

Creating a Quality-of-Life Measure Informed by the Autistic Community

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BACKGROUND

Quality of life (QoL) is commonly defined as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.” (The World Health Organization Quality of Life [WHOQoL] Group, 1995).

Autistic people across the lifespan often report a **lower QoL than non-autistic people** (Ayers et al., 2018).

However, existing QoL measures:

- **Lack the nuance** required to meaningfully measure QoL in alignment with Autistic people’s priorities.
- Have been designed **with and for non-autistic people**.

Autistic people and researchers have identified the **need for acceptable and accessible measures of QoL** that have been **co-designed** with Autistic people from the start (Benevides et al., 2020).

Research teams have begun consulting with autistic adults and adapting existing measures to capture the unique needs and priorities of the autistic community. This contribution, though essential, has resulted in a lengthier, inaccessible QoL measure (McConachie et al., 2018)

THE CURRENT STUDY

Therefore, the purpose of the current study was to develop an **initial iteration of a novel QoL measure**, in partnership with an autistic adult, that reflects the needs and priorities of the autism community (LaPoint et al., 2025).

RESULTS

Autistic quality of life is a multi-dimensional construct that focuses on what constitutes a good life from the perspective of an autistic person, emphasizing their needs, values, and strengths rather than neuro-normative expectations.

FIGURE 3

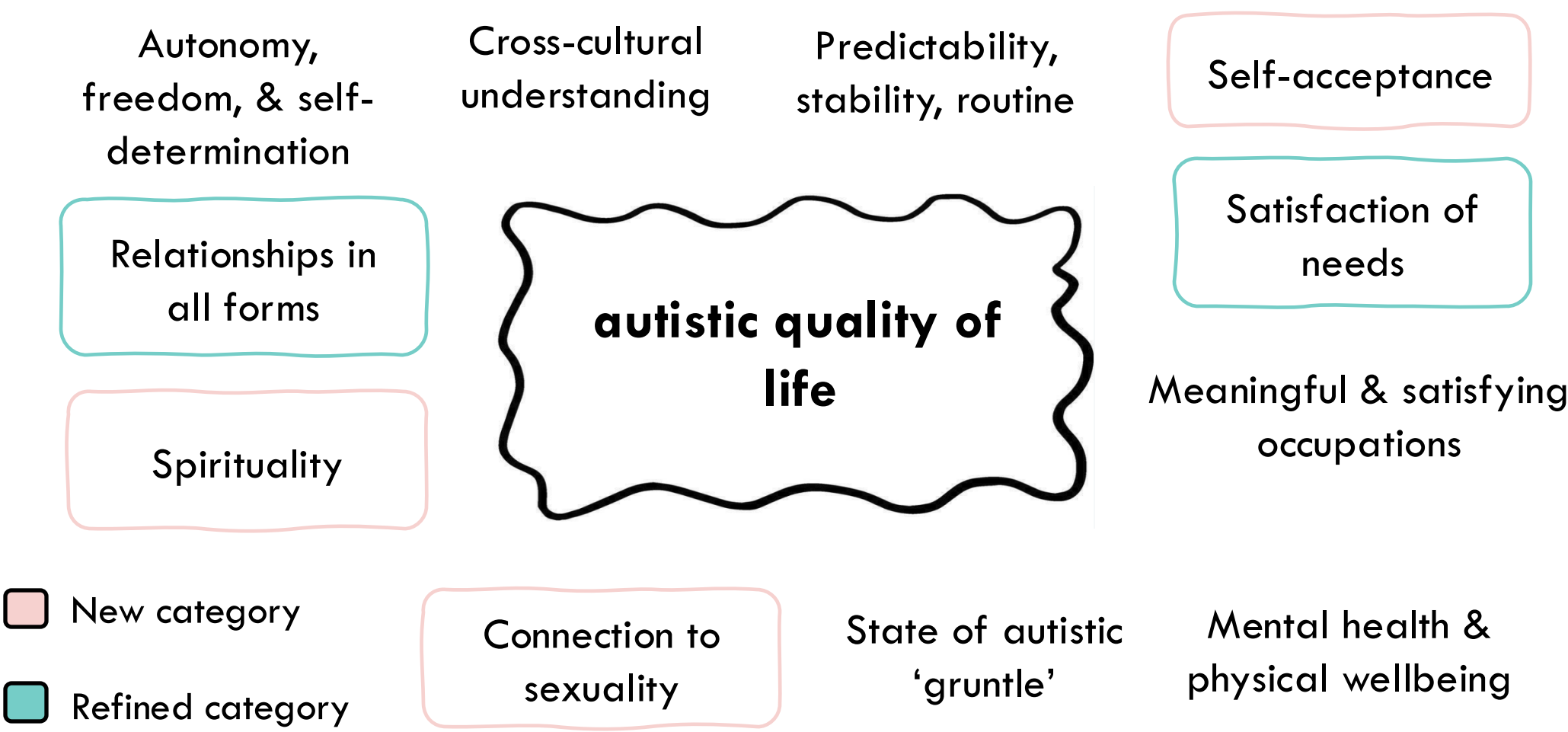


Figure 3: Refined AQoL domains based upon semi-structured interviews

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METHODS

Preliminary Data: Autism Level UP! received 159 survey responses from Autistic people that described what they consider to be a good QoL. The coding team identified domains of Autistic QoL (AQoL) based upon these responses.

FIGURE 1

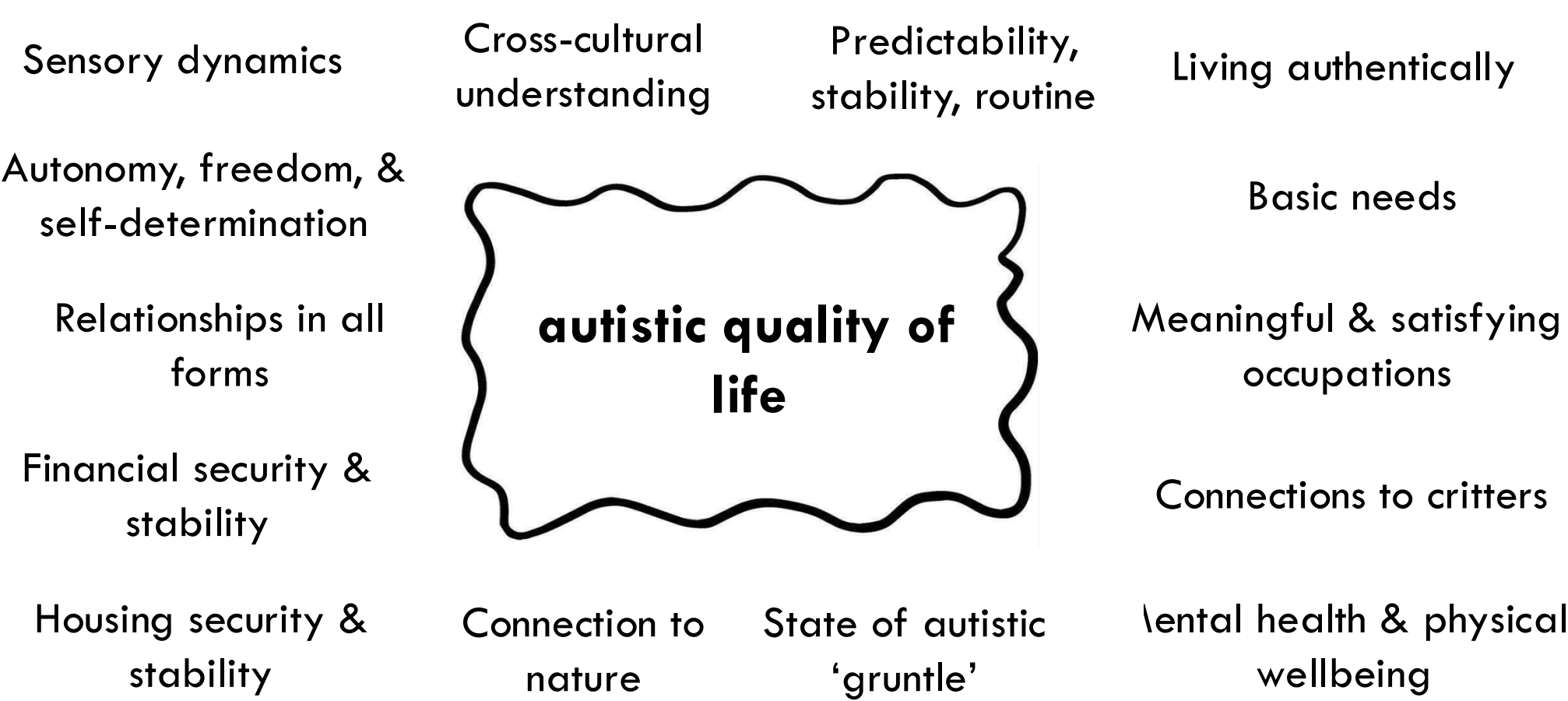


Figure 1: Original AQoL domains based upon open-ended survey responses

Materials & Procedures:

Semi-structured interviews were conducted with 24 Autistic adults to gather feedback on the AQoL domains, resulting in a refined version of the construct.

FIGURE 2

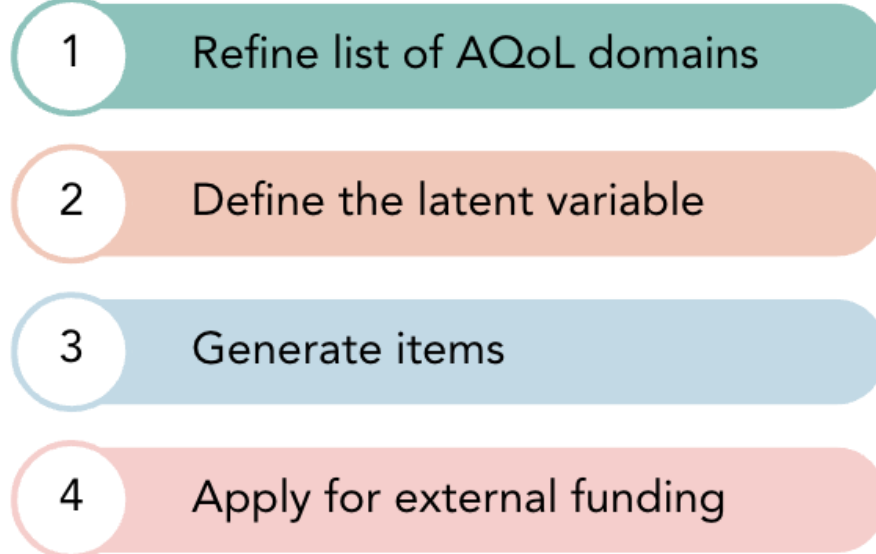


Figure 2. FYAP project activities

DISCUSSION

This study is the first to 1) gather feedback from Autistic adults on AQoL domains and 2) codesign an AQoL measure with Autistic people from the start.

The AQoL construct does not reflect the perspectives of non-speaking Autistic adults or Autistic adults living outside the US.

NEXT STEPS: Examine the content and substantive validity, refine the AQoL measure based on findings from expert review panel & cognitive interviews, and examine the structural and external validity.

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