THE ASSESSMENT - INTERVENTION PROCESS OF YOUNG CHILDREN WITH AUTISM: CONTRIBUTIONS OF THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH FOR CHILDREN AND YOUTH.

Susana Castro

University of Pretoria
CAAC
2013
The concept of Development

Development Contextualistic Approaches

Ecological and Bioecological Models (Bronfenbrenner, 1979/2005)

Transactional Model (Sameroff, 1975/2009)

General and Dynamic Systems’ Theory (Von Bertalanfy, 1969; Skyttner, 2005; Wachs, 2000)
Models of Disability

- **Medical Model**
- **Social Model**

Simeonsson, 2006

- **“Third way” in conceiving Disability**
  (Kristiansen, Vehmas and Shakespeare, 2009)

**BIOPSYCHOSOCIAL FORMULATIONS**

**DEVELOPMENTAL CONTEXTUALISTIC APPROACHES**
The ICF-CY framework

Health condition

Body Functions and Structures

Activities

Participation

Personal Factors

Environmental Factors

WHO (2001; 2007)
The ICF-CY framework

WHO, 2001; 2007
Purpose of Doctoral Thesis

• To provide evidence that supports potential applications of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY; WHO, 2007) to the assessment-intervention process in preschool children with autism.
Four studies to analyze the added value of the ICF-CY to the assessment-intervention process in young children with Autism Spectrum Disorders (ASD)

- The “state-of-art” of the assessment-intervention process.
- Linking measurements of children’s functioning and development with the ICF-CY dimensions: frequency of components and level of agreement.
- Development of a new assessment instrument based on the ICF-CY classification system.
- To study children’s functioning patterns, beyond diagnostic criteria.
Study 1: The “state-of-art” of the assessment-intervention process of young children with ASD

- The development of Individualized Education Programs (IEP) is directly related with the quality of services received by students (Shriner & Destefano, 2003).

- The development of the IEP is particularly difficult in children with ASD due to the extreme heterogeneity evidenced within this group of children (Menousek et al., 2007).
Study 1: The “state-of-art” of the assessment-intervention process of young children with ASD

• Purpose:
To analyze Individualized Education Programs (IEP) of preschool children with autism using the ICF-CY framework as pre-defined matrix of categories.

• Data Analysis Procedure / Analytical Approach:

Study 1: The “state-of-art” of the assessment-intervention process of young children with ASD

Deductive Content Analysis

Psychometric perspective (Creswell, 1998);

Manifest analysis (Elo & Kyngas, 2007);

Deductive coding (Creswell, 1998);

Linking rules (Cieza et al., 2005);

Unit of Analysis: Individualized Education Programs (IEP) (Elo & Kyngas, 2007);

Two content areas: descriptions of assessments and intervention goals (Graneheim & Lundman, 2004);

Meaningful concepts (Cieza et al., 2005) / Meaning units (Graneheim & Lundman, 2004).
**Study 1:** The “state-of-art” of the assessment-intervention process of young children with ASD

**Results:** N= 33 IEP

<table>
<thead>
<tr>
<th>ICF-CY components</th>
<th>Assessment &amp; Intervention</th>
<th>Assessment</th>
<th>Intervention</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of Functioning dimensions in each IEP section</td>
<td>242 (23,1%)</td>
<td>542 (51,8%)</td>
<td>263 (25,1%)</td>
<td>1047</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ICF-CY components</th>
<th>Assessment &amp; Intervention</th>
<th>Assessment</th>
<th>Intervention</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Functions &amp; Structures</td>
<td>42 (17,4%)</td>
<td>159 (29,3%)</td>
<td>42 (15,9%)</td>
<td>243</td>
</tr>
<tr>
<td>Activities &amp; Participation</td>
<td>200 (82,6%)</td>
<td>238 (43,9%)</td>
<td>219 (83,3%)</td>
<td>657</td>
</tr>
<tr>
<td>Environmental Factors</td>
<td>0</td>
<td>143 (26,4%)</td>
<td>0</td>
<td>143</td>
</tr>
<tr>
<td>Non definable</td>
<td>0</td>
<td>2 (0,4%)</td>
<td>2 (0,8%)</td>
<td>4</td>
</tr>
<tr>
<td>Mean number of functioning dimensions</td>
<td>7,33</td>
<td>16,42</td>
<td>7,97</td>
<td>31,73</td>
</tr>
</tbody>
</table>
Study 1: The “state-of-art” of the assessment-intervention process of young children with ASD

• Discussion:

  - Difficulty in implementing a multidimensional approach in the assessment-intervention process, which considers both child and environmental features, concurrently;

  - Inconsistency in documenting the assessment-intervention process;

  - The ICF-CY proved to be a useful tool to individual documentation.
Study 2: Linking measures of functioning and development with the ICF-CY: frequency of components and inter-rater agreement issues

• Background:

- The alignment of ICF-CY codes with extant measurements is one of the recommended research areas regarding the ICF-CY (Lollar & Simeonsson, 2005);

- This is already an established line of research (Cerniauskait et al., 2011).
Study 2: Linking measures of functioning and development with the ICF-CY: frequency of components and inter-rater agreement issues

• Purpose:
  - To identify the dimensions of functioning covered by currently used instruments in the assessment of children with ASD;
  - To determine the level of agreement between coders when mapping instruments’ content with the ICF-CY categories.


Study 2: Linking measures of functioning and development with the ICF-CY: frequency of components and inter-rater agreement issues

- **Instruments:**
  - Carolina Curriculum for Preschoolers with Special Needs (CCPSN; Jonhson-Martin, Attermeier & Hacker, 2004);
  - The Schedule of Growing Skills II (SGS-II; Bellman, Longam & Aukett, 1996);
  - Griffith’s developmental scales (Griffith’s, 1970);
  - Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1999);
  - Autism Diagnostic Interview Revised (ADI-R; Rutter et al., 2003);
  - Childhood Autism Rating Scale (CARS; Schopler, Reicheler & Renner, 1988).
Study 2: Linking measures of functioning and development with the ICF-CY: frequency of components and inter-rater agreement issues

• Procedure:

Two independent coders with knowledge and training on the ICF-CY –specific phases:

1. To acquire knowledge on the instrument to be analyzed;
2. To acquire Knowledge and to establish a common understanding on the linking rules and content analysis procedures;
3. To conduct an independent definition of the items’ meaningful concepts followed by consensus;
**Study 2:** Linking measures of functioning and development with the ICF-CY: frequency of components and inter-rater agreement issues

- **Procedure:**

4. To conduct *independent coding of meaningful concepts*;

5. To calculate the *probability of agreement* (Cohen’s Kappa);

6. To *discuss to obtain consensus* on final coding.

7. To resolve coding differences – a *third party judgment* on final coding.
Study 2: Linking measures of functioning and development with the ICF-CY: frequency of components and inter-rater agreement issues

**Results:** Frequencies of ICF-CY Functioning dimensions per instrument

<table>
<thead>
<tr>
<th>Instruments</th>
<th>Body Functions</th>
<th>A &amp; P</th>
<th>Environmental</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCPSN</td>
<td>60</td>
<td>101</td>
<td>0</td>
</tr>
<tr>
<td>SGS-II</td>
<td>66.6</td>
<td>105.2*</td>
<td>0</td>
</tr>
<tr>
<td>GRIFFITH’S</td>
<td>22.1</td>
<td>113.1*</td>
<td>0</td>
</tr>
<tr>
<td>ADOS</td>
<td>102.1*</td>
<td>152.1*</td>
<td>0</td>
</tr>
<tr>
<td>ADI-R</td>
<td>67.3</td>
<td>77.5</td>
<td>1.1</td>
</tr>
<tr>
<td>CARS</td>
<td>280.2</td>
<td>173.4</td>
<td>0</td>
</tr>
</tbody>
</table>

* More than one meaningful concept per item
Study 2: Linking measures of functioning and development with the ICF-CY: frequency of components and inter-rater agreement issues

- Results: agreement between coders using Cohen’s Kappa

  - Kappa values vary within a wide range;

  - The level of agreement is probably more dependent on the concept being coded, than on the coders ability to use the ICF-CY.
• **Discussion:**

- Formal instruments currently used to assess children with ASD **do not account for environmental features**, thus, jeopardizing a multidimensional approach to the assessment;

- Instruments based on diagnostic criteria, besides providing cut-off points, yield relevant information **about children’s functioning which is not considered in the final score, but that is useful for intervention purposes**;

- Some ICF-CY dimensions **need to be more clearly defined** to increase agreement levels when assigning content.
Study 3: Development of a reduced set of ICF-CY codes for the assessment-intervention process in preschoolers with ASD

• Background:

- A classification needs to be exhaustive but should not be too complex to be used in everyday practice. A specific set of ICF-CY codes is needed (core-set) that is wide enough to address three aspects:

(1) the general health condition of the child;

(2) the individual and specific functioning of the child;

(3) the environmental factors of the different contexts where the child develops and interacts.

(Üstün et al., 2004, p.7)
Study 3: Development of a reduced set of ICF-CY codes for the assessment-intervention process in preschoolers with ASD

• Purpose:

To identify *Essential features of functioning that should necessarily be taken into account when conducting an assessment-intervention process with young children with an ASD*, or presenting signs or symptoms of that health condition, by inquiring national and international experts on the field of child development, child psychopathology and/or Autism Spectrum Disorders.

**Study 3:** Development of a reduced set of ICF-CY codes for the assessment-intervention process in preschoolers with ASD

**Questionnaire 1:**
N=150
To select *important* functioning dimensions for children from birth to 6 years of age with ASD diagnosis or characteristics.

*Criteria: 80% agreement*

**Questionnaire 2:**
N=106
To select, among the dimensions resulting from phase 1, the ones that are *important, Very Important* or *Essential*

*Criteria: 50% agreement*

**Questionnaire 3:**
N=54
To confirm the dimensions regarded as *Essential.*

*Criteria: 50% agreement*
Study 3: Development of a reduced set of ICF-CY codes for the assessment-intervention process in preschoolers with ASD

Questionnaire 1: N=150  Questionnaire 2: N=106  Questionnaire 3: N=54

- The majority of the Participants presented similar characteristics across questionnaire rounds:
  - Mainly psychologists and teachers working in the field of education, experienced and qualified.
Study 3: Development of a reduced set of ICF-CY codes for the assessment-intervention process in preschoolers with ASD

- **Results:** Percentage of ICF-CY components in the core-set per age-range

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Activities &amp; Participation</th>
<th>Body Functions</th>
<th>Environmental Factors</th>
<th>Total of codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-2 years of age</td>
<td>4 (28,6%)</td>
<td>0</td>
<td>10 (71,4%)</td>
<td>14</td>
</tr>
<tr>
<td>2-6 years of age</td>
<td>35 (52,8%)</td>
<td>11 (16,9%)</td>
<td>19 (29,2%)</td>
<td>65</td>
</tr>
<tr>
<td>Total</td>
<td>39 (49,4%)</td>
<td>11 (13,9%)</td>
<td>29 (36,7%)</td>
<td>79</td>
</tr>
</tbody>
</table>
**Study 3:** Development of a reduced set of ICF-CY codes for the assessment-intervention process in preschoolers with ASD

**Discussion:**

- **Environmental factors are considered essential by experts** in the assessment-intervention process, although they are not regarded by professionals in the intervention plans (study 1);

- The functioning dimensions viewed as essential by experts, **cover a much broader array of characteristics when compared to the diagnostic criteria for ASD**;

- However, a **higher number of international experts is needed**.
Study 4 A: The development of the Matrix for Assessment of Activities and Participation (MAAP)

• Background:

- “A key function of a classification system is its ability to serve as a framework for the development of assessment measures reflecting the specified dimensions of that classification”.

- There is a limited availability of measurements that are brief and effective, based on an international taxonomy to assess functional limitations among children.

(Simeonsson et al., 2003, p. 603)
Study 4 A: The development of the Matrix for Assessment of Activities and Participation (MAAP)

1. **Dimensions from the core-set** (study 3) were reformulated into easily understandable items, based on the ICF-CY descriptors;

2. Items were assigned a **rating scale**, equivalent to the ICF-CY Universal Qualifier scale.

   - The descriptions for each value of the rating scale were developed based on criteria of **Frequency** of the difficulty in functioning observed and **level of that difficulty** considering the **amount of time** that it affects daily functioning.

3. Items were assigned a second scale portraying the child’s **developmental level** based on the **instruments previously linked with the ICF-CY** on study 2.
Study 4 A: The development of the Matrix for Assessment of Activities and Participation (MAAP)

1. Dimensions from the core-set (study 3) were reformulated into easily understandable items, based on the ICF-CY descriptors;

2. Items were assigned a rating scale, equivalent to the ICF-CY Universal Qualifier scale.

3. Items were assigned a second scale portraying the child’s developmental level based on the instruments previously linked with the ICF-CY.

Study 4 A:
The development of the Matrix for Assessment of Activities and Participation (MAAP)
Study 4 A: The development of the Matrix for Assessment of Activities and Participation (MAAP)
Study 4 A: The development of the Matrix for Assessment of Activities and Participation (MAAP)

4. A questionnaire for **assessment of aspects of the environment** was developed based on *essential* Environmental Factors appointed by experts (study 3);

5. An **engagement in routines scale** was also developed, as a way to assess certain dimensions of the concept of **participation**, not easily accessible by following the ICF-CY taxonomy in the Activities and Participation component.

- Routines are identified by professionals working with the children in their natural contexts and engagement level is rated in a scale from 1 to 5, according with precise instructions based on scientific evidence.
Study 4 A: The development of the Matrix for Assessment of Activities and Participation (MAAP)

- **MAAP dimensions and items:**

<table>
<thead>
<tr>
<th>ICF-CY Dimensions</th>
<th>Number of Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning and applying knowledge</td>
<td>18</td>
</tr>
<tr>
<td>General tasks and demands</td>
<td>5</td>
</tr>
<tr>
<td>Communication</td>
<td>8</td>
</tr>
<tr>
<td>Self-care</td>
<td>6</td>
</tr>
<tr>
<td>Interpersonal Interactions</td>
<td>5</td>
</tr>
<tr>
<td>Major Life areas – Engagement in play</td>
<td>3</td>
</tr>
</tbody>
</table>
**Study 4 A:** The development of the Matrix for Assessment of Activities and Participation (MAAP)

- **MAAP dimensions and items:**

<table>
<thead>
<tr>
<th>ICF-CY Dimensions for the Questionnaire of Assessment of Factors of the Environment</th>
<th>Number of Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support and relationships</td>
<td>7</td>
</tr>
<tr>
<td>Attitudes</td>
<td>8</td>
</tr>
<tr>
<td>Services, Systems and Policies</td>
<td>4</td>
</tr>
</tbody>
</table>
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

- **Purpose:**

  - To study the **reliability** properties of data obtained with the MAAP;
  - To analyze the extant to which the **functional profiles** of children with ASD differ from the functional profiles of children with other types of health conditions and from typically developing children;
  - To analyze the extant to which **environmental factors and Engagement in routines are good predictors of children’s functioning** profiles.
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

• Method:

Participants: 66 children from 3 to 6 years of age:
- 22 typically developing;
- 22 with ASD diagnosis;
- 22 with other types of disabilities.

Measurements:
MAAP and Abilities’ Index (Simeonsson & Bailey, 1991).
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

• **Results:** *Differences between groups* (*series of Mann-Whitney tests*)

• Both children with **ASD** and children with **other types of disabilities** differ from typically developing in almost all MAAP variables;

• Children with **ASD** do not differ from children with **other types of disabilities** in 34 out of 45 (75%) of the items.
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

**Results**: Differences between groups (series of Mann-Whitney tests)

- Both children with ASD and Children with other types of disabilities differ from typically developing in almost all MAAP variables.
- Children with ASD do not differ from children with other types of disabilities 34 out of 45 (%) of the items.

**Similar results**:
- Abilities’ Index;
- Engagement in routines and Environmental factors.
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

• Results: Reliability analysis and cluster analysis

  - Reliability of data collected with MAAP is very good:
    \[ \alpha = .98 \]

  - Children grouped in three Clusters illustrating different patterns of functioning, equivalent to different levels of severity in disability and limitation in functioning:
    
    - **Cluster 1**: Normal functioning;
    - **Cluster 2**: Mild to moderate limitation in functioning;
    - **Cluster 3**: Moderate to severe limitation in functioning;
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

- Results:

[Diagram showing clusters and numbers of children with different levels of functioning and diagnoses]
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

- **Results:** Analysis of differences between clusters
  
  - **One-way ANOVA:**
    
    *Variables: Abilities’ Index*
    
    *Groups: 3 clusters*
    
    *Post Hoc: Scheffé test*
    
  - All clusters differ from each other in **social competence**, **intellectual function**, **understanding others** and **communicating with others** with **large effect sizes** (**eta squared**).
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

**Results:** Environmental Factors and Engagement in routines as predictors of functioning patterns

- The selection of predictors was based on:
  - Environmental factors variables from QAFE and Engagement in routines variables which were mentioned by more than 50% of the professionals;
  - Assumption of no perfect multicolinearity (variables with correlation higher than .80 were excluded from the model).
  - A multiple regression analysis was conducted using the forced entry (Enter) method (Field, 2009).
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

• Results:

Environmental Factors
- Support of the mother
- Support of peers

Engagement in Routines
- Structured Activities
- Recess /Outdoors
- Snack routines

Functioning Patterns (cluster membership)
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

Results:

Environmental Factors

- Support of the mother
- Support of peers

Engagement in Routines

- Structured Activities
- Recess / Outdoors
- Snack routines

\[ R^2 = .15^{**} \]
\[ \beta = -.35^{*} ; \Delta R^2 = .15^{**} f^2 = .58 \]

Functioning Patterns (cluster membership)

**p ≤ .05
***p ≤ .001
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

• Results:

Environmental Factors
- Support of the mother
- Support of peers

Engagement in Routines
- Structured Activities
- Recess / Outdoors
- Snack routines

Functioning Patterns (cluster membership)

\[ R^2 = .14 \]
\[ \beta = -.05; \Delta R^2 = .004 \]

**\( p \leq .05 \)
***\( p \leq .001 \)
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

• Results:

Environmental Factors
- Support of the mother
- Support of peers

Engagement in Routines
- Structured Activities
- Recess /Outdoors
- Snack routines

\[ R^2 = .47^{***} \]
\[ \beta = -.39^{***}; \Delta R^2 = .32^{***} f^2 = .89 \]
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

• Results:

Environmental Factors
- Support of the mother
- Support of peers

Engagement in Routines
- Structured Activities
- Recess / Outdoors
- Snack routines

\[ R^2 = .59^{**} \]
\[ \beta = -.36^{**}; \Delta R^2 = .13^{**} f^2 = 1.45 \]

Functioning Patterns (cluster membership)

**p ≤ .05
***p ≤ .001
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

• Results:

Environmental Factors
- Support of the mother
- Support of peers

Engagement in Routines
- Structured Activities
- Recess / Outdoors
- Snack routines

\[ R^2 = .69^{**} \]
\[ \beta = -.29^{**}; \quad \Delta R^2 = .09^{**} \quad f^2 = 2.23 \]

Functioning Patterns (cluster membership)
Study 4 B: How children “naturally” group: Functioning versus Diagnosis

• Discussion:

  • Functioning is more informative than diagnostic criteria to characterize children and the ICF-CY is a useful framework to document and guide assessment-intervention processes;

  • Intervening in maternal support, and especially in children’s engagement level in daily routines may have a strong impact on improving their functioning patterns.

  • The MAAP is a useful tool to guide assessment of functioning and may actually be applied to all types of disabilities.
Discussion and integration of findings

• The need for improving assessment-intervention practices in line with development contextualistic and functional approaches;

• The usefulness of the ICF-CY in analyzing and supporting the assessment-intervention process;

• Evidence on the pertinence of a functional approach in addition to diagnostic information about the child.
Informing future research

- Development of functioning-based assessment-intervention programs;

- Need to support the implementation of a functioning approach to assessment-intervention, professional development in early childhood intervention and special education;

- Future research should provide scientific evidence on the efficacy of professional development programs in improving specific functioning outcomes in children with disabilities, in their natural settings.
THE ASSESSMENT - INTERVENTION PROCESS OF YOUNG CHILDREN WITH AUTISM: CONTRIBUTIONS OF THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH FOR CHILDREN AND YOUTH.

Susana Castro

University of Pretoria
CAAC
2013