

## Development of an autism-specific quality of life assessment for use with autistic adults



### Background

Autistic adults have described a poorer quality of life (QoL) than their non-autistic peers. Contributing factors include decreased mental health, limited opportunities for employment and education, and fewer social relationships. Autistic people make up 32% of all national disability insurance scheme participants, and many seek support from health professionals to assist with these needs.

The goal of health clinicians working alongside autistic adults is to improve QoL, but how do we know if we are achieving this?



### Aim

This research project aimed to co-produce and develop a pilot autism-specific quality of life tool for use with autistic adults.



### How we did the research

#### Longitudinal data

In preparation for the project, the [Australian Longitudinal Study of Adults with Autism \(ALSAA\)](#) data was analysed from the special interest category of ALSAA's 'adult self-report questionnaire'. This analysis provided background to this research, including identifying common areas of special interest and a brief insight into its relationship to QoL.

#### Interviews

The first empirical study involved 29 autistic individuals from the Australian community aged between 18 and 55 who participated in interviews (face-to-face, online, text) to identify common areas of importance to their quality of life. The findings were used to guide the second empirical study, which sought to gain further in depth understanding of QoL from the perspective of autistic adults.



### Who took part

5

autistic adults formed the membership of the consumer steering group

29

autistic adults participated in an interview

15

autistic adults participated in photovoice

15

autistic adults participated in an online survey

14

health clinicians participated in an online survey

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How we did the research

**Participatory research — Photovoice**

Participatory research included the use of ‘photovoice’ to capture autistic adults’ QoL experiences, and to determine factors that contribute to their QoL. A total of 15 autistic individuals aged between 18-55 were recruited across Australia to capture digital images that related to their meaning and understanding of factors that contributed to their QoL. All participants took part in a follow up interview and shared up to 20 photos they felt were related to their QoL.

**Pilot quality of life tool**

The third empirical study involved utilising the dominant themes from study 1 and 2 to create a pilot autistic QoL self-report tool for use with autistic adults. The pilot tool consisted of 111 factors related to autistic QoL and was created in collaboration with the autistic steering group.

**Validate quality of life tool**

To determine the validity of the pilot autistic QoL tool, an online survey of 14 autistic adults between the ages of 18 and 55, living in Australia was utilised. Further to this 15 health clinicians working with autistic adults in Australia provided feedback on content validity and clinical utility of the tool.



What we found

The main finding of this project is that for autistic adults QoL is unique and is often impacted by factors other than those measured in traditional QoL assessments.



This research project has taken a first and important step towards developing a pilot assessment tool of QoL.



This project delivers insight into the domains of QoL most relevant to autistic adults, and the facilitators and detractors of their unique QoL.



Autistic individuals’ ability to pursue passions, and safe and meaningful relationships is paramount.



This new knowledge has informed a pilot QoL tool drawn from an autistic perspective, enabling for the first time, meaningful measurement of the construct within the autistic community.



The co-produced nature of this research provides opportunities to employ and further develop research methodologies.



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### Find out more

Download the final report and executive summary on the Autism CRC website: [autismcrc.com.au/reports/QoL](https://autismcrc.com.au/reports/QoL)



The Quality of Life Photovoice Gallery is a unique output of this research. It offers an insight into what affects quality of life for autistic adults, told from their own perspective, through photography and spoken word.

The Photovoice Gallery was presented as an event in November 2020.

To view the event recording and Photovoice Gallery, go to [autismcrc.com.au/photovoice-gallery](https://autismcrc.com.au/photovoice-gallery)



### Who did the research



UNSW  
AUSTRALIA



DEPARTMENT OF  
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NEUROPSYCHIATRY



Curtin University

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