Development of an Assessment of Functioning Measure based on the ICF Core Sets for Autism Spectrum Disorder

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Acknowledgements

The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

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A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, when speaking of adults we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector, and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

1. Background

The last two decades have heralded a paradigm shift in disability models and disability service provision, from a singular focus on deficits to a more holistic and strengths-based approach to functioning. This has been demonstrated on a global level, with the World Health Organisation (WHO) shifting from their three-level taxonomy of impairments, disabilities and handicaps[1] to the International Classification of Functioning, Disability and Health (ICF)[2].

The ICF recognises the interplay between body functions, activities and participation, and environmental factors. Whilst the ICF was designed as a common language for all key stakeholders to work together, the vast number of items in the ICF framework taxonomy and the absence of user-friendly assessment measures has restricted the integration of the ICF into clinical practice and research. Policy guidance on assessment, diagnosis and intervention is still emerging.

At a local level, Australia's first national guideline autism diagnosis[3] was published in 2018. Development of the guideline involved extensive consultation with individuals on the autism spectrum, families, clinicians and peak bodies, and it was clearly established that assessment of functioning is a fundamental component of the diagnostic process and ongoing clinical pathway. An entire section, with National Health Research Medical Council (NHMRC) approved recommendations, was subsequently included on this topic. The guideline highlighted that an adequate assessment of functioning measure did not exist, or did not have sufficient evidence, for implementation in Australia. This finding is congruent with The Joint Standing Committee on the National Disability Insurance Agency (NDIA) recommendation that a fit-for-purpose assessment of functioning measure for people on the autism spectrum be co-designed with end-users[4].

The recently published ICF Core Sets for Autism Spectrum Disorder (ASD: hereafter, autism)[5] represent a significant advancement in the assessment of functioning for individuals on the autism spectrum, identifying ICF items relevant to autism in five versions: Comprehensive - 111 items; Common brief - 60 items; 0-5 years - 73 items; 6-16 years - 81 items; and 17 years+ - 79 items. Whilst the ICF Core Sets for Autism is linked to the WHO ICF-Core Set Documentation Form (6), the assessment measure generated utilises terminology drawn from the standard ICF definitions. This terminology is not well suited to the self-report of functioning by individuals on the autism spectrum or their caregivers and requires significant interpretation from a clinician to translate professional jargon into layperson language. This research project subsequently aimed to co-produce assessment of functioning measures based on the ICF Core Sets for Autism.

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Specific objectives were to:

- identify and critique existing standardised assessment of functioning measures
- map items from existing standardised assessment of functioning measures against the ICF Core Sets for Autism
- co-produce user friendly descriptions for each item of the ICF Core Sets for Autism, where the new definitions are clear, salient and valid
- develop and pilot clinician-administered, caregiver-report and self-report versions of a prototype assessment of functioning measure
- describe the functioning of children, adolescents and adults on the autism spectrum using new and existing measures
- share research findings with end-users.

2. Research design and methods

This research project included two desk-based studies and three empirical studies. The first desk-based study involved a scoping review of 18 assessment of functioning measures, where the psychometric properties were evaluated by two researchers using the Outcome Measures Rating Form and measures were linked to the ICF. The second desk-based study involved linking 10 assessment of functioning measures to the ICF Core Sets for Autism and other relevant Core / Code Sets for young children with neuro-developmental conditions.

The first empirical study involved seven autistic adults and eight caregivers of individuals on the autism spectrum who participated in workshops and document review to co-produce new layperson definitions for items from the ICF Core Sets for Autism[5]. In addition, the participants provided feedback on visual illustrations utilised in the card-sort interview in the first empirical study and suggested alternative images to capture the essence of each item.

The second empirical study involved the development and piloting of a clinician-administered assessment of functioning protocol to complete the ICF Core Sets for ASD Documentation Form[5,6], whilst adhering with all relevant recommendations outlined in A National Guideline for the Assessment and Diagnosis of Autism in Australia[3]. This protocol (Appendix A) was co-designed with caregivers of individuals on the autism spectrum and clinicians, and included a review of treating health professional reports, completion of existing standardised measures, a card-sort interview and semi-structured observations. The clinician-administered assessment of functioning protocol was piloted with 105 children / adolescents who have been diagnosed with autism or

another neurodevelopmental condition and their caregivers during home visits in New South Wales, Queensland, Victoria and Western Australia.

The third empirical study involved the development and piloting of self- and caregiver-reported versions of an online assessment of functioning measure based on the ICF Core Sets for Autism[5]. This measure was co-designed with an autistic adult, caregivers of individuals on the autism spectrum and clinicians (Appendix B, noting that the self-report version follows a very similar structure to the enclosed caregiver proxy-report version). The measure included the co-produced layperson definitions from the first empirical study and a combination of illustrations and photographs taken by an autistic adult. Participants were asked to indicate their current level of functioning for each item from the body functions, activity and participation and environmental factors domains of the ICF using the WHO rating scale, and options were available to identify areas of strength and record free-text responses. A set of standardised measures were also conducted to determine validity. In total, 29 caregivers of children / adolescents on the autism spectrum piloted the caregiver-proxy version of the measure and 30 autistic adults piloted the self-report version. Quantitative data analysis involved descriptions (frequency, range, mean / standard deviation and/or median / interquartile range), correlations (Pearson's and/or Spearman's rho correlation coefficient) and other statistical tests to determine specific psychometric properties (Cronbach's alpha, percentage agreement and weighted kappa). Qualitative data analysis involved an iterative approach by multiple researchers to identify themes and sub-themes.

3. Findings

The findings from this project are presented in a series of appendices in their original format.

> **These appendices are embargoed whilst they undergo peer review and/or assessment, but will be made available in the project Final Report on the Autism CRC website once the embargo lifts.**

Findings from the two desk-based studies are provided in Appendices C and D.

Appendix C is the precursor to a journal manuscript titled "Review of psychometric properties of assessment of functioning measures" by Hayden-Evans et al. This manuscript describes the findings of a comprehensive scoping review that identified 18 eligible measures (associated with 42 original research articles, one review paper and three assessment manuals) and evaluated a range of psychometric properties (reliability, content validity, construct validity, criterion validity,

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responsiveness and overall utility). Overall ratings of the measures ranged from poor to excellent, with 16 of the 18 measures receiving a rating of adequate or above.

Appendix D is the open-access journal article (https://pubmed.ncbi.nlm.nih.gov/34369196/) "Content validation of common measures of functioning for young children against the International Classification of Functioning, Disability and Health and Code and Core Sets relevant to neurodevelopmental conditions" by D'Arcy et al. This manuscript describes the content validity of 10 eligible measures against the ICF Core Sets for Autism and other relevant Core / Code Sets for young children with neuro-developmental conditions. Overall, measures covered between one-fifth and two-thirds of the Core / Code Sets, with measures primarily focusing on activity and participation chapters of the ICF.

Findings from the three empirical studies are provided in Appendices E to H.

Appendix E is the precursor to a journal manuscript titled "Revising the definitions included in the ICF Core Set for Autism via co-production" by Hayden-Evans et al. This manuscript describes the layperson definitions for ICF Core Sets for Autism items that were co-produced by seven autistic adults and eight family members of individuals on the autism spectrum. The changes to definitions included simplifying the language and providing a range of examples, with the resulting average reading age reducing by five years.

Appendix F is the precursor to a journal manuscript titled "The iterative development of a comprehensive clinician-administered assessment of functioning for young people with neurodevelopmental conditions" by D'Arcy et al. This manuscript describes preliminary psychometric properties and feedback about the clinician-administered measure (Appendix A).

Appendix G is the precursor to a journal manuscript titled "Preliminary support for an online caregiver-reported assessment of functioning measure based on the ICF Core Sets for Autism Spectrum Disorder" by Hayden-Evans et al. This manuscript describes preliminary psychometric properties and feedback about the online caregiver-report measure (Appendix B).

Appendix H is the precursor to a journal manuscript titled "Strengths, struggles and strategies from the perspective of autistic adults" by Evans et al. This manuscript summarises the self-reported strengths (activity and character related strengths), functioning (body functions, activities and participation and environmental factors) and support needs (current supports and unmet needs). Preliminary psychometric properties and feedback about the online self-report measure (similar to Appendix B) are also described.

4. Limitations

When interpreting findings from this research project, it is important to consider that the convenience sample was smaller than planned for the online caregiver proxy- and self-report assessment of functioning measures based on the ICF Core Sets for Autism. It is felt that recruitment is likely to have been impacted by participant burden due to recent research consultations during the development of the national guideline in the earlier stages of the research project and the impact of COVID-19 during the later stages of the project.

5. Implications for research and practice

This research project has taken a first and important step towards improving the assessment of functioning process in Australia, whilst confirming that there is not a 'one size fits all' assessment measure to understand functioning of autistic individuals. Areas for future research include continuing to improve upon and evaluate the assessment protocols and measures developed during this research project, with a focus on maintaining a co-production approach through ongoing collaboration with autistic adults, caregivers and clinicians. Once assessment protocols and measures are ready for use in clinical practice, they should be utilised in accordance with the national guideline recommendations for a Comprehensive Needs Assessment. Whilst the assessment protocols and measures will not be available for government departments to adopt in the immediate future, the desk-based studies provide a solid foundation for selecting existing standardised measures for use within a comprehensive assessment of functioning process that is undertaken by skilled clinicians using a variety of information collection methods across multiple settings[3].

6. Key recommendations

There is continued need for comprehensive assessment measures and processes that focus on the strengths, environmental contexts and support needs of autistic individuals when considering their functioning and quality of life. The assessment protocols and measures developed through this research project should be further co-produced with autistic individuals. This will ensure that a neurodiversity perspective is embedded, whilst facilitating the inclusion of easily understood purpose and content. This may include additional work to co-produce acceptable examples, illustrations and relatable language (including layperson definitions for ICF Core Set for Autism items).

7. References

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3. Whitehouse, A. J. O., Evans, K., Eapen, V., & Wray, J. (2018). A national guideline for the assessment and diagnosis of autism spectrum disorders in Australia. Summary and recommendations. Cooperative Research Centre for Living with Autism, Brisbane.

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5. Bölte, S., Mahdi, S., de Vries, P. J., Granlund, M., Robison, J. E., Shulman, C., . . . Selb, M. (2018). 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. Retrieved from doi:10.1177/1362361318755522

6. ICF-based Documentation Tool. Retrieved from https://www.icf-core-sets.org/

Our values

Inclusion
Working together with those with the lived experience of autism in all we do

Innovation
New solutions for long term challenges

Evidence
Guided by evidence-based research and peer review

Independence
Maintaining autonomy and integrity

Cooperation
Bringing benefits to our partners; capturing opportunities they cannot capture alone

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