Formalising an Assessment of Functioning Process for Individuals Undergoing an Autism Diagnostic Evaluation and/or Service Planning in Australia

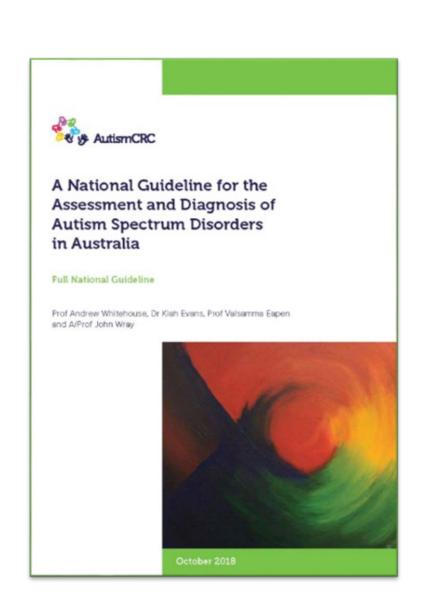
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Background

An international review of autism diagnostic guidelines revealed functioning as an important topic to evaluate during a diagnostic evaluation, however varied emphasis was placed on an assessment of functioning as a necessary component. The 'Australian National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder' (ASD) articulates an assessment of functioning as the first step when an individual is referred for an assessment of ASD concerns [1]. This assessment of functioning:

- may be undertaken by a range of medical / allied health professionals with relevant training and expertise in specified areas;
- should cover a broad range of domains of functioning, activity and character related strengths, environmental barriers and facilitators, and both observed and expressed support needs;



- should involve information collection within natural contexts through multiple methods (e.g. interviews, observations, standardised assessment tools);
- outcomes should include specific support needs and connection with appropriate services.

The Australian guideline concludes with a recommendation for researchers to investigate the psychometric properties of existing tools that assess functioning.

Project aim

This project aimed to investigate the psychometric properties and usability of existing standardised assessment of functioning tools, specifically the Vineland-3 and PEDI-CAT (ASD).

Methods

Published evidence on the psychometric properties of the Vineland-3 [2] and PEDI-CAT (ASD) [3] was critiqued using the 'CanChild Outcome Measures Rating Form' [4,5]. All items from the Vineland-3 and PEDI-CAT (ASD) were linked to the International Classification of Functioning, Disability and Health – Children and Youth (ICF-CY) using established rules [6-8].

Clinical assessments [9] were conducted with 172 caregivers of young people diagnosed with neurodevelopmental conditions (including 81% on the autism spectrum) at one to three time points. Caregivers (n=141) completed computer-based administrations of the Vineland-3 Parent / Caregiver Form and PEDI-CAT (ASD) and these were repeated approximately three weeks later (n=57 and n=107). Sub-samples also completed an occupational therapist administered Vineland-3 Interview (n=52) and/or PEDI-CAT (Original) (n=39). A comprehensive assessment of functioning that met Australian guideline recommendations (n=105) was conducted by an occupational therapist in the home setting, including the use of an ICF Core Set tool (results reported elsewhere [10,11]). Data were analysed using quantitative approaches.

Caregivers provided feedback (n=53) on the Vineland-3 and PEDI-CAT (ASD) tools through an interview or online survey [9]. Feedback from clinicians (n=55) regarding the clinical utility of the Vineland-3 and PEDI-CAT (ASD) tools was obtained through focus groups. Data were analysed using qualitative approaches.

- 6. World Health Organization. (2004). International classification of functioning, disability and health. Version for children and youth
- 7. Cieza, A., Fayed, N., Bickenbach, J., & Prodinger, B. (2019). Refinements of the ICF Linking Rules to strengthen their potential for establishing comparability of health information. Disability and Rehabilitation, 41(5), 574-583.
- 8. Manuscript under preparation contact emily.darcy@postgrad.curtin.edu.au 9. Manuscript under preparation – contact kiah.evans@telethonkids.org.au
- 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.
- 11.Manuscript sunder preparation contact emily.darcy@postgrad.curtin.edu.au or kiah.evans@telethonkids.org.au

Results

| Psychometric Property / Usability Aspect | Vineland-3 | PEDI-CAT (ASD) |
|--|---|---------------------------------|
| Literature review of psychometric properties | Adequate to excellent | Adequate to excellent |
| ICF linking - content validity | Focused on a restricted range of activity and participation items of the ICF-CY Does not adequately cover all items with the ICF Core Sets for ASD [10] | |
| Concurrent validity | Poor to good (with each other) | |
| Internal consistency | Unacceptable to excellent | Good to excellent |
| Alternative forms reliability | Moderate to good (Parent / Caregiver and Interview Forms) | Good (with Original version) |
| Test-retest reliability | Moderate to excellent (Parent / Caregiver Form) | Good to excellent |
| Inter-rater reliability | Moderate to excellent (Interview Form) | N/A |
| Caregiver acceptability and clinical utility | Neither is suitable to be used in isolation to assess functioning, but adequate as part of a suite of tools Each tool presents with strengths and weaknesses | |

Conclusions

The Vineland-3 and PEDI-CAT (ASD) do not adequately cover the wide range of categories in the ICF Core Sets for ASD. Although the Vineland-3 and PEDI-CAT (ASD) appear to have adequate psychometric properties, caregivers and clinicians agreed that additional sources of information are required to comprehensively assess functioning.

The Australian guideline recommends assessment of functioning information should be collected using multiple methods (in addition to just interviews or survey) and information should be collected on a broader range of topics than assessed using the Vineland-3 and PEDI-CAT (ASD).

Research is subsequently underway to develop and evaluate a suite of tools based on the ICF Core Sets for ASD Documentation Form for future translation into clinical practice [10, Related Presentations].

What are the key strengths, challenges and needs that inform future service delivery, so that the individual and their caregivers can reach their full potential in relation to activities and participation in society?

Key Question in an Assessment of

Functioning

Related Presentations:

- 1. #33472 Development and piloting of an ICF Core Set based assessment of functioning tool for young people diagnosed with autism or other neurodevelopmental conditions
- 10.Bölte, S., Mahdi, S., de Vries, P. J., Granlund, M., Robison, J. E., Shulman, C., ... & Segerer, W. (2019). The Gestalt of functioning in 2. #34533 Co-producing holistic proxy- and self- report assessment of functioning tools based on the ICF Core Sets for ASD
 - 3. #34618 Using the International Classification of Functioning, Disability and Health (ICF) Core Sets to describe functioning for young children with, or at risk of neurodevelopmental conditions: A case study











Further Information

spectrum disorders in Australia. Cooperative Research Centre for Living with Autism, Brisbane.

. Manuscript under preparation – contact maya.hayden-evans@postgrad.curtin.edu.au

Whitehouse, A. J. O., Evans, K., Eapen, V., & Wray, J. (2018). A national guideline for the assessment and diagnosis of autism

Evaluation of Disability Inventory: Development, standardization and administration manual (Version 1.4.3). Boston, MA: Boston

Law, M. (2004). Outcome measures rating form and guidelines. Retrieved from https://canchild.ca/en/resources/137-critical-review-

Sparrow, S., Cicchetti, D., & Saulnier, C. (2016). Vineland Adaptive Behavior Scales (3rd ed.) Minneapolis: Pearson Inc.

Haley, S. M., Coster, W. J., Dumas, H. M., Fragala-Pinkham, M. A., Moed, R., Kramer, J., . . .Ludlow, L. H. (2019). *Pediatric*

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