

Co-producing holistic proxy- and self-report assessment of functioning tools based on the International Classification of Functioning, Disability & Health (ICF) Core Sets for Autism Spectrum Disorder (ASD)

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PROJECT AIM
To simplify the definitions of functioning included in the ICF Core Sets for ASD and inform the development of proxy- and self-report versions of an assessment of functioning tool for autistic individuals.

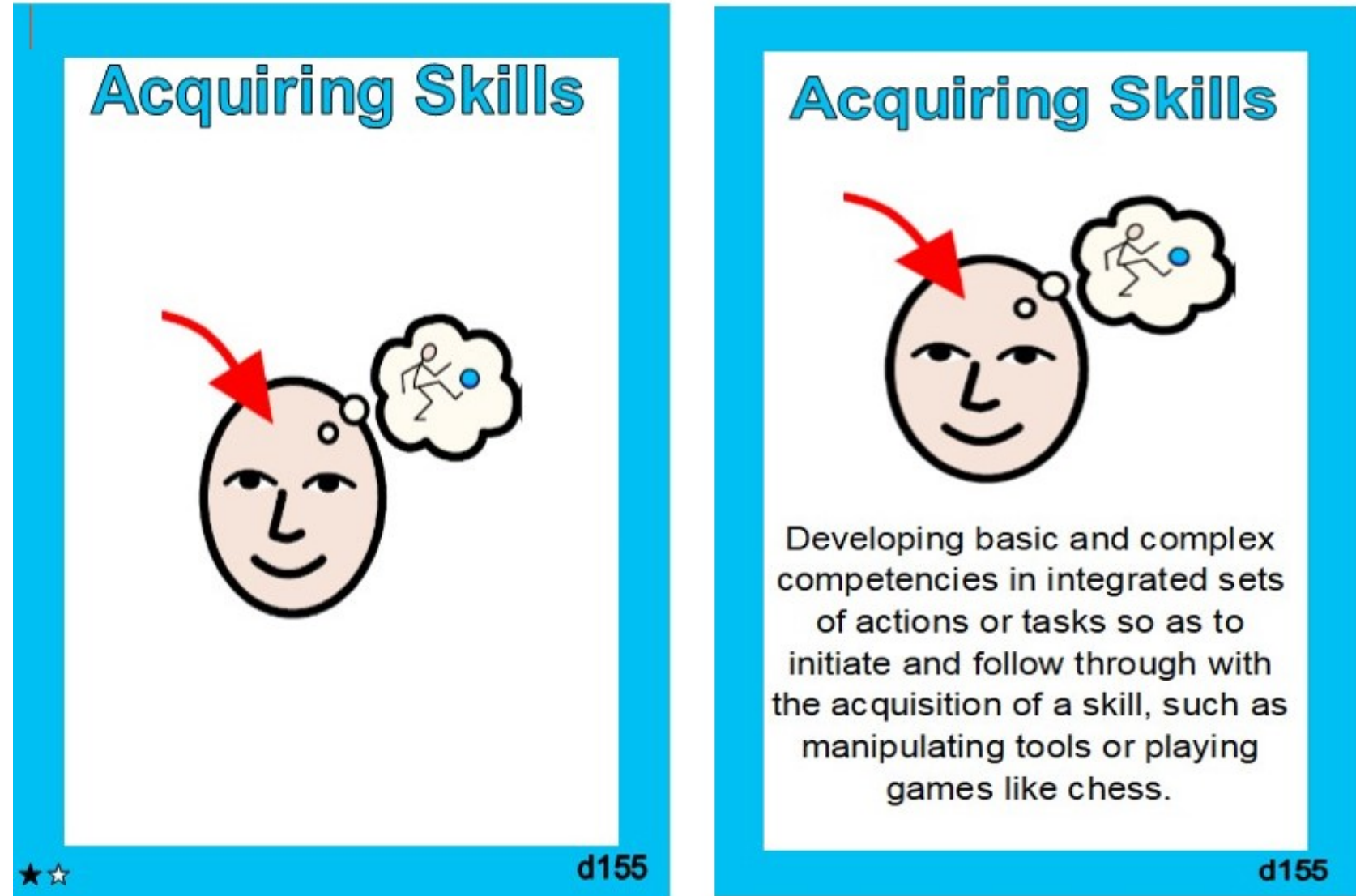
Background
There is currently no widely accepted assessment of functioning tool taking a holistic approach to capturing ability and disability in autism. The ICF Core Sets for autism have recently been developed for infants, children, and adults (Bölte et al., 2019). The ICF Core Sets provide comprehensive descriptions of functioning relevant to autism across the lifespan, but may be difficult for autistic individuals and their families to interpret.

Example of current ICF Core Sets documentation form

	0	1	2	3	4	8	9
d155 Acquiring skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Developing basic and complex competencies in integrated sets of actions or tasks so as to initiate and follow through with the acquisition of a skill, such as manipulating tools or playing games like chess.							
Inclusion: acquiring basic and complex skills							
Sources of information:							
<input type="checkbox"/> Case history <input type="checkbox"/> Patient reported questionnaire <input type="checkbox"/> Clinical examination <input type="checkbox"/> Technical investigation							
Description of the problem:							

Methods
This qualitative project utilised inclusive research methods of co-production, involving autistic individuals and their families in the research process. A consumer reference group consisting of two autistic adults and three caregivers of individuals on the spectrum was convened to provide feedback on the research process. Interactive workshops were conducted in four cities across Australia, as well as online via teleconference. A total of 17 participants (10 caregivers and seven autistic adults) provided feedback on the definitions and diagrams used to portray the ICF items. The qualitative data generated during these discussions were analysed thematically.

Example of diagram and definition presented to participants



Results

- Participants considered the current ICF definitions lengthy and difficult to understand.
- Participants suggested layperson definitions for each of the items included in the comprehensive ICF Core Set for ASD, as well as use of direct questions, concrete examples and photographs to aid understanding.

Example of revised definition: d155 Acquiring skills

Original definition:
Developing basic and complex competencies in integrated sets of actions or tasks so as to initiate and follow through with the acquisition of a skill, such as manipulating tools or playing games like chess.

Suggested new definition:
Developing the ability to carry out sets of actions needed to learn new skills.

- The symbolic diagrams were perceived as ambiguous, with the potential to negatively influence a person’s understanding of the item.
- Participants suggested photographic illustrations should be used to visually represent the items.
- Ideas for photographic illustrations were provided for the majority of items in the Activities and Participation domain.

Conclusions
This project represents an important first step towards increasing the usability of the ICF Core Sets for ASD.

A set of photographs were co-produced with an autistic photographer, based on the feedback provided by participants.

The findings of this study have informed the development of proxy- and self-report versions of a questionnaire-style assessment of functioning tool that incorporates the new definitions and photographs.

This tool will be piloted later in 2020 to determine it’s psychometric properties and acceptability among end-users.

This assessment is the first tool co-produced with autistic individuals and their families.

Example of photographic illustration



- Objectives**
- Co-produce user-friendly descriptions of the items included in the ICF Core Sets for ASD
 - Determine end-user acceptability of diagrams used by the research team to portray the items included in the ICF Core Sets for ASD

Reference
Bölte, S., Mahdi, S., de Vries, P. J., Granlund, M., Robison, J. E., Shulman, C., . . . Selb, M. (2019). The Gestalt of functioning in autism spectrum disorder: Results of the international conference to develop final consensus International Classification of Functioning, Disability and Health core sets. *Autism*, 23(2), 449-467. doi:10.1177/1362361318755522

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