

Development and piloting of an International Classification of Functioning, Disability and Health (ICF) Core Set based assessment of functioning tool for young people diagnosed with autism or other neurodevelopmental conditions

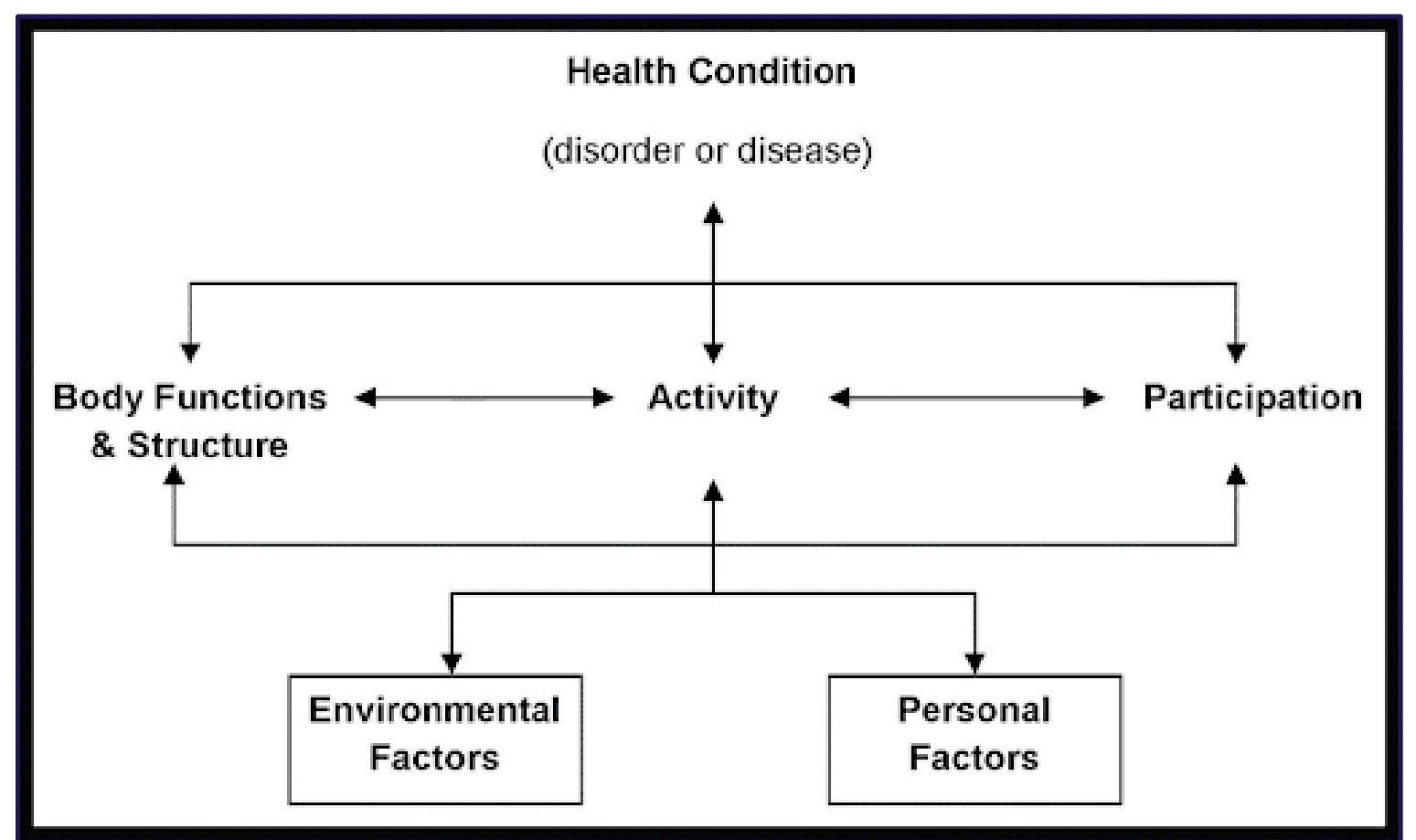
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Background: ICF and Core Sets

The International Classification of Functioning, Disability and Health (ICF) is the World Health Organization’s psychosocial model of disability and functioning. The ICF, and children and youth version (ICF-CY) contain a nested code structure for the classification of body functions and structures, activities and participation and environmental factors. Due to the ICF-CY containing over 1600 codes, sub-sets of codes determined to be relevant to functioning for individual conditions have been developed, called Core Sets.

This project combined the items of the Autism Spectrum Disorder (ASD) (Bölte, Mahdi, de Vries, et al., 2019), Attention Deficit/Hyperactivity Disorder (ADHD) (Bölte, de Schipper, Holtemann, et al., 2017), and Cerebral Palsy (CP) (Schiariti, Selb, Cieza, & O’Donnel, 2015) Core Sets as items of an assessment tool to comprehensively assess functioning for young people with neurodevelopmental conditions (NDCs).



The International Classification of Functioning, Disability and Health (ICF)

Methods and tool development

The tool was developed through an iterative process by the research team including clinicians and caregivers of individuals on the autism spectrum. The assessment was designed to meet the criteria of a holistic and comprehensive assessment of functioning outlined in the National Guideline for Assessment and Diagnosis of Autism Spectrum Disorder in Australia.

Subjects were assessed using the ICF Core Set Assessment by occupational therapists using a home visit. Multiple sources of information were integrated using clinical judgement for the final score of each item. The observations were video recorded to assess inter-rater reliability. The PEDI-CAT (ASD) and Vineland-3 were used to assess concurrent validity.

Parents also completed a background survey assessing medical and developmental history, quality of life, and containing several standardised assessment tools, including the Participation and Environment Measures, and Strengths and Difficulties Questionnaire.

Caregivers completed a feedback survey or interview to determine consumer acceptability. An online survey and multiple clinician focus groups were conducted to determine clinical utility.

Clinician administered, parent card sort

- Individual ratings for all core set items
- Sections for Body functions, Activities and participation and Environmental factors

Clinical observations (in home environment)

- Snack time
- Free play activity
- “About me” drawing/writing task

Contact with other professionals

Other standardised assessment tools

Final Rating

ICF NDC Core Set Documentation Form

Body functions (Impairment)
Activities and participation (Difficulty)
Environmental factors (Facilitator; Barrier)

Sample

The tool was administered with caregivers of n= 103 subjects (66% male) aged 3.41-19.42 years (mean 10 years) from four states in Australia. 78% had diagnosis of ASD, 26% had an intellectual disability. Approximately 50% of caregivers provided feedback about the tool (n= 45), and n= 55 clinicians provided clinical utility feedback.

Results

	Positives	Negatives
Consumers	<ul style="list-style-type: none"> • Detailed • Considered environmental factors • Liked physical cards and scales • Multiple sources of information • Assessed strengths 	<ul style="list-style-type: none"> • Confusing/hard to understand • Takes a long time • Observation scores depend on the day child is observed
Clinicians	<ul style="list-style-type: none"> • Multiple sources of information • Considers support needs, environmental factors • Visual and engaging • Based on ICF- gold standard, international model 	<ul style="list-style-type: none"> • Needs standardisation/norms • Takes a long time • Not available yet, some aspects of clinical utility hard to assess.

Consumer acceptability and clinician feedback was mixed, with several areas for improvement recommended. The tool showed unacceptable to excellent internal consistency, with poor consistency more common in chapters with fewer items. Concurrent validity was poor to moderate, if significant, suggesting tools were assessing different constructs, with similarities between some domains (e.g. functional performance capacity).

Internal consistency at chapter level	Unacceptable-excellent	Body functions
	Fair-excellent	Activities and participation
	Good	Environmental (facilitator)
Inter-rater reliability	Good	Environmental (barrier)
	Excellent	(using sub-sample of 20%)
Concurrent validity	When significant at 0.05:	Activity and participation chapters compared to domains of PEDI-CAT and Vineland-3
	Poor-moderate	

Conclusions

This is the first study to attempt to operationalise these ICF Core Sets for clinical use. Feedback highlighted areas for improvement but overall, supported the concept. The tool shows promise, warranting the further work required to revise tool for clinical use.

Objectives

1. Develop an ICF Core Sets based assessment of functioning tool
2. Establish preliminary psychometrics of the tool
3. Collect feedback about initial clinical utility
4. Collect feedback about initial consumer acceptability

Related presentations:

1. #34533: Co-produced initial stages of developing a self and proxy version of the tool
2. #34618: Describing functioning for young children with NDCs using the tool
3. #33474 Developing assessment of functioning process in Australia

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