



RQ: What do older autistic adults (aged 50+) feel are the most important factors that have assisted them in maintaining their own physical & mental well-being?

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Breaking News: Children with Autism become Adults with Autism & then Elderly Adults with Autism!

'Autism is a **Life long** developmental disability...'³

*"and yet current Autism research focuses on children and neglects adults and older adults."*⁴



• Research in Autism tends to focus on proxy accounts from professionals, parents and carers.⁵

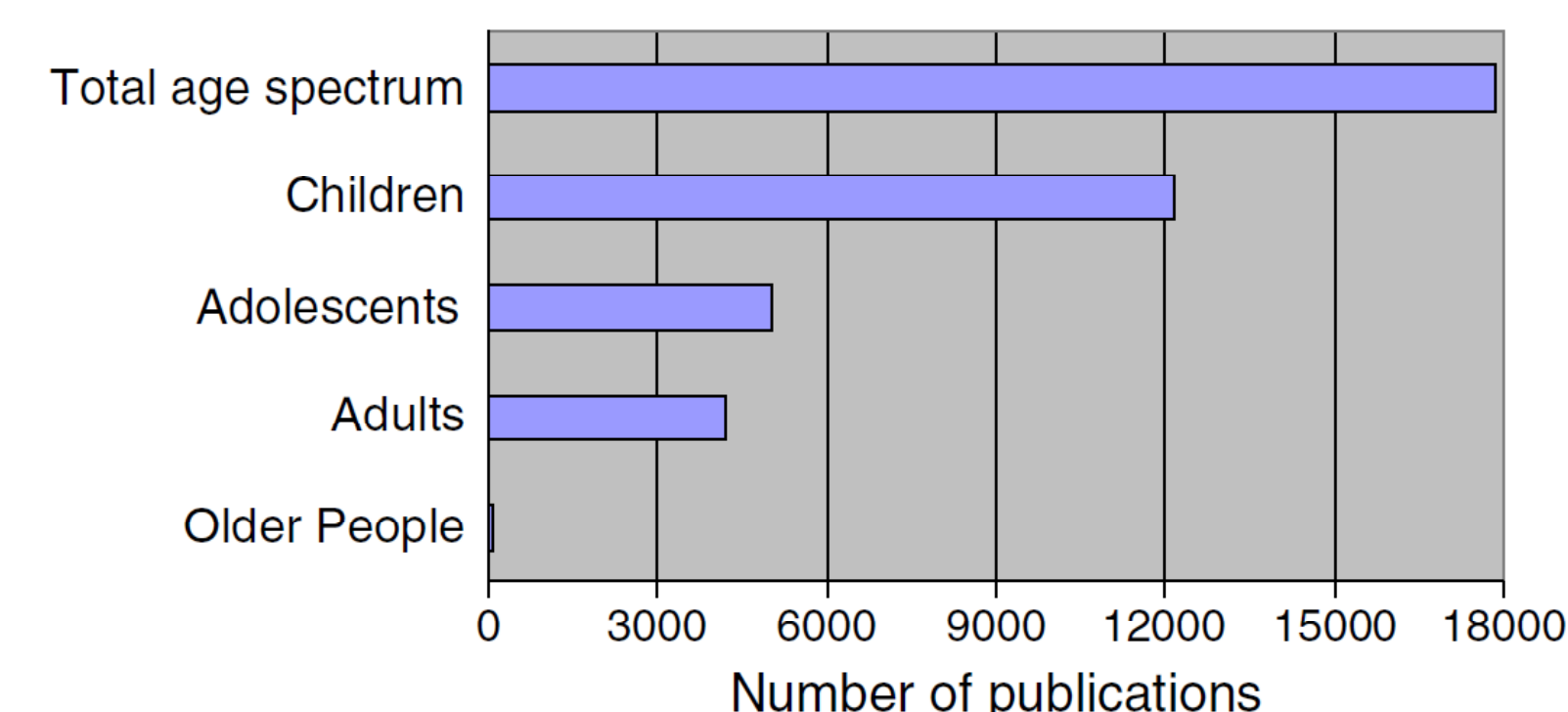
• Autistic individuals without an associated learning disability are able to give insightful accounts of living with Autism.³

• Autistic individuals are the experts on Autism.⁷

• Participation of Autistic individuals in qualitative research should be encouraged to increase awareness of the distinct way in which Autistic individuals experience the world.⁵

• *'It is important to have more research dedicated into exploring the experiences of older autistic adults, as there may be some exciting surprises ahead.'*⁴

Autism Research



Current research in Autism focuses on children and neglects adults and older adults. A search of PubMed for Autism studies that had been published between 1946-2011 by age of participants gave the results shown.⁸

Terminology

- The terminology used here is in accordance with the views expressed by adults and their families that the term 'autistic' be used⁹
- 13/1 interviewees in this study stated that they have no preference in terminology used.

Objective & Methodology

- To gain from the insight into the life experiences of individuals with Autism across the course of their life.
- *'Wider understanding of Autism can promote an improved living environment & more accepting society for individuals with a diagnosis of Autism.'*²
- This is a Grounded Theory study using in-depth semi structured interviews to explore the life experiences of older autistic adults to gather data that provides insight into autism across the lifespan & how autistic individuals adapt.
- Data from first interview were analyzed using thematic analysis, a second interview was conducted to discuss themes identified, to ensure clarity of researcher's understanding and verify interpretation



Study Design/ Research Process



Recruitment

Inclusion Criteria = Age 50 +, diagnosis of Autism, able to fully partake in interview process.

Interviewees were recruited via; conference pack flyer of the EHU Autism conference, Twitter, FB, via internal University electronic newsletter and snowballing.



Personalised Interview Design

The Interview process was designed individually with interviewees. Personal adjustments made included;

- mode of interview that best suited interviewer (face to face, telephone, skype or instant messenger),
- consideration of sensory issues,
- structure of interview,
- individual communication and documentation preferences,
- preferred terminology,
- assurance of data ownership (ability to withdraw data post interview).

Preliminary Results

- 15 interviewees have been recruited into the study and have been interviewed at least once. Initial analysis has taken place. Further analysis, secondary interviews and confirmation of shared understanding is ongoing, (estimated completion Jan 2019).
- Insights into methodological approach will be disseminated via publication.
- Data collection has highlighted many positive aspects of Autism not often discussed in the literature.

• A selection of the initial themes emerging from the data are;

- Acceptance -experience and effect of
- 'Against all odds... I'm still here' resilience
- 'Burnout'
- Coping Strategies
- 'Facing the Future'
- Importance of diagnosis
- 'Getting wise to myself'
- Life long masking (effect of)
- Positive attributes of Autism
- Self care—importance of
- Service provision—appropriate and inappropriate
- Socialising 'Importance of prioritising own needs'
- Trauma/PTSD
- Value of ASC social groups.
- Vulnerability



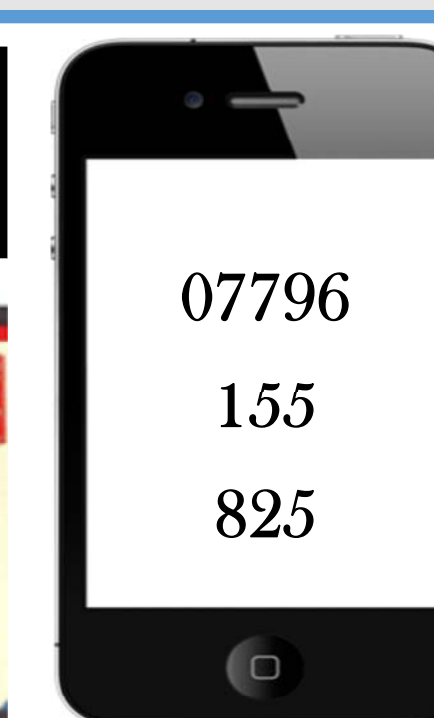
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