>
<td>Functioning &amp; Disability</td>
<td>English / Portuguese</td>
</tr>
<tr>
<td></td>
<td></td>
<td>b. Prevalence of HI in children in US/Brazil</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SLPs</strong></td>
<td>a. Descriptive Synthesis</td>
<td>a. Mapped assessment measures</td>
<td>Functioning &amp; Disability</td>
<td>English</td>
</tr>
<tr>
<td></td>
<td>b. Translation</td>
<td>b. ICS-Portuguese</td>
<td>Contextual Factors</td>
<td>Portuguese</td>
</tr>
<tr>
<td></td>
<td>c. Survey</td>
<td>c. Questionnaires to PD, Instructors</td>
<td></td>
<td>English/Portuguese</td>
</tr>
<tr>
<td><strong>SLPs</strong></td>
<td>Survey</td>
<td>Theoretical framework of ICF-CY to examine assessment practices for SSD</td>
<td>Functioning &amp; Disability</td>
<td>English/Portuguese</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Contextual Factors</td>
<td></td>
</tr>
<tr>
<td><strong>Children and</strong></td>
<td>Mixed Methods</td>
<td>Child and parent reports regarding SSD and limitations to life activities</td>
<td>Activities &amp; Participation</td>
<td>English/Portuguese</td>
</tr>
<tr>
<td>Parents**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td>Descriptive Quantitative</td>
<td>Nasometry studies of typical and atypical speakers</td>
<td>Functioning &amp; Disability</td>
<td>English/Portuguese</td>
</tr>
</tbody>
</table>
Mapping FIPSE Research to ICF

Health Condition
- Disorder or disease that informs predicted comorbidities and prognosis

Body Functions and Structures
- Anatomical parts and their physiological functions
  - [Prevalence Reviews; Mapping; Nasometry]

Environmental and Personal Factors
- Physical, social, attitudinal, and environmental factors within the individual’s life
  - [Survey Practices]

Activities and Participation
- Execution of tasks or involvement in life situations
  - [ICS-P; Survey Practices; Child/Parent Interviews]

Continuum of FIPSE Research Relative to ASHA’s Change Model

Run
- Narrative reviews
- Mapping
- Surveys

Grow
- ICS-Portuguese Child/Parent Interviews

Transform
- Publish in U.S. and Brazil
- Continuing education in both countries
- Surveys of PDs, Instructors, and SLPs
Aligning ICF with ASHA’s Change Model

**Run**
- Research
- Educate
- Create awareness

**Grow**
- Build skills
- Develop and disseminate clinical resources and tools

**Transform**
- Shift paradigms and mindsets
- Promote, endorse, push, publicize
- Help clients achieve their desired outcomes
## Resources

### Selected Books and Articles

### ASHA Resources
- ASHA *Scope of practice in speech-language pathology* [Scope of practice].

### Clinical Tools
- ICS-Portuguese
- QUACC (Quan-Qual Assessment of Impact of Environmental Factors on Everyday Life and Communication in Children; Neumann & Zelinski, in preparation)
- Parental Appraisal of Cleft Questionnaire (Shuttlewood, Dalton, & Cooper, 2013)
- ASHA Resources (case studies of ICF life-participation goals: www.asha.org/slp/icf)
- Intercultural Development Inventory (IDI; Hammer, Bennett, & Wiseman, 2003)

### ASHA Strategic Pathway 2025

**ASHA Strategic Pathway 2025**: [http://www.asha.org/uploadedFiles/ASHA-Strategic-Pathway-to-Excellence.pdf](http://www.asha.org/uploadedFiles/ASHA-Strategic-Pathway-to-Excellence.pdf)
4. Using the ICF to support person-centered practices with Jamaican-Creole speaking preschoolers and their families

Karla Washington, Ph.D., CCC-SLP, University of Cincinnati
Sharynne McLeod, Ph.D., SLP, Charles Sturt University
Hubert Devonish, Ph.D., University of the West Indies
Maureen Samms-Vaughan, MD, PhD University of the West Indies
Disclosure Statement

• The presenter acknowledges that she is a translator for one of the clinical tools outlined in this presentation

• Research presented was funded by:
  • ASHA – Students Pursuing Academic Research Careers
  • Australian Council Future Fellowship Award (FT0990588)
  • Endowment to the University of Cincinnati Foundation
  • University of Cincinnati Faculty Development Grant
  • University of Cincinnati International Program Development Grant
  • Vice-president for Research Start-up funds, University of Cincinnati
Context and population

- **Jamaica**, one of two English speaking islands in the Greater Antilles in the Caribbean
- Population of about **2.8 million people**
- Part of the British Commonwealth of Nations
- Granted Independence in 1962
- **English** and **Jamaican Creole** are spoken
  - English is the language of the classroom

- Less than 10 licensed SLPs – registered with the *Council for Professions Supplementary to Medicine*
- Services within a medical model
- **SLP**: Currently no SLP programs, but slated to begin in Fall 2015
  - Joint program between Humanities and Medicine
- Jamaican Speech-Language Pathology Association

Context and population

- **Jamaicans**, who are greater than 90% African or Afro-European decent, comprise 18.8% of the Caribbean-born population in the US, exceeded only by Cuba (28.6%) and the Dominican Republic (22.9%)

- Between **2007 (597,940)** and **2014 (705,804)** there has been a steady increase in the number of Jamaican-born Americans in the U.S. (see figure)

- The number of Jamaican-Americans as has also increased from **904, 501 in 2007** to **1,091,482 in 2013**

- Little attention on Jamaicans in the cultural and diverse speech-language literature in contrast to the emphasis on Spanish-English Speakers

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Rationale

- In speech-language pathology we have access to a wide variety of developmental procedures and assessments that support our diagnostic roles for determining whether or not a child qualifies for services.
- Conceptualize child development as well as our approaches to services within a broader perspective supportive of culturally competent practice.
- ICF-CY provides an internationally recognized bio-psycho-social model for conceptualizing normal functioning and disability in birth- to 18-year range.

Rationale

- The ICF-CY can support a comprehensive approach that includes consideration of **multiple domains** and **respondents** that enhances the usefulness of our assessments for Jamaican children and their families.
- The nature of true disorder is yet to be characterized in Jamaican children.
- Approach to **assessment** must be **comprehensive** if it is to be informative.

<table>
<thead>
<tr>
<th>Domains (area)</th>
<th>Domain (Respondents)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Functioning and Disability</strong></td>
<td><strong>Contextual Factors</strong></td>
</tr>
<tr>
<td>1. Speech and language</td>
<td>1. Parents</td>
</tr>
<tr>
<td>2. Cognition</td>
<td>2. Teachers</td>
</tr>
<tr>
<td>3. Socialization</td>
<td>3. SLP</td>
</tr>
<tr>
<td>5. Oral Motor</td>
<td></td>
</tr>
<tr>
<td>Target Area</td>
<td>Measure</td>
</tr>
<tr>
<td>-----------------</td>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td>1. Parent</td>
<td>consent x2</td>
</tr>
<tr>
<td>2. Parent</td>
<td>questionnaire - ICSs</td>
</tr>
<tr>
<td>3. Parent</td>
<td>questionnaire</td>
</tr>
<tr>
<td>4. FOCUS</td>
<td>Parent version</td>
</tr>
<tr>
<td>5. FOCUS</td>
<td>Clinician version</td>
</tr>
<tr>
<td>6. Teacher</td>
<td>Teacher questionnaire</td>
</tr>
<tr>
<td>7. Verbal assent</td>
<td>Ask child OK to research, audio, video</td>
</tr>
</tbody>
</table>

**Category 1**

| 8. Hearing      | Audiometric Screen                               | Screen hearing skills                                                       | 3                             |                                 |
| 9. Nonverbal IQ | Primary Test of Nonverbal Intelligence (PTONI)    | Formal evaluation of nonverbal thinking skills                             | 7                             |                                 |
| 10. Oral Motor Skills | DEAP – Oral Motor Assessment substest               | Tool used to evaluate oral motor skills                                     | 3                             |                                 |
| 11. Receptive Language | Peabody Picture Vocabulary Test (PPVT)                    | Evaluates word-level receptive language                                     | 10                            |                                 |
| 12. Receptive Language | CELF: Sentence structure (SS) subtest (yellow)            | Evaluates sentence-level receptive language                                 | 5                             |                                 |
| 14. Children’s Feelings | Speech Participation and Activity Assessment in Children (SPAA–C)       | Picture-based rating scale about speech skills                             | 2                             |                                 |

**Category 2 (Standard Jamaican English)**

**First**

| 16. Expressive Language | Spontaneous language sample (morphemes, mean length of utterance, syntax) | 10                             |                                 |
| 17. Speech Skills       | Diagnostic Evaluation of Articulation Phonology (DEAP) Articulation and Phonology subtests | Formal measure of articulation and phonology skills | 14                            |                                 |
| 19. Expressive Language | CELF Expressive Vocabulary (EV) (Blue) | Formal measure of expressive vocabulary | 5                             |                                 |

**Category 2 (Jamaican Creole)**

**Second**

| 20. Expressive Language | Spontaneous language sample (morphemes, mean length of utterance, syntax) | 10                             |                                 |
| 21. Speech Skills       | DEAP Articulation and Phonology subtests | Articulation and phonology skills | 14                            |                                 |
| 22. Expressive Language | CELF Word Structure (WS) (Purple) | Expressive morphology and syntax | 10                            |                                 |
| 23. Expressive Language | CELF Expressive Vocabulary (EV) (Blue) | Formal measure of expressive vocabulary | 5                             |                                 |

**Multilingual and Multicultural Experiences in Communication Sciences and Disorders – Education Abroad Program Jamaica**
# Application of the ICF (Research)

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Material</th>
<th>Description</th>
<th>ICF-CY</th>
<th>Language</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent</td>
<td>Questionnaire</td>
<td>Demographic information, Language use at home, Speech intelligibility, Strengths and Weaknesses, Home reading, Functional Communication</td>
<td>Functioning and Disability, Contextual Factors</td>
<td>English and Jamaican Creole</td>
</tr>
<tr>
<td>Teacher</td>
<td>Questionnaire</td>
<td>Speech, language, behaviour</td>
<td>Functioning and Disability</td>
<td>English</td>
</tr>
<tr>
<td>Clinician</td>
<td>Questionnaire</td>
<td>Functional Communication, Literacy</td>
<td>Functioning and Disability, Contextual Factors</td>
<td>English</td>
</tr>
<tr>
<td>Child</td>
<td>Direct Assessment</td>
<td>Oral motor, cognition, hearing, speech, language, Feelings about talking</td>
<td>Functioning and Disability, Contextual Factors</td>
<td>English Jamaican Creole</td>
</tr>
</tbody>
</table>
Parents

1. Speech and Language
   • On a scale of 0-5 how concerned are you about your child’s talking

| 1. | 0 Not concerned | Research use 0 |
| 2. | 1 Sometimes concerned | 1 |
| 3. | 2 Often quite concerned | 2 |
| 4. | 3 Always quite concerned | 3 |
| 5. | 4 Often very concerned | 4 |
| 6. | 5 Always very concerned | 5 |

• If you said you were concerned please indicated the area(s) in which your child has difficulty (tick as many as appropriate)

| a) | Reluctant to speak | No | Yes |
| b) | Speech not clear to family | No | Yes |
| c) | Speech not clear to others | No | Yes |
| d) | Difficulty finding words | No | Yes |
| e) | Difficulty putting words together | No | Yes |
| f) | Doesn’t understand you when you speak | No | Yes |
| g) | Doesn’t understand others when they speak | No | Yes |
| h) | Voice sounds unusual | No | Yes |
| i) | Stutters, stammers | No | Yes |
| j) | Lisps | No | Yes |
| k) | Persistent hearing loss | No | Yes |
| l) | Cleft lip and/or palate | No | Yes |
| m) | Developmental delay | No | Yes |
| n) | Other | No | Yes |
| o) | Don’t know | No | Yes |
Parents

2. Background information about languages spoken in your home

**QUESTIONS ABOUT YOUR CHILD**

14. a) How long has your child lived in Jamaica? whole life /

b) Has your child lived in another place? yes / no

c) If yes, where did he/she used to live and for how long?

15. What language(s) does your child speak and how well?

<table>
<thead>
<tr>
<th></th>
<th>Very well</th>
<th>Somewhat well</th>
<th>Not very well</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Jamaican /Patois/Patwa/Creole</td>
<td>1.</td>
<td>2.</td>
<td>3.</td>
</tr>
<tr>
<td>b. English</td>
<td>4.</td>
<td>5.</td>
<td>6.</td>
</tr>
<tr>
<td>c.</td>
<td>7.</td>
<td>8.</td>
<td>9.</td>
</tr>
<tr>
<td>d.</td>
<td>10.</td>
<td>11.</td>
<td>12.</td>
</tr>
<tr>
<td>e.</td>
<td>13.</td>
<td>14.</td>
<td>15.</td>
</tr>
</tbody>
</table>

16. a) What language(s) does your child ______________ speak most often at home?

b) What language(s) does your child hear most often at home?

17. a) What language(s) does your child speak most often at pre/school?

b) What language(s) does your child hear most often at pre/school?

18. What percentage of the week would your child speak and hear these languages?

<table>
<thead>
<tr>
<th></th>
<th>% of week your child speaks</th>
<th>% of week your child hears others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jamaican /Patois/Patwa/Creole</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>English</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>=100%</td>
<td>=100%</td>
</tr>
</tbody>
</table>
# The FOCUS: Parent Form

**FOCUS on the Outcomes of Communication Under Six**

<table>
<thead>
<tr>
<th>Name of Child</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Date Completed</td>
<td>Year</td>
</tr>
<tr>
<td></td>
<td>Month</td>
</tr>
<tr>
<td></td>
<td>Day</td>
</tr>
<tr>
<td>Date of Birth</td>
<td>Year</td>
</tr>
<tr>
<td></td>
<td>Month</td>
</tr>
<tr>
<td></td>
<td>Day</td>
</tr>
<tr>
<td>Chronological Age</td>
<td>Year</td>
</tr>
<tr>
<td></td>
<td>Month</td>
</tr>
<tr>
<td>Name of Person Completing Form</td>
<td></td>
</tr>
<tr>
<td>FOCUS Completion #</td>
<td></td>
</tr>
<tr>
<td>Name of Speech-Language Pathologist</td>
<td></td>
</tr>
</tbody>
</table>

**Administration Instructions**

The FOCUS is an outcome measure that takes a ‘snapshot’ of your child’s skills as they are today. Some items may not apply to your child right now, if so, please select “Not at all like my child”. Your child may begin to learn some of these skills during therapy and choosing this option will let us measure all of the changes that your child is making. Please be sure to answer every question. Thank you.

**Definitions:**

- “Talking”, “tell”, “speaks”, “speech” and “words” refer to verbal speech. (e.g. “My child talks a lot.”)
- “Communicating”, “conversations”, “participates” and “asking” can be any form of communication (pecs, AAC, sign). (e.g. “My child will ask for help.”)

---

**FOCUS TOTAL SCORE**

---

**Parents**


---


FOCUS Scoring Profile

ICF-CY Body Function/Capacity Items

<table>
<thead>
<tr>
<th>Speech</th>
<th>Expressive Language</th>
<th>Pragmatics</th>
<th>Receptive Language / Attention</th>
</tr>
</thead>
</table>

Total Score: 3  Total Score: 6  Total Score: 5  Total Score: 4
Average Score:  Average Score:  Average Score:  Average Score:

ICF-CY Performance Items

<table>
<thead>
<tr>
<th>Intelligibility</th>
<th>Expressive Language</th>
<th>Social / Play</th>
<th>Independence</th>
<th>Coping Strategies / Emotions</th>
</tr>
</thead>
</table>

Total Score: 4  Total Score: 4  Total Score: 12  Total Score: 5  Total Score: 7
Average Score:  Average Score:  Average Score:  Average Score:  Average Score:

Domain | Speech | Expressive Language | Pragmatics | Receptive Language / Attention |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>ICF-CY Body Function/Capacity Scores</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domain</td>
<td>Intelligibility</td>
<td>Expressive Language</td>
<td>Social / Play</td>
<td>Independence</td>
</tr>
<tr>
<td>ICF-CY Performance Scores</td>
<td>Coping Strategies / Emotions</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

FOCUS TOTAL SCORE

This study uses questionnaires (or part of) developed for **GROWING UP IN AUSTRALIA: THE LONGITUDINAL STUDY OF AUSTRALIAN CHILDREN** (LSAC). These questionnaires are the property of the Australian Government Department of Families, Community Services and Indigenous Affairs. LSAC is an initiative of the Australian Government Department of Families, Community Services and Indigenous Affairs (www.facsia.gov.au), and is being undertaken in partnership with the Australian Institute of Family Studies (www.aifs.gov.au).
Clinicians

The FOCUS: Clinician Form

FOCUS on the Outcomes of Communication Under Six

Name of Child

Date Completed
Year ________ Month ________ Day ________
Date of Birth
Year ________ Month ________ Day ________
Chronological Age
Year ________ Month ________
Name of Person Completing Form

FOCUS Completion #

Name of Speech-Language Pathologist

Administration Instructions
The FOCUS is an outcome measure that takes a ‘snapshot’ of your client’s skills as they are today. Some items may not apply to your client right now. If so, please select “Not at all like my client”. Your client may begin to learn some of these skills during therapy and choosing this option will let us measure all of the changes that your client is making. Please be sure to answer every question. Thank you.

FOCUS Definitions:
When reading FOCUS items, the words “talking”, “tell”, “speaks”, “speech” and “words” refer to verbal speech. FOCUS items that refer to “communicating”, “conversations”, “participates” and “asking” apply to any form of communication (pecs, AAC, sign).

FOCUS Scoring Profile

ICF-CY Body Function/Capacity Items

Speech

Expressive Language

Pragmatics

Receptive Language / Attention

Total Score

Average Score

ICF-CY Performance Items

Intelligibility

Expressive Language

Social / Play

Independence

Coping Strategies / Emotions

Total Score

Average Score

Domain

Speech

Expressive Language

Pragmatics

Receptive Language / Attention

ICF-CY Body Function/Capacity Scores

ICF-CY Performance Scores

FOCUS TOTAL SCORE

Holland Bloorview Kids Rehabilitation Hospital


Children

- 2-hour comprehensive assessment with a clinician

<table>
<thead>
<tr>
<th>Category 1</th>
<th>Description</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Hearing</td>
<td>Audiometric Screen</td>
<td></td>
</tr>
<tr>
<td>2. Nonverbal IQ</td>
<td>Primary Test of Nonverbal Intelligence (PTONI)</td>
<td></td>
</tr>
<tr>
<td>4. Receptive Language</td>
<td>Peabody Picture Vocabulary Test (PPVT)</td>
<td></td>
</tr>
<tr>
<td>5. Receptive Language</td>
<td>CELF: Sentence structure (SS) subtest (yellow)</td>
<td></td>
</tr>
<tr>
<td>6. Emergent Literacy</td>
<td>Preschool Word and Print Awareness (PWPA)</td>
<td></td>
</tr>
<tr>
<td>7. Children’s Feelings</td>
<td>Speech Participation and Activity Assessment in Children (SPAA-C)</td>
<td></td>
</tr>
<tr>
<td>8. Drawings</td>
<td>Sound Effects Study Protocol</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Happy</td>
<td>In the middle</td>
</tr>
<tr>
<td>---</td>
<td>-------</td>
<td>---------------</td>
</tr>
<tr>
<td>1. How do you feel about the way you talk?</td>
<td>🧡</td>
<td>🧐</td>
</tr>
<tr>
<td>2. How do you feel when you talk to your best friend</td>
<td>🧡</td>
<td>🧐</td>
</tr>
<tr>
<td>3. How do you feel when you talk to your brother?</td>
<td>🧡</td>
<td>🧐</td>
</tr>
<tr>
<td>4. How do you feel when you talk to your mum and dad?</td>
<td>🧡</td>
<td>🧐</td>
</tr>
<tr>
<td>5. How do you feel when you talk to your school teachers?</td>
<td>🧡</td>
<td>🧐</td>
</tr>
<tr>
<td>6. How do you feel when your teachers ask you a question?</td>
<td>🧡</td>
<td>🧐</td>
</tr>
<tr>
<td>7. How do you feel when you talk to the whole class?</td>
<td>🧡</td>
<td>🧐</td>
</tr>
<tr>
<td>8. How do you feel when you play with the children at school?</td>
<td>🧡</td>
<td>🧐</td>
</tr>
<tr>
<td>9. How do you feel when you play on your own?</td>
<td>🧡</td>
<td>🧐</td>
</tr>
<tr>
<td>10. How do you feel when people don’t understand what you say?</td>
<td>🧡</td>
<td>🧐</td>
</tr>
</tbody>
</table>


Data courtesy of the “Jamaican Children’s Speech and Language Skills” research project
Investigators: Karla Washington, Sharynne McLeod, Maureen Samms-Vaughan, & Hubert Devonish
Funding: Vice President for Research, University of Cincinnati Start-up Funds and the Australian Research Council Future Fellowship Award (FT0990588)
Children
• Drawing Protocol

“‘I want you to draw a picture for me. Is it OK if I keep it when you are done?’
‘Draw a picture of you talking to someone’

Replica Drawing

Questions
1. Who is in the drawing?
   him and mommy + daddy

2. How do you know this person (i.e. friend, brother etc)?
   mom + daddy

3. Do you usually like talking to this person?
   yes

4. Where are you?
   school

5. What are you/they doing?
   talking

6. What are you saying/talking about?
   T.V.

7. Ask them to identify any unknown objects.
   “How do you feel about the way you talk?” (circle the picture)

Happy | In the middle | Sad | Another feeling | Don’t know

Notes

Data courtesy of the “Jamaican Children’s Speech and Language Skills” research project
Investigators: Karla Washington, Sharynne McLeod, Maureen Samms-Vaughan, & Hubert Devonish
Funding: Vice President for Research, University of Cincinnati Start-up Funds and the Australian Research Council Future Fellowship Award (FT0990588)
Children

• Drawing Protocol

"I want you to draw a picture for me. Is it OK if I keep it when you are done?"
"Draw a picture of you talking to someone"

Replica Drawing

Questions
1. Who is in the drawing?
2. Who is not in the drawing?
3. Are there any animals (cat, dog, brother etc.)?
4. Can you explain in which situation (circles the picture)?

<table>
<thead>
<tr>
<th>Happy</th>
<th>In the middle</th>
<th>Sad</th>
<th>Another feeling</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>😊</td>
<td>😐</td>
<td>😞</td>
<td>😘</td>
<td>🎆</td>
</tr>
</tbody>
</table>
Children

- 2-hour comprehensive assessment with a clinician

<table>
<thead>
<tr>
<th>Category 2 (Standard Jamaican English)</th>
<th>First</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Expressive Language</td>
<td>Spontaneous language sample</td>
</tr>
<tr>
<td>2. Speech Skills</td>
<td>Diagnostic Evaluation of Articulation Phonology (DEAP) Articulation and Phonology subtests</td>
</tr>
<tr>
<td>4. Expressive Language</td>
<td>CELF Expressive Vocabulary (EV) (Blue)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Category 2 (Jamaican Creole)</th>
<th>Second</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Expressive Language</td>
<td>Spontaneous language sample</td>
</tr>
<tr>
<td>6. Speech Skills</td>
<td>DEAP Articulation and Phonology subtests</td>
</tr>
<tr>
<td>7. Expressive Language</td>
<td>CELF Word Structure (WS) (Purple)</td>
</tr>
<tr>
<td>8. Expressive Language</td>
<td>CELF Expressive Vocabulary (EV) (Blue)</td>
</tr>
</tbody>
</table>

I have to say it in English for this “Aunty”

Mi a go chat iina Jamiekan fi dis “Anti”
## Assessment Approach

<table>
<thead>
<tr>
<th>Domain</th>
<th>Mode</th>
<th>Measure/Technique</th>
<th>Description</th>
<th>Languages Elicited</th>
</tr>
</thead>
</table>
| Speech sound production - Articulation | Verbal – single word      | *Diagnostic Evaluation of Articulation and Phonology* *(DEAP; Dodd et al. 2002)* | Articulation subtest                | • Jamaican Creole  
• Standard Jamaican English |
| Speech sound production - Phonology | Verbal response – single word | *DEAP* *(Dodd et al. 2002)*                                                      | Phonology subtest                   | • Jamaican Creole  
• Standard Jamaican English |
| Expressive Language-Vocab       | Verbal response – single word | *Clinical Evaluation of Language Fundamentals – Preschool 2* *(CELF-P2; Wiig et al., 2004)* | Expressive vocab subtest            | • Jamaican Creole  
• Standard Jamaican English |
| Expressive Language-Morphosyntax | Verbal response- single word/phrase/short sentence | *CELF-P2* *(Wiig et al., 2004)*                                                  | Word structure subtest              | • Jamaican Creole  
• Standard Jamaican English |
| Spontaneous Production          | Verbal response            | Elicitation of spontaneous sample during play                                     | Free play with SLP                  | • Jamaican Creole  
• Standard Jamaican English |
## Resources - Clinical

<table>
<thead>
<tr>
<th>Clinical Tool</th>
<th>Author(s)</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grammatical Morphemes Patterns – Jamaican Creole (n=145, 3-to-6 year olds)</td>
<td>Washington, McLeod, Devonish, Samms-Vaughan (2014)</td>
<td>Not yet available</td>
</tr>
</tbody>
</table>
Mezha fi Oomoch ada Piipl kyan
Andastan di Pikni: Jamiekan
Intelligibility in Context Scale: Jamaican Creole (McLeod, Harrison, & McCormack, 2012)
Translated by: Karla N. Washington, Ph.D., University of Cincinnati, USA
   and Hubert Devonish, Ph.D., University of the West Indies, Mona Campus, Jamaica, 2014

Di pikni nisim (Child's name):

Di diet di pikni baan (Child's date of birth):
A Bwa-pikni/Gyal-pikni (male/female):
Bait dong di langwii dem we di pikni tayk (Language(s) spoken):
Tide diet (Current date):
Di pikni iqi (Child's age):
Di amadi niem we a ful out dis ya faam (Person completing this form):
A uu yu bi tu di pikni - Se if yu a mada, fada, antu, or wa? (Relationship to the child):

Wi a go aks yu kwestian bout wen yu pikni chat, omoch a we di pikni se ada piipl kyan andastan. Yu fi ansa azkzadn tu yu yu pikni did a chat ina mont we di saan. Jraa wan sorki roun jov wan nomba fi evri kwestian.
(The following questions are about how much of your child's speech is understood by different people. Please think about your child's speech over the past month when answering each question. Circle one number of each question)

---

<table>
<thead>
<tr>
<th>Evri ti am</th>
<th>Muos tain</th>
<th>Somtaim</th>
<th>Aadil eva</th>
<th>Neva</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Always)</td>
<td>(Usually)</td>
<td>(Sometimes)</td>
<td>(Rarely)</td>
<td>(Never)</td>
</tr>
</tbody>
</table>

1. Yu andastan wen yu pikni chat?
   (Do you understand your child?)

2. Wen di pikni chat, di famli memba dem we liw di pikni andastan?
   (Do immediate members of your family understand your child?)

3. Wen di pikni chat, famli we no liv widd di pikni andastan?
   (Do extended members of your family understand your child?)

4. Yu pikni fren dem andastan wen yu pikni a chat?
   (Do your child's friends understand your child?)

5. Wen yu pikni chat, ada piipl we di pikni nua andastan?
   (Do other acquaintances understand your child?)

6. Wen yu pikni chat, di tilcha dem andastan?
   (Do immediate members of your family understand your child?)

7. Wen yu pikni chat tu schrienja, di schrienja dem andastan?
   (Do strangers understand your child?)

---

Evrining ad op tu (TOTAL SCORE) = /35
AVRIU fi evrining (AVERAGE TOTAL SCORE) = /5

---

(For any questions with no clear answer, please circle the number that best represents the situation.)

Intelligibility in Context Scale is licensed under Creative Commons Attribution-NonCommercial-NoDerivs 3.0 Unported License.

<table>
<thead>
<tr>
<th>Grammatical structure (morpheme)</th>
<th>JC Rule</th>
<th>Realization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present progressive (ing)</td>
<td>/a/ before root verbs to signal continuative/progressive aspect</td>
<td>Playing = a plie (a play)</td>
</tr>
<tr>
<td></td>
<td>-Tense not overtly marked</td>
<td></td>
</tr>
<tr>
<td>Regular third person (s)</td>
<td>To signal habitual use -unmarked form of the verb with all subjects</td>
<td>Plays = plie (play)</td>
</tr>
<tr>
<td></td>
<td>Tense not overtly marked</td>
<td></td>
</tr>
<tr>
<td>Irregular past (change in root verb)</td>
<td>Use of unchanged root verb to mark irregular past</td>
<td>Flew = flai (fly)</td>
</tr>
<tr>
<td>Regular past (ed)</td>
<td>Use of unmarked verb form to signal completive aspect</td>
<td>Played = plie (Play)</td>
</tr>
<tr>
<td>Comparative (er)</td>
<td>Comparative –a and superlative- is in suffix position</td>
<td>faster = faasa</td>
</tr>
<tr>
<td>Superlative (est)</td>
<td></td>
<td>fastest = faasis</td>
</tr>
<tr>
<td>Pronoun (she, him, her, they)</td>
<td>Gender typically undifferentiated</td>
<td>She = shi/im (She/him)</td>
</tr>
<tr>
<td></td>
<td>Case can be undifferentiated</td>
<td>He = im</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Him = im; her = ar/im</td>
</tr>
<tr>
<td></td>
<td></td>
<td>They/Them = dem</td>
</tr>
<tr>
<td>Possessive &quot;s&quot;</td>
<td>Possessor “di” is in the front position</td>
<td>Boy’s ball = di bwai baal; fi</td>
</tr>
<tr>
<td></td>
<td>* “fi” could be added for emphasis</td>
<td>di bwai baal; a di Bwai uon</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Phonetic Transcription Guide

<table>
<thead>
<tr>
<th>Sample word</th>
<th>Phonetic transcription</th>
<th>Known Error</th>
<th>Consonants Correct</th>
<th>Vowels Correct</th>
<th>Phonemes Correct</th>
<th>Lexical change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pig</td>
<td>[pɪɡ] [pɪɡə] [pɪɡɪ] [pɪɡz]</td>
<td>[pɪkə] [bɪɡ]</td>
<td>2(3)</td>
<td>1(2)</td>
<td>3(4)</td>
<td>no</td>
</tr>
<tr>
<td>Sock</td>
<td>[sɒk] [sæk] [saks] [səks] [wən fut a sakə]</td>
<td>[θək] [θəkθ] [θaks]</td>
<td>2(3)</td>
<td>1(4)</td>
<td>3(4, 11)</td>
<td>yes</td>
</tr>
<tr>
<td>Thumb</td>
<td>[θəm] [təm] [bɪɡ fɪŋɡə] [fɪŋɡə] [fɪŋɡəu]</td>
<td>[təŋ] [fəm]</td>
<td>2(3,5)</td>
<td>1(2)</td>
<td>3(5, 6, 8)</td>
<td>yes</td>
</tr>
</tbody>
</table>
## Resources - Additional

<table>
<thead>
<tr>
<th>Topic</th>
<th>Resource</th>
<th>Reference</th>
</tr>
</thead>
</table>
5. Measuring communicative participation outcomes in Canadian preschoolers using the ICF framework

Nancy Thomas-Stonell, B.Sc., D.S.P.
Speech-Language Pathologist & Scientist, Bloorview Research Institute
Assistant Professor, University of Toronto
Disclosure Statement

• The FOCUS© outcome measure is available for download at no cost through the Holland Bloorview Kids Rehabilitation Hospital website.

• I am the author of the FOCUS and currently employed at the Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital.

Funding provided by:
• Canadian Institutes of Health Research
• SickKids Foundation
• Bloorview Research Foundation
What is the FOCUS?

The FOCUS is a valid, reliable, responsive treatment outcome measure that captures ‘communicative participation’ changes following speech and language treatment.
The FOCUS:

• is an outcome measure for preschool children (1.5 – 6 yrs.) attending speech-language therapy.
• can be used with children who have a variety of communication disorders.
• has 50 items.
• takes 10 minutes to complete.
• is primarily a parent measure.
The FOCUS

• The FOCUS is criterion referenced.

• It takes a verbal ‘snapshot’ of the child’s skills at Time 1 and Time 2.

• The difference in the scores measures change.
Developed and Validated by 11 Preschool Programs across Canada
The FOCUS is Valid

√ It measured more change during a treatment interval than during a wait list interval (p < .01).

Wait List Interval: + 6 points
Treatment Interval: + 18 points

√ Convergent and discriminant validity with the ASQ-SE
FOCUS agrees with Speech and Language Measures

✓ FOCUS change scores significantly agreed (p<.05) with change scores obtained from randomized, blinded analysis of pre and post treatment videos.

- Child Speech Intelligibility Measure (CSIM)
- Percent Consonants Produced (PCC-R)
- Developmental Sentence Scoring (DSS)

✓ Disagreements made sense.
The FOCUS is Reliable

√ Parent & clinician test-retest reliability was very high. \((r > .95)\)

√ Clinician inter-rater reliability was higher than most tests! \((ICC = 0.93)\) \((CI = .87-.97)\)

[Schumacker, 2005]
Who is the FOCUS designed for?

• The FOCUS is designed for children with a variety of communication disorders.

• Included in the database are children with a variety of communication disorders (e.g., speech, language delay, SLI, ASD, hearing impairment, global developmental delay, and those using AAC).
PREVALENCE OF COMMUNICATION DISORDERS IN PRESCHOOLERS
Communication Disorders in Preschool Children

• Prevalence data often reported for specific communication disorders (e.g., speech disorders) rather than overall prevalence.

• 1 in 4 preschool children (25%) are identified by parents/teachers as having speech and/or language difficulties. (McLeod and Harrison, 2009)
Communication Disorders in Preschool Children

• Boys are twice as likely as girls to start primary school unable to speak properly.
  (www.telegraph.co.uk/education/education; Mar 26, 2015)

• Ontario data shows that 66% of preschoolers receiving speech-language therapy are boys (N=18,000).
Rationale for using the ICF-CY

“It speaks for itself.”
Developing the FOCUS

• We collected data from 210 parents of preschoolers receiving speech-language therapy and their clinicians.

• After therapy they answered the following questions:
  • My child is now able to…
  • What other changes did you see?
  • Why is that important?
Completed a Content Analysis of the Data

- Content analysis is the “systematic, objective analysis of message characteristics” to make valid inferences from text. (Neuendorf, 2002).
- Three researchers independently analyzed the data and then compared categories to organize them into schema.
- Percentages of occurrence for each category were calculated.
Comments aligned with the ICF-CY

- Health Condition
  - Body Functions & Structures
  - Activities
    - Environmental Factors
    - Personal Factors
  - Participation
FOCUS items were developed for every category with ≥10% occurrence.

Parent Comment

“His play with peers has improved in terms of sharing, turn-taking, following conversations, acting less aggressively.”

Category/ICF-CY coding:

- Complex Interpersonal Interactions d720

FOCUS Item

“My child plays well with other children.”
Method: 6 Linked-Steps

1. Created FOCUS items
2. Tested the measure with clinicians and families
3. Revised the measure using the parent and clinician feedback and measurement science
4. Tested the revised measure
5. Revised measure again
6. Tested measure a third time
Three revisions reduced the FOCUS from 104 items to 50 items

<table>
<thead>
<tr>
<th>Initial FOCUS</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Functions</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>Activities/Capacity</td>
<td>28%</td>
<td></td>
</tr>
<tr>
<td>Participation/Perf.</td>
<td>54%</td>
<td></td>
</tr>
<tr>
<td>Personal Factors</td>
<td>20%</td>
<td></td>
</tr>
<tr>
<td>Environ. Factors</td>
<td>3%</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Final FOCUS</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Functions</td>
<td>2%</td>
<td></td>
</tr>
<tr>
<td>Activities/Capacity</td>
<td>34%</td>
<td></td>
</tr>
<tr>
<td>Participation/Perf.</td>
<td>56%</td>
<td></td>
</tr>
<tr>
<td>Personal Factors</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>Environ. Factors</td>
<td>0%</td>
<td></td>
</tr>
</tbody>
</table>

- FOCUS now measures ‘communicative participation’.
- Activities and Participation items increased to 90%.
- FOCUS takes 10 minutes to complete.
Why is participation important?

• We need to look at the impact of treatment on the whole child.
• If we are treating articulation, what is the impact on the child’s life?
  • Better understood?
  • Less frustrated?
  • Play better/more with other children?
  • Less teased by other children?
FOCUS Scoring Profile provides additional information for clinicians.

- Items grouped according to the ICF-CY Body Function/Capacity and Performance components and categorized by communicative participation skills.
- The Scoring Profile shows where the child has made the most/least change. This information supports treatment planning.
The Scoring Profile

- ICF-CY Body Function/Capacity
  - Speech
  - Expressive language
  - Pragmatics
  - Receptive Language/Attention

- ICF-CY Performance
  - Intelligibility
  - Expressive Language
  - Social/Play
  - Independence
  - Coping Strategies/Emotions
Canadian Outcome Measurement Data
Nova Scotia Hearing and Speech Centres

- NSHSC serves all of Nova Scotia and provides more than 50,000 visits per year.

- NSHSC has piloted implementation strategies (parent vs clinician forms) for using the FOCUS across the Province.

- They collected change data on 140 children.
Value of Outcome Measures
More numbers do not necessarily reflect an effective service!
Sixty-three percent of children made clinically significant change
Why <9?

• Review of cases <9 (25%) indicated that…

• some parents became more aware of their child’s communication difficulties as treatment progressed.

• young children with profound delays/disorders made less change.

• children with mild delays/disorders in one domain (e.g., Lisp) made less change.
Parent vs Clinician Forms

- Clinician Form
- Parent Form

ASHA November 2015
Parent Comments

- Parents reported that the FOCUS helped them be better observers of their child’s communication skills.
- It helped them understand the treatment process.
- Having their observations solicited made them feel more like partners in the rehabilitation process.
Speech-Language Pathologists’ Comments

• SLPs changed their intake procedures after using the FOCUS to obtain information from the parents regarding the child’s communication abilities at home and in the community.

• The FOCUS increased SLPs’ awareness of the importance of participation outcomes in speech-language therapy.
Nova Scotia Hearing and Speech Centres’ Recommendations

• FOCUS implemented as of July 2015.
• Parent form is the primary form.
• Clinician form will be used in specific circumstances.
• FOCUS will be administered at:
  • Assessment
  • End of Treatment Program
  • or after 6 months
Ontario Preschool Speech-Language Program (PSLP)

- The FOCUS was introduced into their Outcome Measure Strategy in Oct 2012.
- PSLP serves all of Ontario and provides service to more than 58,000 children per year between birth and Senior Kindergarten.
- FOCUS change data has now been collected on more than 18,000 children.
Partnering with the Ontario Preschool Speech-Language Program

• The majority of children made clinically significant change (>16 pts) six months after assessment.
• Clinically significant change was found across ages and communication disorder severity.
• Exception: Similar to NS data - younger children (<2 yrs) with severe communication disorders made less change.
CURRENT RESEARCH

A New Version of the FOCUS with 34 items: FOCUS-34
FOCUS-34

• Large amount of data from Ontario provides the opportunity to refine the FOCUS to increase its clinical efficiency.

• Data were grouped by age, presence/absence of treatment and the severity of delay/disorder according to the five Communication Function Classification System (CFCS) levels.
Results of Data Analyses

- Cronbach’s Alpha and Item Response Theory models were run on subgroups.
- 16 items were identified that:
  - contributed less to the total change score
  - did not work as well for some of the groups of children
  - were redundant with other FOCUS items
Results of Data Analyses

• FOCUS-34 predicts the 50 item FOCUS total scores at each administration \((r = .99)\).
• FOCUS-34 change scores predicts FOCUS change scores \((r = .97)\)
• FOCUS-34 has identical psychometric properties to the FOCUS.
FOCUS vs FOCUS-34

<table>
<thead>
<tr>
<th>FOCUS</th>
<th>FOCUS-34</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Functions</td>
<td>2 %</td>
</tr>
<tr>
<td>Activities/Capacity</td>
<td>34 %</td>
</tr>
<tr>
<td>Participation/Perf.</td>
<td>56 %</td>
</tr>
<tr>
<td>Personal Factors</td>
<td>10 %</td>
</tr>
<tr>
<td>Body Functions</td>
<td>0 %</td>
</tr>
<tr>
<td>Activities/Capacity</td>
<td>38 %</td>
</tr>
<tr>
<td>Participation/Perf.</td>
<td>53 %</td>
</tr>
<tr>
<td>Personal Factors</td>
<td>9 %</td>
</tr>
</tbody>
</table>

- Body Function items removed
- Continued emphasis on Activities and Participation items (91%)
- Majority of Personal Factors items retained
FOCUS-34 Revisions

- All negatively worded items were removed.
- Activity/Capacity Profile Categories were realigned.

✗ Speech category (Body Function items)

✓ More emphasis on Expressive Language
✓ Pragmatics and Receptive Language/Attention items were retained.
All Performance Categories Retained

- Intelligibility
- Expressive Language
- Social/Play
- Independence
- Coping Strategies/ Emotions
- Highest emphasis remains on the social/play items (~40% of items).
FOCUS-34

Now available for clinical use!
Resources
Where do I find the FOCUS?

The FOCUS webpage is part of the Holland Bloorview website:

www.hollandbloorview.ca
  • search for FOCUS in upper right-hand corner of page

www.focusoutcomemeasurement.ca

The FOCUS and FOCUS-34 are copyrighted and licensed and available for free download from Flintbox. A link is provided on the FOCUS webpage.
Webpage Statistics

- FOCUS webpage is receiving over 100 hits a month.
- FOCUS has been downloaded by over 30 countries around the world: USA, England, Ireland, Scotland, Australia, New Zealand, Malaysia, Russia, Poland, Singapore, India, Iceland and more…
FOCUS Webpage contains:

- FOCUS Outcome Measure (FOCUS and FOCUS-34)
- FOCUS forms available in paper and pdf fillable versions
- Administration Manual
- Parent Instruction Sheets
- Links to published papers
- Training Power Points
- Excel scoring program
- Frequently Asked Questions
FOCUS Translations

- Agreements have been reached with several international SLP researchers to translate the FOCUS.
- FOCUS was translated by SLP’s fluent in the language and back translated by a different SLP.
- The back translation was reviewed by the FOCUS team to ensure fidelity with the original FOCUS.
FOCUS Translations

- Review of the back translated items is essential to ensure items retain their original meanings.
- FOCUS item: “My child takes turns.”
- Back-translated item: “My child takes turns speaking and listening.”
- These items are not the same. This item is meant to capture both verbal and non-verbal turn-taking and needed to be revised.
FOCUS Translations

- FOCUS has been translated into: Afrikaans, Chinese, Danish, French, German, Hebrew and Spanish.
- Japanese and Greek translations are pending.
- In keeping with Canada’s multi-cultural society, the Parent Instruction sheets have been translated into **14 languages**: Arabic, Traditional and Simplified Chinese, Farsi, French, German, Hebrew, Korean, Punjabi, Serbian, Spanish, Tagalog, Tamil and Urdu.
A Little Light Reading

• Validation of the Focus on the Outcomes of Communication Under Six outcome measure

• Measuring communicative participation using the FOCUS©: Focus on the Outcomes of Communication Under Six.

• nthomasstonell@hollandbloorview.ca
• focus@hollandbloorview.ca
6. Why and how to use the ICF in person-centered care of individuals with dementia (Canada)

Tammy Hopper, Ph.D. CCC-SLP
University of Alberta, Alberta, Canada
Disclosure Statement

- Financial Disclosures:
  - Dr. Hopper is employed by the University of Alberta
  - Dr. Hopper has received honoraria from ASHA for past presentations

- Non-Financial Disclosures: Dr. Hopper has no relevant non-financial disclosures
Context and population

• Dementia
  • A syndrome defined by multiple cognitive impairments
  • Irreversible dementia can be caused by several health conditions

Percentage of dementia cases caused by different diseases

- Alzheimer's disease: 55%
- Vascular disease: 15%
- Lewy body disease: 15%
- Frontotemporal disorders: 10%
- Other: 5%
Context and Population

- Canada’s population is ~35,000,000; 2 official languages (French and English)
- Seniors make up 14% of the total population in 2011 (4.9 million)
  - Almost 30% of Canadian seniors (65+ years) are immigrants
  - Approximately 12-13% of seniors speak a non-official language at home
  - 7-8% of seniors belong to a visible minority group
  - Only 4% of Aboriginal people in Canada are over the age of 65 years
- The estimated number of individuals with dementia ~700,000 (2011); will increase to 1.4 million by 2030

Statcan.ca; alzheimer.ca
Rationale

Alzheimer’s Disease

Cognitive Impairments

Communication Limitations, Social Participation Restrictions

Home? LTC? Family support? Caregiver attitudes?

Past Communication Patterns

(ICF: WHO, 2001)
Application of the ICF in Dementia

• Maximizing function through focusing on activities/participation in direct interventions with clients
  • Person-centered care is consistent with the ICF – patients/clients and their family members are team members and make decisions about their own care and goals, in partnership with the clinician
  • Cultural and linguistic considerations will, then, be central in the process
• Evidence based, person-centered direct interventions to improve communication functioning of people with dementia include:
  • Written and graphic cues in the form of memory books and wallets (Bourgeois, 2013)
  • Reminiscence therapy
  • Spaced retrieval training (Camp & Brush, 2000)
Application of the ICF in Dementia

- Indirect interventions that focus on environmental variables can have several foci

<table>
<thead>
<tr>
<th>Constructs</th>
<th>Relevant “e” codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Services, systems &amp; policies</td>
<td>Health services in residential care facilities e580; educational &amp; training services e5850</td>
</tr>
<tr>
<td>Support &amp; relationships</td>
<td>Immediate family e310; Acquaintances e325; Personal care provider e340; Health professionals e355</td>
</tr>
<tr>
<td>Attitudes</td>
<td>Immediate family e410; personal care providers e440; health professionals e450; social norms, practices &amp; ideologies e465</td>
</tr>
<tr>
<td>Natural &amp; human-made changes to the environment</td>
<td>Light e240 (intensity e2400 /quality e2401); Sound e250 (intensity e2400 /quality e2401)</td>
</tr>
</tbody>
</table>
Application of the ICF in Dementia

• Services/Systems issues: Long-term Care
  • In a survey of SLPs working with older adults in Canada, only 3% reported working in LTC settings (Hopper et al., 2007)
  • In LTC, SLPs reported that they often did not provide treatment to individuals with dementia because patients with more acute concerns have priority (e.g., those with dysphagia or with aphasia following stroke)
  • Referrals were a barrier as well: SLPs reported a lack of referrals from other health care professionals – attitudes?
Application of the ICF in Dementia

• Attitudinal barriers: Lack of knowledge
• “I need some input regarding cognitive therapy for a woman in a skilled nursing facility in her late 80's who has moderate dementia. She has had a decline in social interaction and increased agitation in the past couple of weeks. I would love to work with her on finding some activities that she could attend to (or be redirected) to ease agitation. She is in a Broda chair and is actively moving throughout the building during the day attempting to clean, fold, and hide things. Family reports she has always been compulsive about cleaning and keeping personal items safe and hidden. She used to work in a hotel in the laundry. I observed her today with a few towels and she helped me fold them for approx. 20 minutes. Does anyone have experience with similar patients?”

• Reply: “That is too much! Hopefully Medicare will deny the dementia 'tx'. How ridiculous and what are they teaching in school?”
Application of the ICF

• Douglas et al (2014) investigated the perceptions of SLPs (and LTC administrators) regarding the use of external memory aids for residents with dementia.

• The authors reported that LP knowledge, perceptions and organizational context all influenced implementation of an EBP such as the use of written and graphic cues in the form of memory aides.

• Even when there is research evidence to support the use of an intervention, environmental barriers may exist that prevent or minimize the use of that intervention.
Application of the ICF

• In summary, the ICF is an important tool to help frame assessment and treatment for individuals with dementia.

• Ever-worsening impairments in cognition mean that SLPs should focus on maximizing functional abilities through direct and/or indirect interventions (A/P and Environmental variables).

• Dementia is a public health priority (WHO, 2012) and interventions that are evidence-based, person-centered and framed using the ICF will be integral to meeting the needs of this diverse and rapidly growing segment of our world’s population.
Resources

• Alzheimer Society of Canada (2010). Rising tide: the impact of dementia on Canadian society. Toronto, ON: ASC.

Handouts: ICF and speech-language pathology: http://www.asha.org/slp/icf/
7. Considerations for SLPs regarding clinical and research applications of the ICF: Resources and conclusions

**Karla Washington**, Ph.D., CCC-SLP, S-LP(C)
University of Cincinnati, Ohio, USA
Websites with free resources

• American Speech-Language-Hearing Association
• Multicultural affairs and resources
  http://www.asha.org/practice/multicultural/
• Speech-Language Therapy – Caroline Bowen
• speech-language-therapy.com
• Multilingual Children’s Speech
  • www.csu.edu.au/research/multilingual-speech/
    • Languages
    • Typical speech acquisition
    • Assessments
    • Intelligibility in Context Scale
ASHA

• Scope of Practice in Speech-Language Pathology (ASHA, 2007), advocates the use of the World Health Organization’s (WHO) conceptual framework, the ICF (WHO, 2001) and (ICF-CY; WHO, 2007) in clinical and research activities for adults and children.

• This document states that, “The ICF framework is useful in describing the breadth of the role of the speech-language pathologist (SLP) in the prevention, assessment, and habilitation/rehabilitation, enhancement, and scientific investigation of communication and swallowing” (ASHA, 2007, p.4).

http://www.asha.org/policy/SP2007-00283/
ICF Framework for SLP:

• Health conditions that represent a continuum of functioning – from intact to completely compromised
  • Body functions and structures
  • Activity and participation
• Contextual factors
  • Environmental factors
• Personal factors

UNESCO Universal Declaration on Cultural Diversity (2001)

“Affirming that respect for the diversity of cultures, tolerance, dialogue and cooperation, in a climate of mutual trust and understanding are among the best guarantees of international peace and security”

Person-centered Outcomes in Culturally and Diverse Contexts:
International application of the ICF

Karla Washington, washink2@ucmail.uc.edu
Jane McCormack, jmccormack@sheffield.ac.uk
Lynn Williams, WILLIAML@mail.etsu.edu
Brenda Louw, LOUWB1@mail.etsu.edu
Nancy Thomas-Stonell, nthomasstonell@gmail.com
Tammy Hopper, tammy.hopper@ualberta.ca