



**AUTISM**  
NATIONAL  
TRAINING FOR  
PSYCHIATRISTS



# Autism in Older Age

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RCPsych Autism Champion



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# PATHOLOGY

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To understand and measure emotional qualities is very difficult. Psychologists and educators have been struggling with that problem for years but we are still unable to measure emotional and personality traits with the exactness with which we can measure intelligence.

—ROSE ZELIGS in *Glimpses into Child Life*\*

## AUTISTIC DISTURBANCES OF AFFECTIVE CONTACT

By LEO KANNER

**S**INCE 1938, there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits—and, I hope, will eventually receive—a detailed consideration of its fascinating peculiarities. In this place, the limitations necessarily imposed by space call for a condensed presentation of the case material. For the same reason, photographs have also been omitted. Since none of the children of this group has as yet attained an age beyond 11 years, this must be considered a preliminary report, to be enlarged upon as the patients grow older and further observation of their development is made.

*Case 1.* Donald T. was first seen in October, 1938, at the age of 5 years, 1 month. Before the family's arrival from their home town, the father sent a thirty-three-page typewritten history that, though filled with much obsessive detail, gave an excellent account of Donald's background. Donald was born at full term on September 8, 1933. He weighed nearly 7 pounds at birth. He was breast fed, with supplementary feeding, until the end of the eighth month; there were frequent changes of formulas. "Eating," the report said, "has always been a problem with him. He has never shown a normal appetite. Seeing children eating candy and ice cream has never been a temptation to him." Dentition proceeded satisfactorily. He walked at 13 months.

Kanner's case 1

# The changing face of autism



# Independent, April 2023

The screenshot shows the Independent news website interface. At the top, the logo 'INDEPENDENT' is visible alongside navigation links for 'NEWS', 'SPORT', 'VOICES', 'CULTURE', 'LIFESTYLE', 'TRAVEL', 'PREMIUM', and 'MORE'. A search bar and 'Amazon Prime Day' promotion are also present. A prominent purple banner advertises 'Zero Booking Fees' with the RailOnline logo and the tagline 'Fairer Fares'. Below this, a news article is featured with the headline 'Record 190,000 patients waiting for autism diagnosis by 2024 with 'devastating' consequences'. The article is categorized under 'News > Health' and includes a sub-headline: 'Exclusive: NHS autism service 'crisis' will leave tens of thousands of patients without diagnosis'. The author is identified as 'Rebecca Thomas Health Correspondent' and the publication date is 'Wednesday 12 April 2023 21:48'. Social media sharing icons for WhatsApp, Facebook, Twitter, and Email are provided. The main image of the article shows wooden blocks spelling out the word 'AUTISM' in a row, with other blocks scattered in the background.

Guardian,  
April 2022

## Autistic children wait up to five years for an NHS appointment

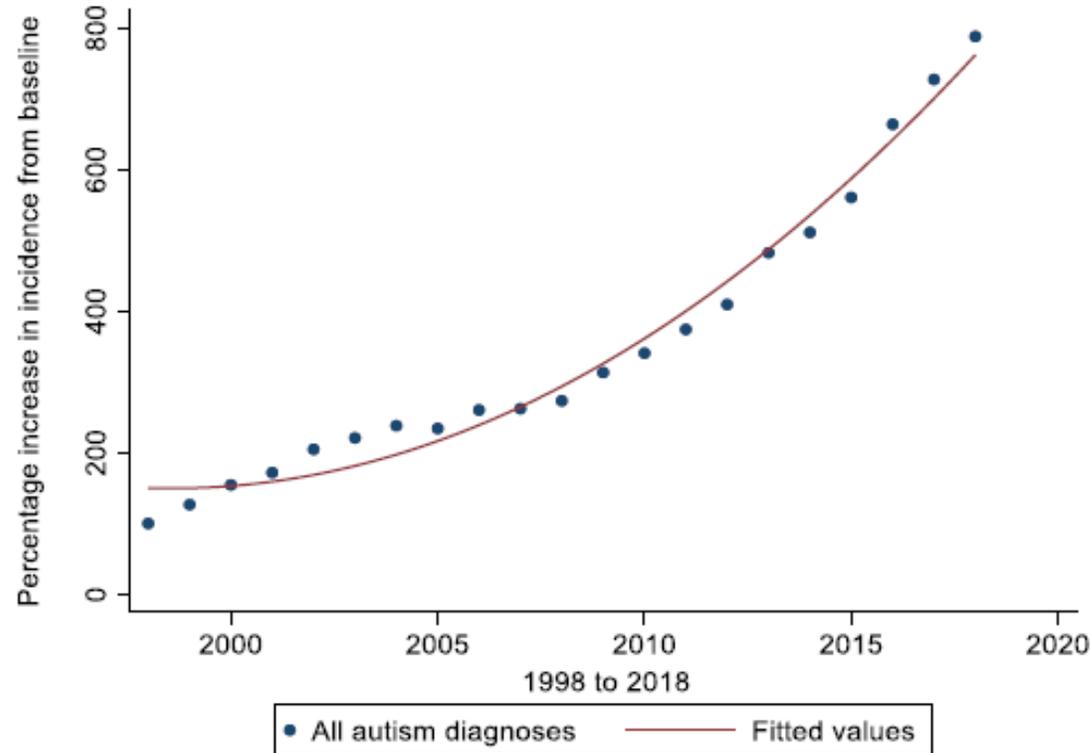
Figures obtained by the Observer show scale of mental health care crisis as families tell of huge impact of delays



📷 Cathy Pyle's daughter, Eva, spent 20 months waiting for an autism assessment from her local NHS child and adolescent mental health services in Surrey. Photograph: Anselm Ebulue/The Observer

Children are having to wait up to five years for an NHS autism appointment, according to figures obtained by the *Observer* that lay bare the [crisis in children's mental health services](#).

# Cumulative prevalence, 1998-2018



- This graph shows percentage increase in incidence of autism diagnosis from 1998 to 2018.

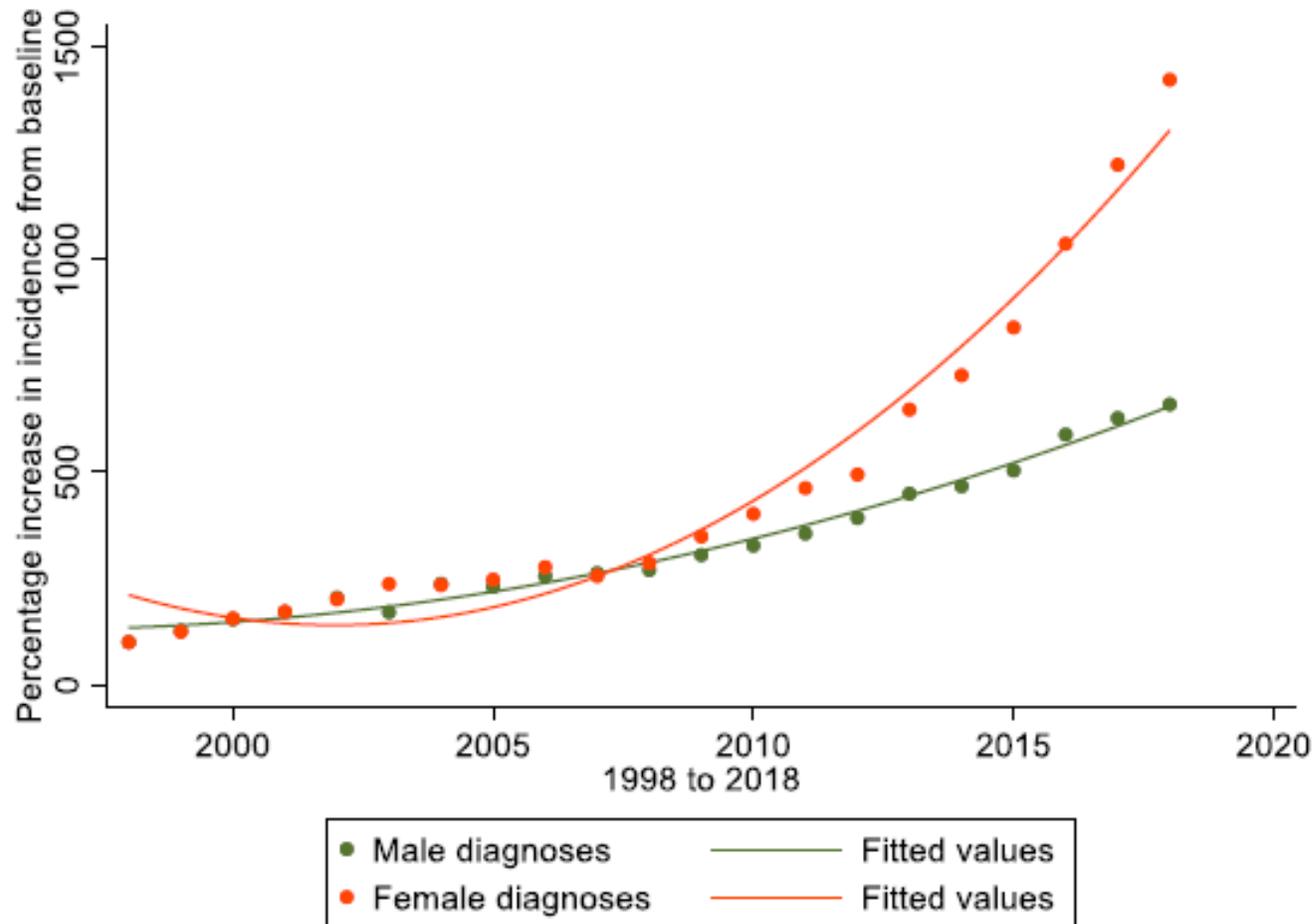
Figure 1 Percentage increase in incidence of autism diagnosis from 1998 to 2018

Russell et al, 2021

# Cumulative prevalence by gender



(ii): By gender.



- This graph shows cumulative prevalence, 1998 – 2018, by male-female gender

Russell et al, 2021

# So is autism being overdiagnosed?



- Higher prevalence rates likely represent better identification and better recognition of more subtle presentations, particularly in females...

...and in any case autism remains substantially **underdiagnosed** and **under-recognised** in certain groups:

- Psychiatric patients (see, for example, Brugha et al 2020)
- Older people (O’Nions et al, 2023)

# The changing face of autism

**Very common in children & young adults**

**Male: female ratio narrowing**

**Less Intellectual Disability**

**High mental health comorbidity**

# Why should psychiatrists care about autism?



## Common

- 1 in 20 CMHT patients
- 1 in 10 inpatients



## Risk

High rates of self harm, suicide, bullying, abuse, exploitation

## Under-recognised

Around half of autistic adults in MH system undiagnosed or misdiagnosed

## High MH needs

30-50% have mental health disorder; multiple MH problems common

# Suicide in autism

- Life expectancy in autism **12 years lower**
- Suicide rate in autism: **7 – 9 times higher**

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 208(3), 232-238. doi:10.1192/bjp.bp.114.160192



The British Journal of  
[Psychiatry](#)

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## Premature mortality in autism spectrum disorder

Published online by Cambridge University Press: 02 January 2018

Tatja Hirvikoski, Ellenor Mittendorfer-Rutz, Marcus Boman, Henrik Larsson, Paul Lichtenstein and Sven Bölte

[Show author details](#) ▼

**Article** [Figures](#) [Supplementary materials](#) [eLetters](#) [Metrics](#)

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### Abstract

#### Background

Mortality has been suggested to be increased in autism spectrum disorder (ASD).

#### Aims

To examine both all-cause and cause-specific mortality in ASD, as well as investigate moderating role of gender and intellectual ability.

#### Method

Odds ratios (ORs) were calculated for a population-based cohort of ASD probands ( $n = 27\,122$ , diagnosed between 1987 and 2009) compared with gender-, age- and county of residence-matched controls ( $n = 2\,672\,185$ ).

#### Results

During the observed period, 24 358 (0.91%) individuals in the general population died, whereas the corresponding figure for individuals with ASD was 706 (2.60%; OR = 2.56; 95% CI 2.38–2.76). Cause-specific analyses showed elevated mortality in ASD for almost all analysed diagnostic categories. Mortality and patterns for cause-specific mortality were partly moderated by gender and general intellectual ability.

#### Conclusions

Premature mortality was markedly increased in ASD owing to a multitude of medical conditions.



**Oliver McGowan**

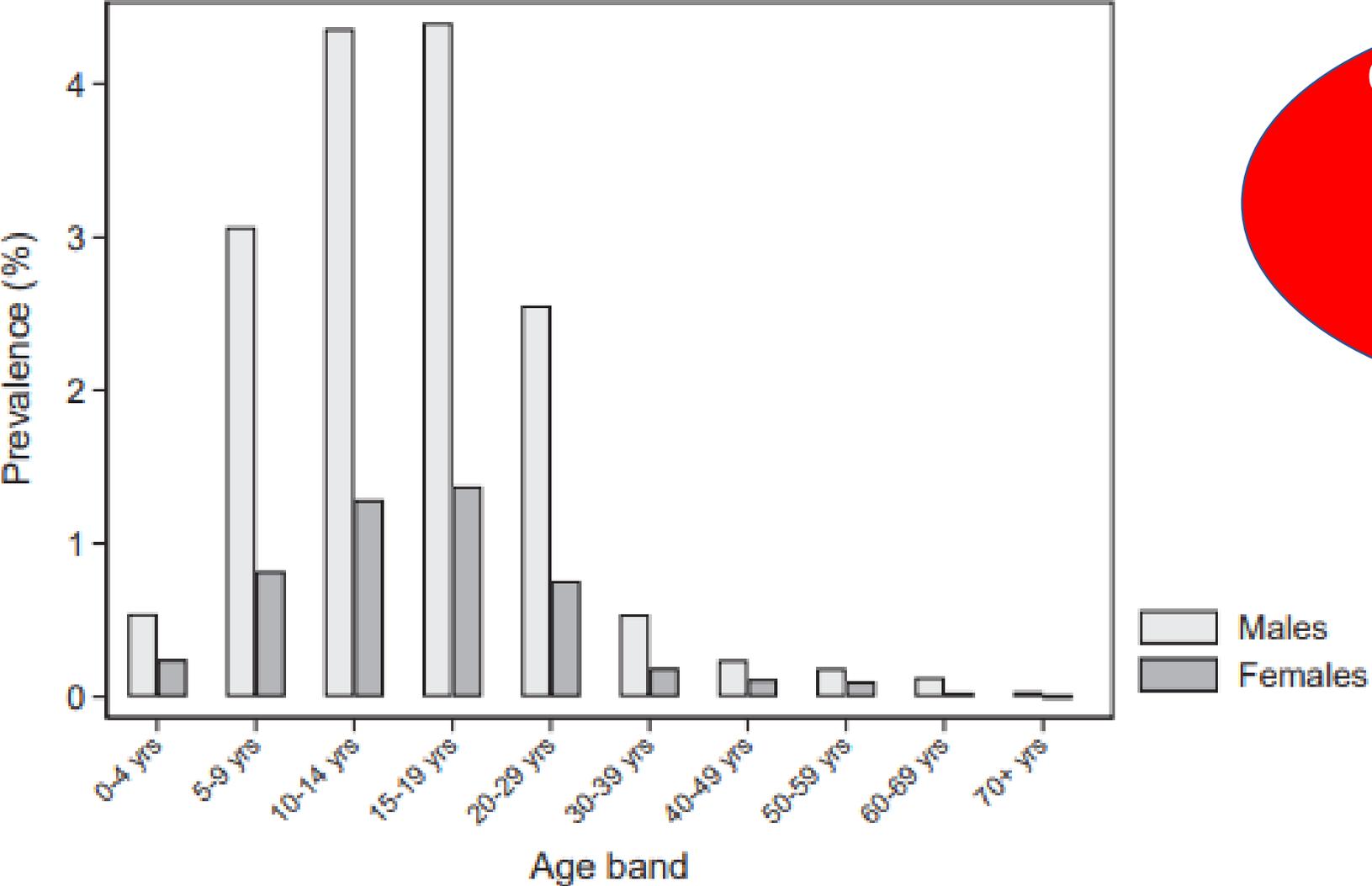
# Autism in older age



Kanner's case 1: Donald Grey Triplett  
B. 1933, D. 2023

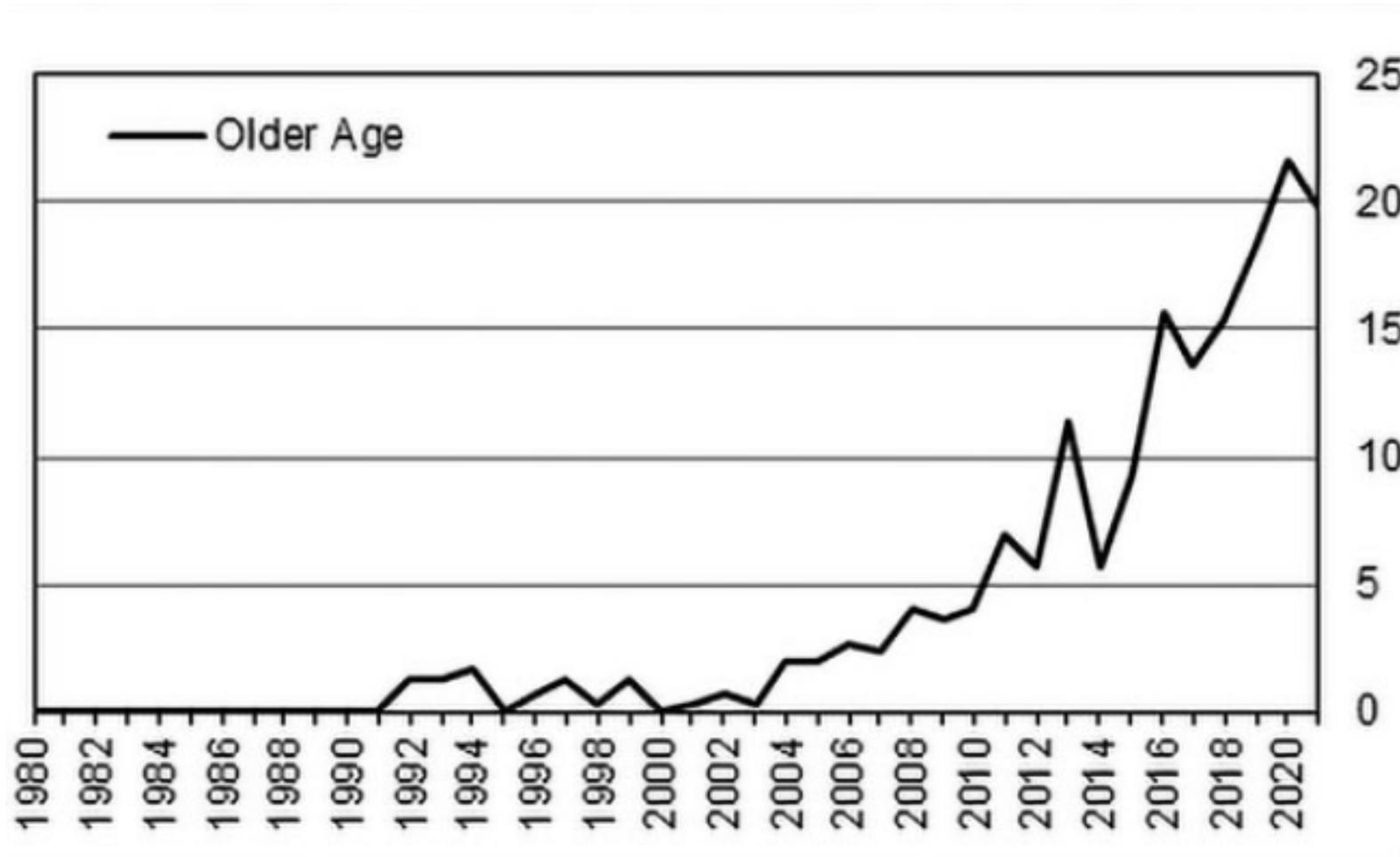
# Percentage of UK population diagnosed with autism, as of 2018 (Taken from Nions et al, 2023)

**A**



Only 0.02% of age 70+ have an autism diagnosis (vs expected prevalence of at least 1%)

# Autism in older age – published papers

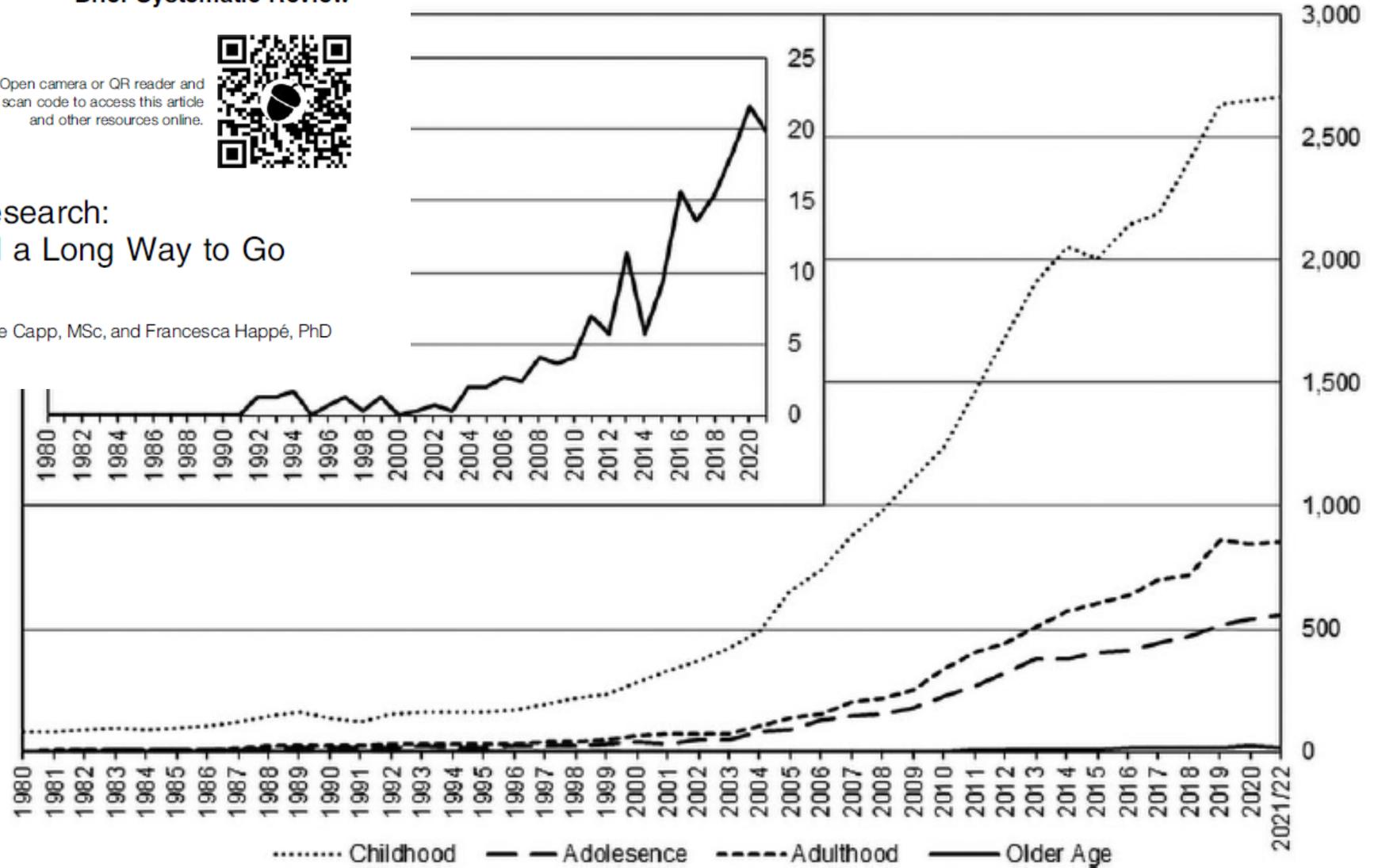


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## Older Age Autism Research: A Rapidly Growing Field, but Still a Long Way to Go

David Mason, MSc,\* Gavin Robert Stewart, PhD,\* Simone Josephine Capp, MSc, and Francesca Happé, PhD



**FIG. 3.** The main graph illustrates the publication trends for the childhood, adolescent, adult, and older adult searches. The inset graph illustrates the number of older age search results over time with a reduced axis scale. The y-axes denote number of studies published.

# Effect of autism on aging



Parallel

- Similar pattern of age-related decline to neurotypical population (Bathelt et al, 2020)

Accelerated

- Autism increases rate of age-related cognitive, mental and physical decline (Geurts & Vissers, 2012)

Safeguarded

- Autism is protective against some aspects of age-related decline (Oberman & Pascual-Leone, 2014)

# Characteristics of Older Autistic Adults: a Systematic Review of Literature (Lei et al, 2021)



- Very difficult to draw firm conclusions, due to:
  - Limited evidence base
  - Small, heterogenous samples
  - Variation in measures used
  - Lack of NT controls
  - Confounding effect of intellectual disability
  - ‘Healthy Survivor’ bias
- Overall, seems that social interaction difficulties and poor physical/mental health outcomes persist into old age

# Does autism predispose to dementia?



- Rhodus et al, 2020:
  - 142 older persons with mild cognitive impairment
  - Caregivers surveyed using Gilliam autism rating scale
  - Those with likely autism (n=23) had younger age of onset and more advanced cognitive impairment.
- Vivanti et al, 2021:
  - Case control study using Medicaid registers
  - Autistic adults were about 2.6 times more likely to be diagnosed with early-onset dementia than adults in the general population.
  - Association remained even after controlling for presence of ID and other risk factors

# How does autism present in older age?



- Child or grandchild diagnosed with autism
- Death or infirmity of spouse/other carer
- Worsening physical health which impacts on daily routines
- Major change of environment (eg move to a care home)
- ?early cognitive impairment 'unmasks' autism features
  
- Note – can present dramatically, eg with agitation, new onset self-harm/suicidality, or acute & transient psychosis (likely underlying driver is extreme anxiety state)

# Assessing autism in older adults



- Autism diagnosis can be very important for care and treatment planning – important not to miss!
- Consider if there is lifelong social/communication difficulties and cognitive/behavioural rigidity
- **Often lack of good developmental history** – passage of time, death of parents, destruction of records
- Assessment tools (eg ADOS) not well validated in older people
- Autism is more stigmatised in older age groups

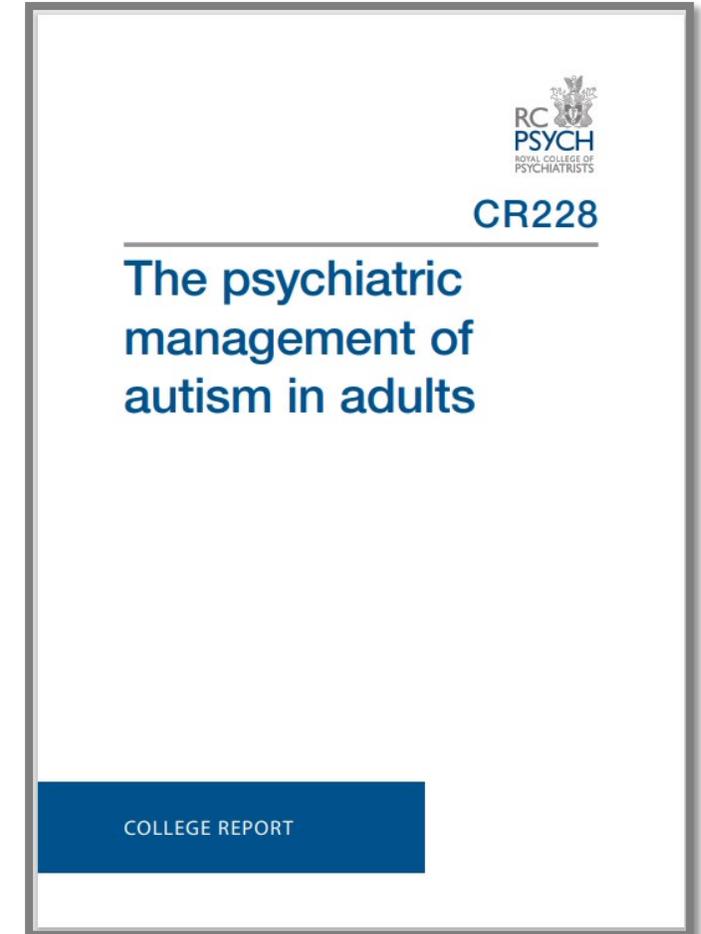
# What is the message to psychiatrists?



**All** psychiatrists should be able to:

- recognise the possibility of autism when assessing patients
- effectively diagnose and treat co-occurring mental health disorders in autistic patients, including in emergency settings
- communicate effectively with autistic patients and make reasonable adjustments where appropriate.

Presence of autism should not bar access to mental health services when there is legitimate MH need.



# What can I do?



Get some training

## National Autism Foundation Training Programme for Psychiatrists



[< back to events](#)

**16**  
MAR Online course

**Timings** 9am-4pm (1BC)

**Location** Online

**CPD** Up to 6 CPD points per day, subject to peer group approval

Free

£0

[Register now](#) 

# What can I do?



## Join the College Neurodevelopmental Special Interest Group

### Neurodevelopmental psychiatry (NDPSIG)

Welcome to the neurodevelopmental psychiatry special interest group (NDPSIG).

NDPSIG seeks to promote a wider discussion and understanding of neurodevelopmental disorder across the whole field of psychiatry.

[Join now!](#)



About us



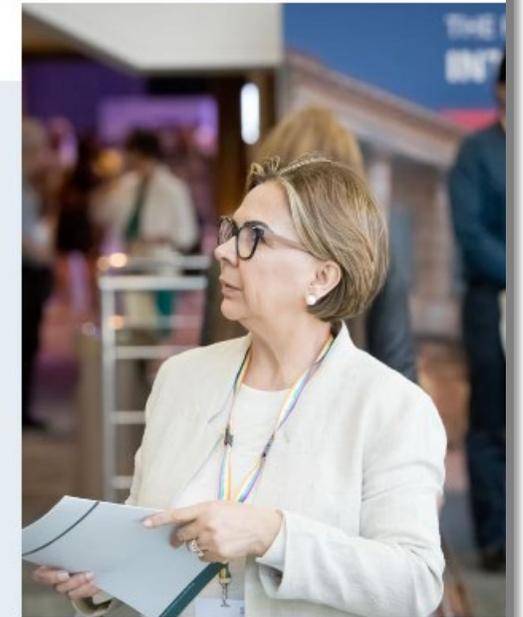
Events



Championing autism



Resources



# Get in touch



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