

**Mental health and quality of life for autistic adults**  
**Findings from the Newcastle University adulthood**  
**and ageing research programme**

**Jeremy Parr**

**Professor of Paediatric Neurodisability**

**@jeremyparr**



# Funding, and interests

I have no financial conflicts of interest

The autism spectrum adulthood and ageing research programme is funded by the UK autism charity Autistica. We received funding from the UK MRC, NIHR and charities for research described

Editorial Committee for the *Autism in Adulthood* journal

Chair, Autistica's DISCOVER Ageing and Physical Health Study Group; I Chair and sit on other national committees regarding research and clinical services

Co-author of Autistica's 'One in a Hundred' report (Wallace et al., )

# Lots of work by lots of people



**Autistic people and relatives, parents of children, children**

Tom Berney, Carla Black, Sam Brice, Tracy Finch, Mark Freeston, Deborah Garland, The Goth, Vicki Grahame, Jahnese Hamilton, Barry Ingham, Ann Le Couteur, David Mason, Joan Macintosh, Morag Maskey, Helen McConachie, Cos Michael, Chris Mitchell, Alison Mulvenna, Alex Petrou, Jacqui Rodgers, Patrick Walsh, Sarah Wigham, Colin Wilson, Marc Woodbury-Smith

**Many other colleagues nationally and internationally. The Programme Advisory and Steering committee**

## The 2013 Newcastle meeting on ASD Lifecourse and Ageing



Thursday 12<sup>th</sup> September 2013



Institute of  
Neuroscience

Institute for  
Ageing

Research priorities: Longitudinal cohort study re the lives of autistic people. Their quality of life, mental health, physical health

Engagement strategies

<https://research.ncl.ac.uk/adultautismspectrum/newsevents/>

**International leaders in autism research registers/databases, and cohorts (cross sectional and longitudinal data)**

**UK research registers/databases (with consent); 80 health providers (NHS Trusts)**

ASD-UK: Over 4700 families of children. 2000 local DaSl<sup>n</sup>e (55% of local families of children with ASD – largest internationally). Co-existing conditions

**Longitudinal cohorts (with consent); work with 60 NHS Trusts, plus community**

Adult ASC-UK: 1800 adults on the autism spectrum, 750 relatives of adults. Among the largest internationally. Mental health, quality of life, physical health, how lives change with time

Expertise and materials shared and exported to other researchers (Ireland, US, Canada)

Co-design of research with autistic people and relatives

# 2018: Newcastle University research programme on autism lifecourse and ageing

**Designing intervention:**  
Methods and measures used in diagnosis

**Understanding:**  
Uncertain futures for autistic people and relatives (Rodgers)

**Design intervention:**  
Personalised phobia treatment

**Designing intervention:**  
Post diagnostic support



**Survey, design intervention & RCT:**  
Personalised anxiety treatment

**Survey, design intervention & RCT:**  
Accessing health care

**Survey, design intervention & RCT:**  
Autism specific health checks in Primary care

**Measurement:**  
Quality of life WHO-QoL-BREF and ASQoL

# Top ten questions for autism research

# AUTISTICA

Building brighter futures through autism research

1

Which interventions improve mental health or reduce mental health problems in autistic people? How should mental health interventions be adapted for the needs of autistic people?



2

Which interventions are effective in the development of communication/language skills in autism?

3

What are the most effective ways to support/provide social care for autistic adults?

4

Which interventions reduce anxiety in autistic people?



5

Which environments/supports are most appropriate in terms of achieving the best education/life/social skills outcomes in autistic people?

# How are autistic people and the research team working together?



- Collaborative working started when shaping the project. Autistic people were not integrated into a pre-designed project
- Autistic people were asked what outcomes we wanted

The autistic researchers' job is ongoing. We meet regularly to:

- suggest ways the research team can engage with autistic adults
- advise on the range of communication methods possible for gathering information
- advise on tailoring autism friendly environments for meeting contributors
- advise on respecting autistic preferences and behavioural traits
- make suggestions, such as providing feedback and updates on progress, to promote inclusion and help keep people engaged over the longer term

# Autism Spectrum-UK

Welcome to Autism Spectrum-UK

Please select which site you would like to visit

For adults and relatives of adults with autism living in the UK



Adult Autism Spectrum Cohort - UK

For parents of children with autism living in the UK



Autism Spectrum Database - UK

For parents of children with autism living in the North East of England



Dasine

# Characteristics of 1800 people who have joined the adult autism cohort



The adult cohort includes 54% males, 44% females, and 2% who report another gender

30% need support to complete materials; 130 people who are unable to consent for themselves (consultee consent)

Age range 16-80 years

50% age 16-35 years, 20% 36-45 years and 30% over age 46; more than 150 people aged over 56 years

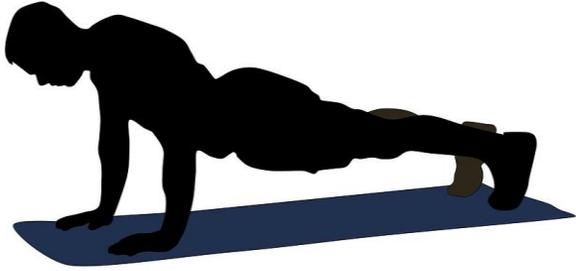
Consent to recontact: update information, give new information, many agreed to meet

# Quality of Life: What is QoL?

- “an individual’s perceptions 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”

WHOQoL user manual (1998)

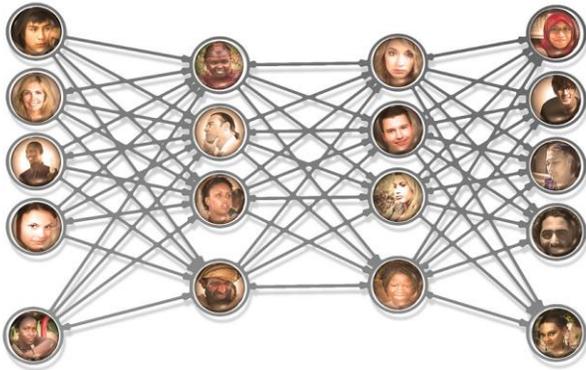
- It is a *subjective* report given by the individual in relation to their *current* life situation
- QoL is conceptualised as having different domains that represent different aspects of a person’s life



- ▶ Physical QoL
  - ▶ pain, medication needs, capacity for work and daily living tasks, sleep, energy, and mobility.

- ▶ Psychological QoL

- ▶ self-esteem, spirituality, mental health, concentration, and bodily appearance

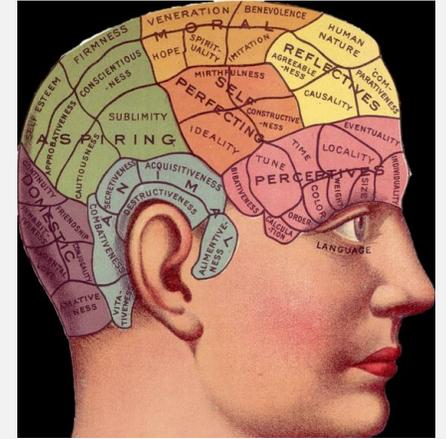


- ▶ Social QoL

- ▶ satisfaction with personal relationships, support from friends, and sex life

- ▶ Environment QoL

- ▶ satisfaction with monetary needs, access to leisure activities, access to health services, transport, safety, and physical environment



# Predictors of Quality of Life for Autistic Adults

Autism Research

David Mason, Helen McConachie , Deborah Garland, Alex Petrou, Jacqui Rodgers, and Jeremy R. Parr

370 people; Autistic adults have lower QoL than the general population

	Positive Predictors	Negative Predictors
Physical	Employed $\beta = .112^*$	Female $\beta = -.133^*$ Mental health condition $\beta = -.211^{***}$ SRS total $\beta = -.413^{***}$
Psychological		Female $\beta = -.150^{**}$ Mental health condition $\beta = -.274^{***}$ SRS total $\beta = -.378^{***}$
Social	In a relationship $\beta = .285^{***}$ Receiving support $\beta = .129^*$	Older age $\beta = -.187^{**}$ Mental health condition $\beta = -.194^{**}$ SRS total $\beta = -.260^{***}$
Environment	Receiving support $\beta = .180^{**}$	Female $\beta = -.160^{**}$ Mental health condition $\beta = -.250^{***}$ SRS total $\beta = -.442^{***}$

\* $p < .05$ , \*\* $p < .01$ , and \*\*\* $p < .001$

# Mental health conditions (equal numbers autistic adults: males and females (1198 people) Petrou et al., in preparation

	n (%) or Mean (SD)				Total (n=1198)	Association between age groups
	16-25 (n=315)	26-40 (n=407)	41-60 (n=408)	61+ (n=68)		
SRS total	107.0 (34.3)	115.7 (25.6)	112.9 (25.5)	103.3 (29.7)	111.7 (28.5)	X <sup>2</sup> (3)=12.5, p=.006
Mental health/neurological conditions						
ADHD	45 (14.3)	44 (10.8)	25 (6.1)	8 (11.8)	122 (10.2)	X <sup>2</sup> (3)=13.5, p=.004
Anxiety	158 (50.2)	226 (55.5)	228 (55.9)	27 (39.7)	639 (53.3)	X <sup>2</sup> (3)=8.20, p=.042
Depression	111 (35.2)	210 (51.6)	221 (54.2)	29 (42.6)	571 (47.7)	X <sup>2</sup> (3)=29.6, p<.001
Access to mental health services						
Tried to access mental health services	194 (61.6)	308 (75.7)	293 (71.8)	45 (66.2)	843 (70.1)	X <sup>2</sup> (3)=17.87, p<.001
Accessed the mental health services needed	128 (40.6)	187 (45.9)	164 (40.2)	26 (38.2)	505 (42.2)	X <sup>2</sup> (3)=15.20, p=.002

## **Health care adjustments / Accommodations: Data from >500 autistic adults and relatives, >100 parents of children** (Brice, Wigham; in preparation)

### **For anxiety: some examples, needed most frequently but infrequently provided**

Therapists with expertise in autism (not just therapy)

Information pre clinic about what to expect

Waiting rooms small, with appropriate activities

Meeting people's sensory needs (lighting, noise)

Health summary document (eg health passport)

Tailoring the appointment according to information given by the person/relative

Follow up appointments to enable further discussion

'It was in an unfamiliar place in an unfamiliar town, though this was my fault because I tend to avoid going out. What was particularly hard was that the building had an outside intercom that, had I been alone, I would not have used, would have panicked instead and returned home'

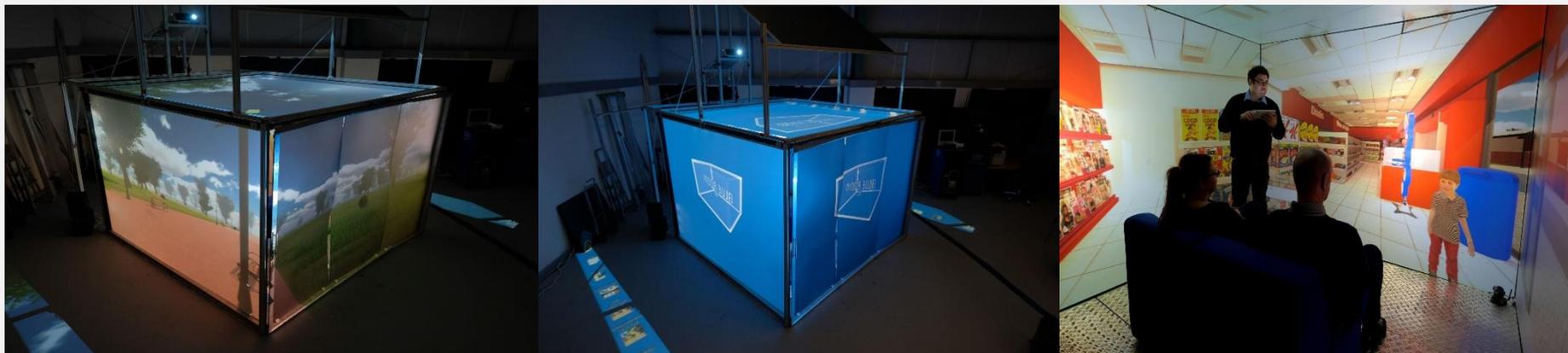
# **BMJ Open Protocol for a feasibility study and randomised pilot trial of a low-intensity psychological intervention for depression in adults with autism: the Autism Depression Trial (ADEPT)**

---

Ailsa Russell,<sup>1</sup> Kate Cooper,<sup>1</sup> Stephen Barton,<sup>2,3</sup> Ian Ensum,<sup>4</sup> Daisy Gaunt,<sup>5</sup> Jeremy Horwood,<sup>5</sup> Barry Ingham,<sup>6,7</sup> David Kessler,<sup>8</sup> Chris Metcalfe,<sup>5</sup> Jeremy Parr,<sup>7</sup> Dheeraj Rai,<sup>8</sup> Nicola Wiles<sup>9</sup>

# What is the Blue Room?

- Immersive technology using computer generated images projected onto the walls and ceilings of a 360 degree seamless screened room
- Participants are not required to wear a headset or goggles; therapist navigates through the scene using a handheld tablet computer
- A therapist remains throughout the 4x30 minute treatment sessions; CBT plus exposure
- Scenes are individualised for person, with gradual exposure to the feared stimulus



# Adults on the autism spectrum: development study (Maskey et al., in press)

5/8 definite improvement at 6 months

Adult	Phobia/situational fear	Supporter and observers of sessions	Responder	
			6 weeks	6 months
A	Open spaces	Friend	No	No
B	Walking through doorways	Parents and support worker	<b>Yes</b>	<b>Yes</b>
C	Spiders	Mother, sister and partner	<b>Yes</b>	<b>Yes</b>
D	Babies/pram	Parents, brother and support worker	No	No
E	Making requests	Mother	<b>Yes</b>	<b>Yes</b>
F	Pigeons	Mother	<b>Yes</b>	<b>Yes</b>
G	Insects/flies	Parents	No	<b>Yes</b>
H	Crowded buses	Mother and support worker	No	No

# **Personalised Anxiety Trial – Autism (PATA) (Brice, Walsh and others)**

Randomised controlled trial of anxiety intervention for adults

People's treatment plan will depend upon what anxiety 'types' they have

Aim: Investigate whether this treatment plan is feasible to deliver for health professionals and acceptable to autistic people

Recruitment now through Northumberland Tyne and Wear NHS Foundation Trust

40 people – randomised into groups (PATA intervention or usual NHS care)

Results in 2020

If this approach seems acceptable, a larger treatment study would be needed; possibly adapt for children?

## Some key messages

Value in research programmes that build critical mass in lifecourse research, including autism adulthood and ageing

Our integrated research approach: use basic science, improved understanding to design trials, improve interventions and services, implement change

Longitudinal studies allow investigation of personal change, and accelerated cohort studies; ideally, across the whole lifecourse

Mental health is important for Quality of Life

New and effective mental health treatments are needed

We are designing and evaluating those locally; implementation is a next step

# Thank You



Jeremy.Parr@ncl.ac.uk

@jeremyrparrr

<http://www.autismspectrum-uk.com/>

[asd-uk@ncl.ac.uk](mailto:asd-uk@ncl.ac.uk)

## Autism Spectrum-UK

Welcome to Autism Spectrum-UK

Please select which site you would like to visit

For adults and relatives of adults with autism living in the UK



Adult Autism Spectrum Cohort - UK

For parents of children with autism living in the UK



Autism Spectrum Database - UK

For parents of children with autism living in the North East of England



DasIne



**Designing intervention:**  
Methods and measures used in diagnosis

**Understanding:**  
Uncertain futures for autistic people and relatives (Rodgers)

**Design intervention:**  
Personalised phobia treatment

**Designing intervention:**  
Post diagnostic support



**Survey, design intervention & RCT:**  
Personalised anxiety treatment

**Survey, design intervention & RCT:**  
Accessing health care

**Survey, design intervention & RCT:**  
Autism specific health checks in Primary care

**Measurement:**  
Quality of life WHO-QoL-BREF and ASQoL