

The co-construction of a reading assessment checklist with adults with Down syndrome: a meaningful literacy approach.

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Abstract

Introduction: The value of learning to read has become more significant as how we use written language in society has evolved. Technological advances have resulted in text messaging often replacing conversation, emailing replacing phone calls and search engines replacing books. Consequently, there is a need to develop appropriate measures of broad-based meaningful reading for adults with Down syndrome and this has been highlighted in the literature.

Aim: In this study we aimed to co-construct a valid and reliable assessment measure that can be used to document meaningful everyday reading, in adolescents and adults with Down syndrome.

Methods: The study was carried out in two stages. Stage 1 used an inclusive participatory design in which individuals with Down syndrome were research collaborators ($n = 46$). Items to be included in the measure were identified and ecological, face and content validity were established through an iterative process. In stage 2 we examined the reliability of the tool and explored potential relationships between meaningful reading score and (1) age, (2) receptive vocabulary, and (3) reading ability as measured by standardized assessments. In addition, we profiled what a pilot cohort of adults with Down syndrome read ($n = 33$) and how they experience reading in their everyday lives.

Results: Results showed that 46 items were generated for inclusion in the Meaningful Reading Measure (MRM). Our preliminary data showed that the tool has internal and external reliability and ecological and content validity. There were no associations between meaningful reading score and any of the other variables examined. There was considerable variability in items read (range 12–44) which reflected a broad range of reading practices. Adults with Down syndrome identified the importance of reading as a pleasurable activity and as something that aids learning.

Conclusion: The MRM developed here can be used (1) as a reading intervention outcome measure to complement existing standardized tools, (2) to profile meaningful reading in adults with Down syndrome, (3) to guide reading module content, and (4) to capture change in adults' perceptions of themselves as readers. Future work is needed to establish the tool's sensitivity to change over time.