

The Impact of Diagnosis Scale – Revised (IODS-R)

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“It was a huge relief. It made sense of what had been a very confusing life up to that point”

Project aim
To develop an impact of diagnosis scale suitable for autistic adults by revising the IODS (Courtney & Makinen, 2016) designed for Borderline Personality Disorder (BPD)

The IODS tool had only preliminary development with 21 adolescents receiving a diagnosis of BPD. It showed modest internal consistency ($\alpha = .66$) across 10 items including 2 screening items.

We conducted a preliminary revision (Arnold et al. 2020), focused on contextualising to autism. For example, removing words like symptoms and difficulties, as characteristics of autism can be both strengths and weaknesses. Autistic research advisors reviewed the tool before data gathering.

Data from 92 autistic adults identified 3 domains, with Item mean scores suggesting that although impact of autism diagnosis was generally perceived as positive for “Self-Acceptance and Understanding”, scores were neutral for “Service Access” and “Bring Understood”. Qualitative responses suggested that further revision of the tool would be beneficial.

Method

The research team and autistic advisors brainstormed an expanded pool of 46 items, scored on 7-point Likert scale, within 6 hypothesised domains; “Service Access, Well-being, Self-acceptance and self-understanding, Diagnostic process, Accuracy of diagnosis, Relating with others”. Scale reduction processes were applied to data from 108 formally diagnosed autistic adults aged 25+ years

Results

Twenty-two items were retained. Internal consistency was good ($\alpha = .81$). Mean scores reiterated themes from preliminary findings, of a generally positive “Well-being” ($M = 5.27, SD = 1.41$), “Self-understanding” ($M = 6.36, SD = .75$), and “Clinician support” ($M = 5.76, SD = 1.17$), though poor “Service access” ($M = 3.34, SD = 1.46$).

Qualitative data reiterated previous findings of *Self-Understanding, Identity and Acceptance, Support and Services, Valence of Response, Relationships and Camouflaging*.

Subdomain	Mean item score*	SD	Min	Max
Well-being (a positive feeling of wellness)	5.27	1.41	1	7
Clinician Support	5.76	1.17	1.6	7
Self-understanding	6.36	.75	3.2	7
Service Access (ability to receive appropriate health and community services)	3.34	1.46	1	6.8

Item (factor loading)	Service Access	Self-understanding	Clinician Support	Well-being
...access to community supports58			
...found psychological therapy or coaching services46			
...access to healthcare supports80			
...found healthcare services that are suitable...	.83			
...eligible for funding (e.g. support pension, NDIS)...	.53			
...I have learned about the diagnosis...		.68		
...helped me understand my life experiences...		.52		
...put me on a pathway of self-discovery		.61		
...understand how I am affected by ... the environment		.74		
...accurate way to describe a lot of my life experiences		.42		
...clinician(s) who diagnosed me were caring and supportive			.94	
...clinician(s) were empathetic when giving me the diagnosis			.97	
...were sensitive to my co-existing ... health conditions			.64	
...I respected the credentials and professionalism...			.62	
...provided with useful information and resources...			.53	
...has made me happier				.76
...has had a negative impact on my quality of life				.80
...gives me less self-confidence				.76
...gives me more hope for my future life and happiness				.72
...feel better about myself (e.g. more positive self-esteem)				.72

($\alpha = .76$) ($\alpha = .75$) ($\alpha = .82$) ($\alpha = .87$)

Background

Autism is increasingly diagnosed in adulthood, however, the few studies that explore self-reported impact of receiving a diagnosis have been primarily qualitative. As yet no measurement tool exists to determine the psychological impact of receiving a diagnosis of autism.

Conclusion

The IODS-R adds new understanding to the experience of receiving an autism diagnosis in adulthood. It is unique in quantitatively measuring the self-reported impact of receiving a diagnosis. More post-diagnosis support is needed for autistic adults. The IODS-R may prove useful for evaluating diagnostic services.

For more information

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