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E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Recount Researching the economic cost of undiagnosed neurodiversity today

The risks and costs associated with undiagnosed ADHD/autism

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“Why do you need a label?” Bc there is comfort in knowing you are a normal zebra, not a strange horse. Bc you can’t find community w other zebras if you don’t know you belong. And bc it is impossible for a zebra to be happy or healthy spending its life feeling like a failed horse

Why is it important?

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Background

Under diagnosis and support

Millions of children and adults are currently undiagnosed with autism and/or ADHD.

Global issue:

A Danish study where over half of the children with early-reported ADHD behaviours were still undiagnosed 8 years later

(Madsen, 2018)

ADHD diagnosed	SDQ ADHD prediction			
	Unlikely	Possible	Probable	Total
No	48,794	680	680	50,154
Yes	727	147	499	1373
Total	49,521	827	1179	51,527

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ADHD variation model (French et al, submitted 2025)

COUNTRY	ESTIMATED ADHD POPULATION			ESTIMATED NUMBER OF TREATED PATIENTS		
	CYP (5-17 years)	Adult (18-65 years)	Overall (5-65 years)	CYP (5-17 years)	Adult (18-65 years)	Overall (5-65 years)
England	442,692	1,209,739	1,652,431	114,958	191,135	306,094
Scotland	38,156	120,610	158,766	5,748	7,673	13,421
Wales	23,220	65,120	88,340	5,244	10,722	15,966
Northern Ireland	16,169	40,374	56,542	N/A*	N/A*	9,155
Great Britain	**504,068**	**1,395,469**	**1,899,537**	**125,950**	**209,531**	**335,481**

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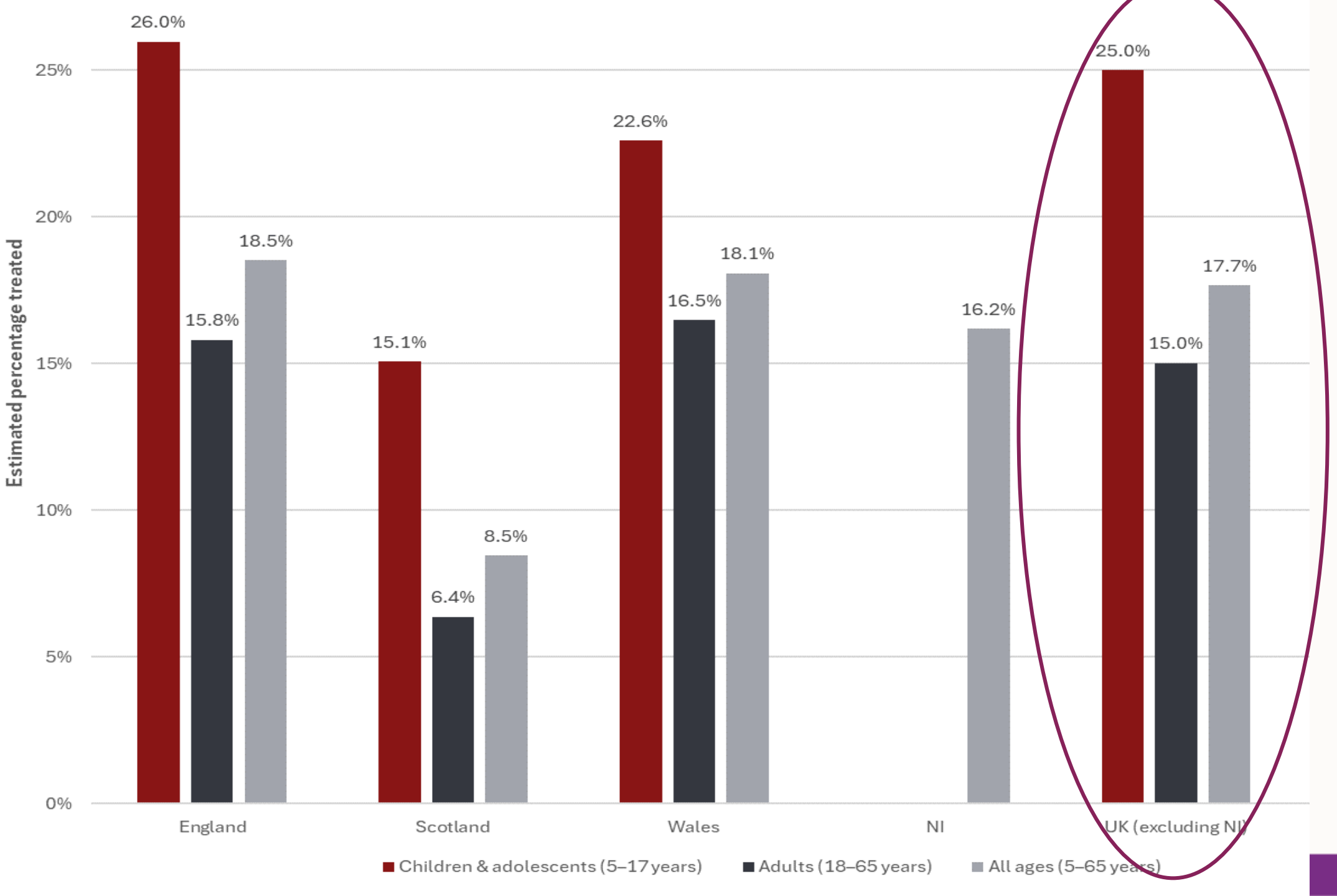
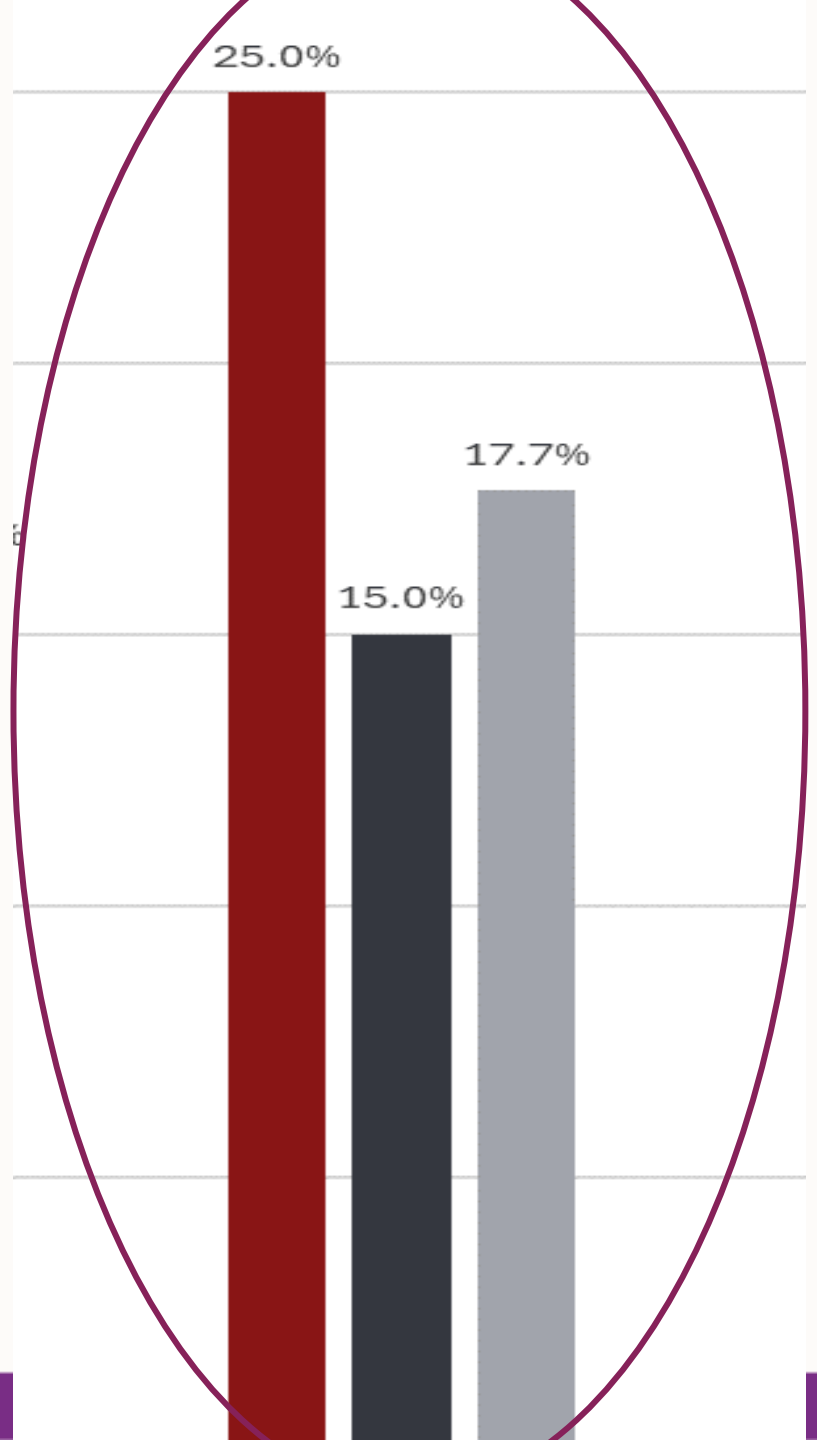

Estimated percentage treated
25%
20%
15%
10%
5%
0%
26.0%
15.8%
18.5%
15.1%
6.4%
8.5%
22.6%
16.5%
18.1%
16.2%
25.0%
15.0%
17.7%
England
Scotland
Wales
NI
UK (excluding NI)
Children & adolescents (5–17 years)
Adults (18–65 years)
All ages (5–65 years)



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Impact of lack of diagnosis

Undiagnosed ADHD is linked to:	Difficulties at **work**.
	Increased **substance abuse** (often as a form of self-medication).
	Higher rates of medical incidents and i**njuries**.
	For parents, impact **parenting** quality and lead to a more chaotic home life.
Undiagnosed autism is associated with:	Higher rates of **psychiatric conditions** and social problems.
	Increased vulnerability to **sexual abuse**, particularly for women.
	Higher likelihood of **chronic pain** and **suicidal behaviors**.

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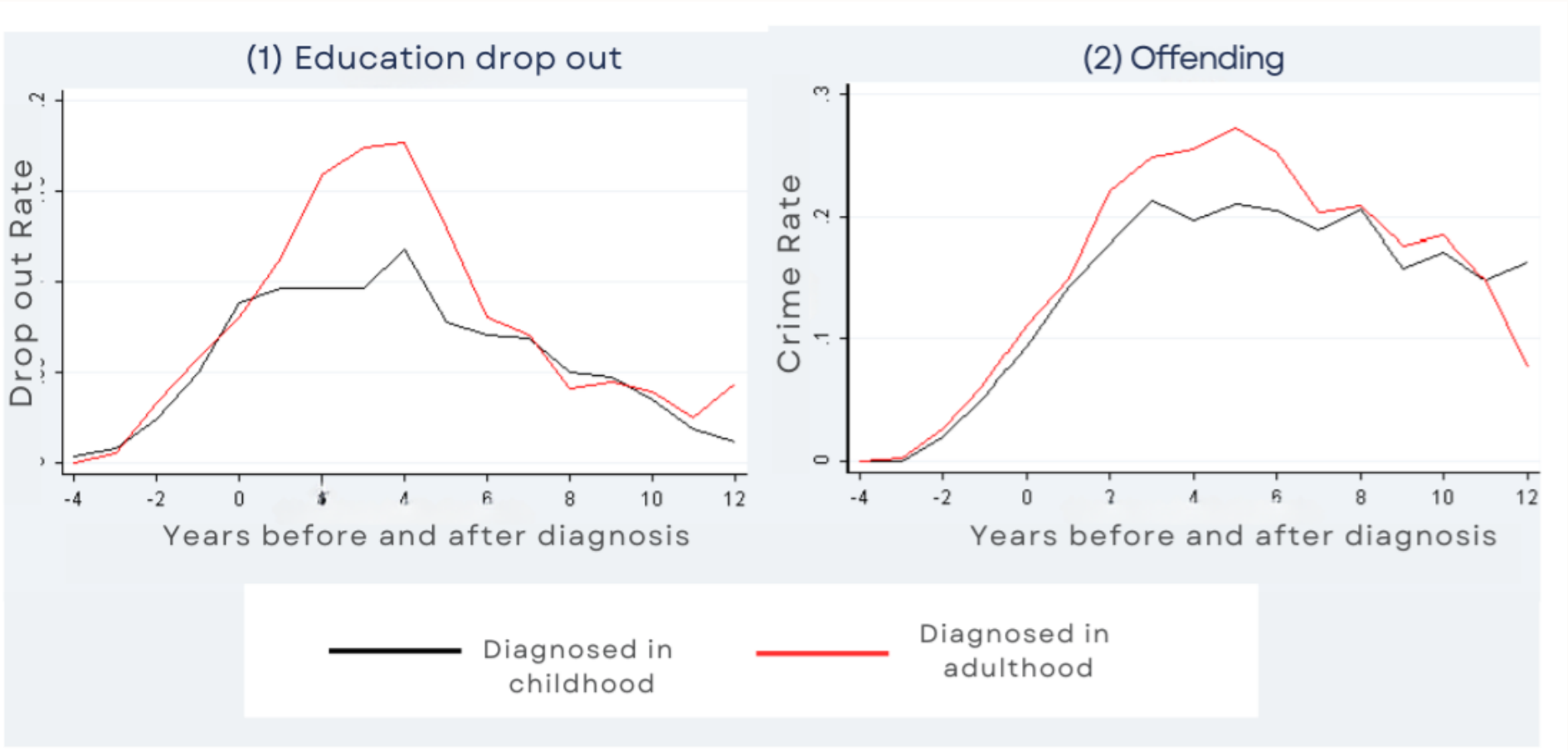
Benefits of receiving support

These risks are attenuated when autism/ ADHD is diagnosed and supported

Swedish population-based data suggest that drug treatment of ADHD may reduce criminality, serious traffic accidents, and suicide rates

(Chang et al, 2012).

Results
(childhood diagnosis at 0 and adult at 5)



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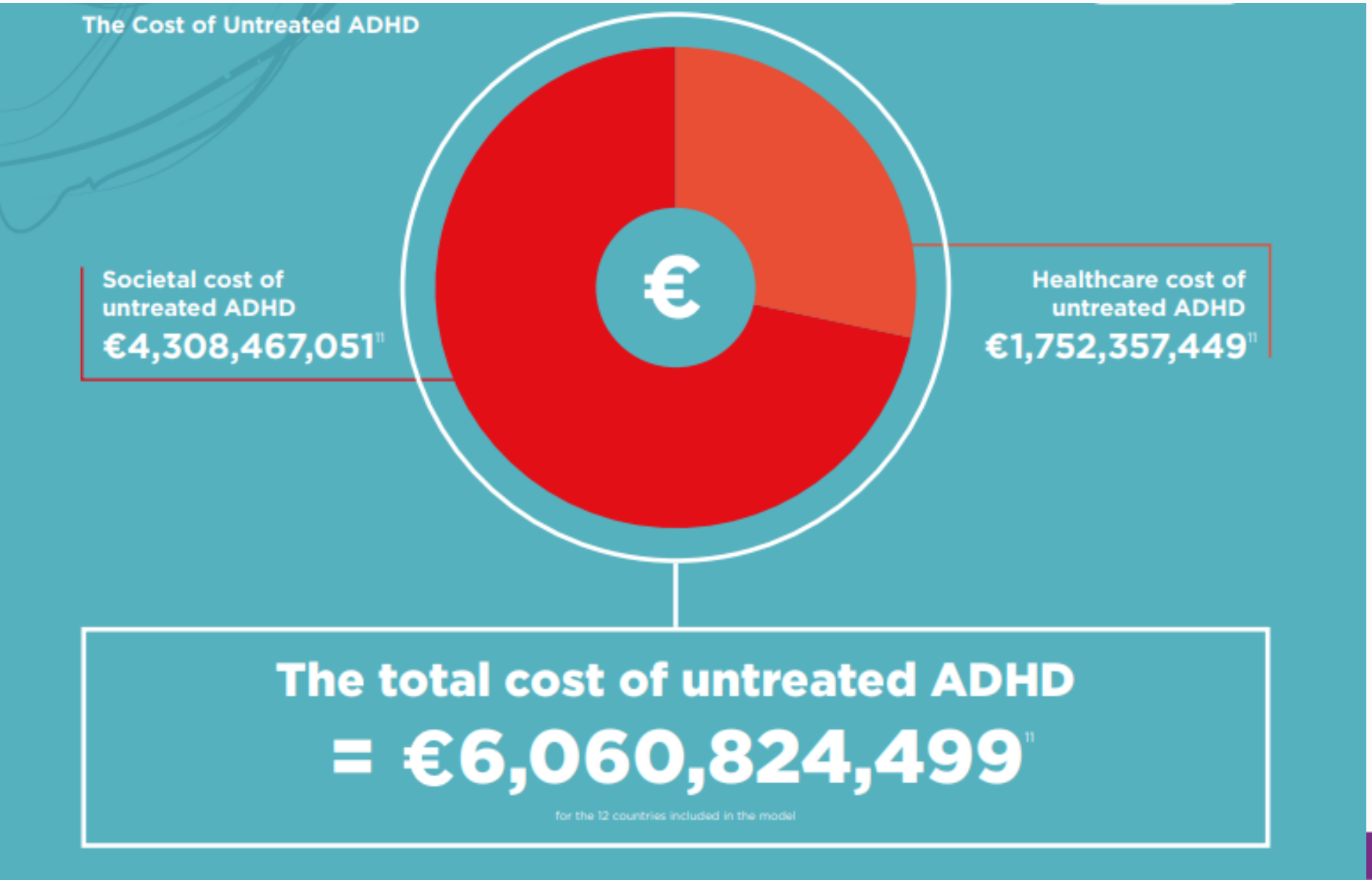
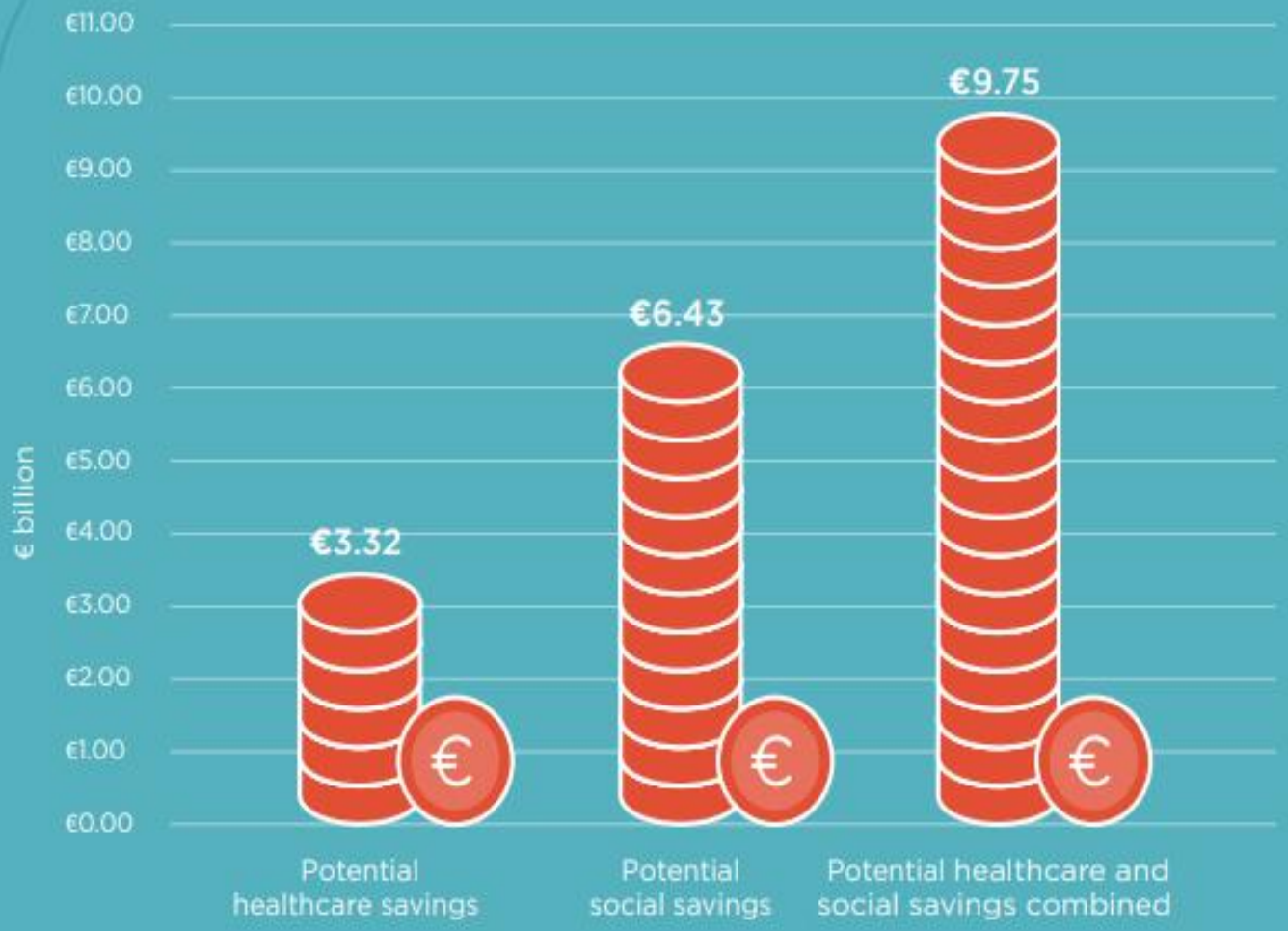
Takeda- Attention on ADHD report (2023)



Potential cost savings of treating to 70%

If the treatment rate were increased to 70% of people living with ADHD across the 12 countries, a total of €9.75 billion healthcare and social savings could be achieved. This would be made up of €3.32 billion of healthcare savings and €6.43 billon of social savings[13]



In summary

Very little data on this topic

But we do know that there are benefits in receiving a diagnosis

Personal

Economic and social

Healthcare perspective

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Researching the Economic Cost of Undiagnosed Neurodiversity Today

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Study 1

SYSTEMATIC REVIEWS

What are the known risks?

Study 2

INTERVIEWS

What are the experiences of undiagnosed/late diagnosed adults?

Study 3

ECONOMIC EVALUATION

What are the individual and societal costs of these associated risks?

In parallel

Advisory group

REGULAR PPIE MEETINGS

Six meetings with lived-experience group.

Collaborations

IMPLEMENTATION AND DESSIMINATION

- London School of Economics
- ADHD collective
- Autistica
- Autism research centre, Cambridge

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Risks associated with undiagnosed ADHD/autism

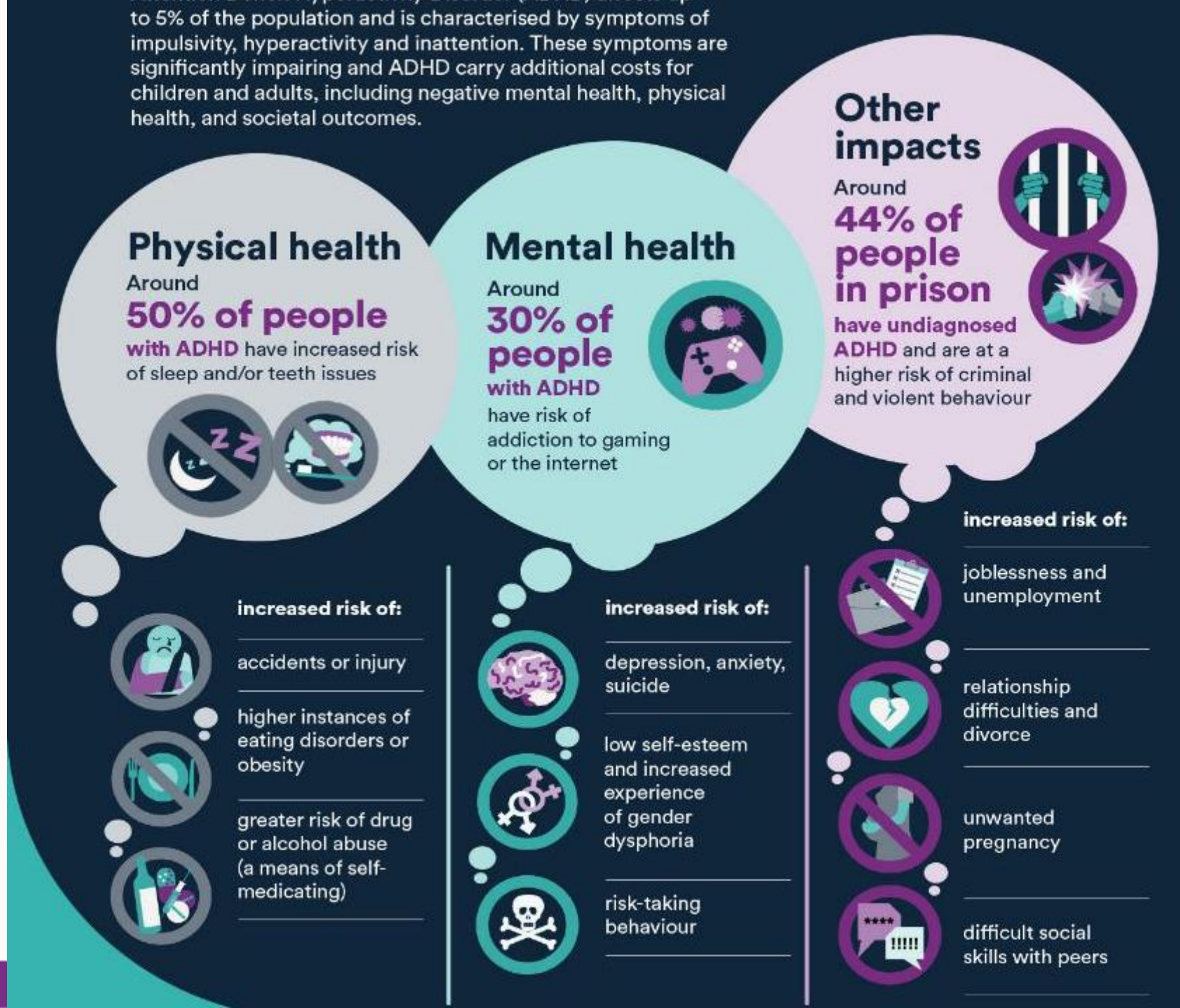
Study 1

Systematic reviews

Reviews

Systematic review	Risks associated with undiagnosed ADHD and/or autism - 17 studies
Umbrella reviews	Risks associated with ADHD – 125 reviews >1,500 studies Risks associated with Autism – 134 reviews >1,300 studies

French, B., Nalbant, G., Wright, H., Sayal, K., Daley, D., Groom, M. J.,& Hall, C. L. (2024). The impacts associated with having ADHD: an umbrella review. *Frontiers in psychiatry*, *15*, 1343314.



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French B, Newell V, Nalbant G, Wright H, Daley D and Cassidy S (2026) Adverse outcomes for autistic people: an umbrella review of mental health, physical health, social and lifestyle domains. Front. Psychiatry 17:1702822. doi: 10.3389/fpsyt.2026.1702822)

Risks associated with undiagnosed autism/ADHD (French et al., 2023)

Mental and physical health

- **Depression**
- **Anxiety**
- Psychiatric inpatients
- Suicide
- Injuries
- Hospitalisation and GP visits

Offending behaviours

- Imprisonment
- **Substance abuse**
  - Drugs
  - Alcohol
  - Tobacco
- Antisocial behaviour

Day-today impact

- Driving
- **Lower education**
- Work
- Lower income
- Lower self-esteem
- Social and relationship issues

Study 2

Interviews

"Going Through Life on Hard Mode" (French & Cassidy, 2024)

Semi-structured interviews:

7 healthcare professionals

13 late-diagnosed adults (5 autistic, 5 with ADHD, and 3 with dual diagnoses)

Reflexive thematic analysis.

Themes

1

Impact on Mental Health:

Lifelong mental health struggles before diagnosis. Receiving a diagnosis can bring validation, hope, and strategies

2

Understanding is Empowering:

A framework to understand past difficulties and fostering self-acceptance

3

Relationships are Key:

Relationships are central to both struggles and support.

4

The Burden of a Label:

The diagnosis can also have a negative side, as it may be met with stigma, misconceptions, and judgment from others.

5

Timing is Crucial:

Emotional readiness is essential for a positive experience. Being unprepared can lead to feelings of anger or regret

Key message

Living without a diagnosis impacts individuals'
well-being,
relationships,
and sense of self,
often leading to years of struggle and self-blame.

RISKS (IDENTIFIED THROUGH INTERVIEWS AND ADVISORY GROUP)

Health	Sleep	Eating issues
Private healthcare, treatments	Feeling tired all the time	eating disorders
Forgotten healthcare appointments	Lack motivation	Food aversion
Alternative therapy	Energy	Forgetting to eat
		Craving sweet

Risky behaviour	Money	Jobs
Car accidents	Debt	Not the right jobs
Stealing things	Impulse spending	Start messing up
Sexual impulsivity	Need to have control	Office politics, scapegoat
One night stand	Lend money, give to partners	Sensory issue
Too many drugs, substance abuse	From pay cheque to pay cheque	Wrong career
Gambling		Difficulties working in teams
Drinking		Missed promotions
Smoking		Change jobs easily

Education	Mental Health	Relationship
Lower grades	Anxiety, depression, burn out	Relationships not working out, too intense
Dislike schools	Aggressive outburst	Lack of confidence to speak out, shy
Drop out	Affect sense of self, low self esteem	Hard to relate to people, immature
School work takes too long, have to study more	Self-destructive, Negative self-talk	Risky, abusive relationships
Breakdowns	OCD, panic disorder	Social awkwardness, too loud, too chatty
Don’t know how to revise	Low mood, mood swings	Didn’t fit in, misunderstood, lack of filter
Not gone as far as could have	Perfectionism, I should be doing better	Wanting to impress, unhealthy relationship, vulnerable
Wrong academic path	Overwhelmed and emotional, Can’t control emotions, nervous	Oversensitive, conflict, argumentative
No accommodation	Self-doubt, Too sensitive, being told that you are stupid	Not understanding social expectations, Misinterpret situations
Bullying	Something wrong with me, feeling useless, feeling broken	Not waiting in turn, no boundaries
Not engaging	Feeling different, not fitting in, insecurities	Falling out with people, few friends
	Feel like can’t cope, can’t keep going	Being late, forgetfulness
	Imposter syndrome, lack of confidence	

Risks identified in study 1 and 2

Education	Mental health	Relationship	Criminal system
Money	Work	Risky behaviour	Physical health: • Eating issues • sleep

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Costs associated with undiagnosed ADHD/autism

Study 3

Economic evaluation

Economic evaluation – Original proposal

- Three groups:
  - Adults diagnosed in childhood/ over 10 years
  - Adults diagnosed within 10 years
  - Undiagnosed adults
- Screening measures
  - ADHD/autism screening (ASRS, AQ-10)
- UK based
- Over 20 years old

Demographic

		Undiagnosed	< 10 years	>= 10 years
Participants (n=837)		**237**	**471**	**129**
Age Mean (SD)		42.5 (10.6)	40.6 (11.5)	39.7 (12.2)
Type	ADHD		126 (26.7%)	12 (9.3%)
	Autism		238 (50.5%)	81 (62.7%)
	Both		107 (22.7%)	36 (28%)
	Undiagnosed	237		
Sex at birth	**Female**	**204 (86.1%)**	**398 (84.5%)**	**88 (68.2%)**
	Male	**33 (13.9%)**	**73 (15.5%)**	**41 (31.8%)**
Ethnicity	White	218 (92.0%)	430 (91.3%)	115 (89.1%)
	Mixed	11 (4.6%)	19 (4.0%)	6 (4.7%)
	Asian	4 (1.7%)	11 (2.3%)	5 (3.9%)
	Black	3 (1.3%)	6 (1.3%)	1 (0.8%)
	Other	1 (0.4%)	5 (1.1%)	2 (1.6%)
Employment	Employed	185 (78.1%)	331 (70.3%)	75 (58.1%)

Reported diagnosis	Screening diagnosis		
	ADHD only	Autism only	Both
ADHD (n=138)	**64**	15	59
Autism (n=319)	6	**208**	105
Both (n=143)	8	35	**100**
Undiagnosed (n=237)	72	64	101

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Generalized linear regression models on four cost perspectives.
Controlled for age, sex, ethnicity, relationship status, and ASRS & AQ-10 clinically significant scores.

Cost group	H&SC	Public sector	Societal	Non-H&SC
Hospital costs	X	X	X	
Primary care costs	X	X	X	
Community mental health services costs	X	X	X	
Social care costs	X	X	X	
Community care costs	X	X	X	
Benefits		X		
Criminal justice		X	X	X
Lost productivity (income lost)			X	X
Lost tax revenue (tax income lost from unemployment)		X		

Greater use of certain services by the diagnosed group including:

- A&E and outpatient department services
- Community mental health services
- Some benefits receipt

Secondary supplementary analysis suggested that:

- Time from diagnosis had no impact on the costs of those diagnosed.
- Those diagnosed reported lower quality of life (EQ-5D-5L) but no impact was found on well-being (ONS4).

Why These results?

Findings consideration

Under powered?

Recruitment bias? (support group/databases)

Function (undiagnosed milder, diagnosed in childhood manage better)

Self selection

Group representation (female vs male, criminal justice)

Screening questionnaires?

Difficult to quantify?

How do you cost difficulties

Capturing softer factors in health economics

Self-report reliance

Different methodologies

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Qualitative versus quantitative data

Cohort data	Qualitative data	Survey
• Relies on reported data, missing key factors	• Understand barriers in accessing care and nuances.	• Self report, doesn't capture difficulties

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Conclusions and implications

- First study of its kind, something to build on
- Getting a diagnosis is helpful for some people
- We know it improves quality of life and outcomes but difficult to cost
- Difficulties
  - Difficult group to capture, difficult costs to capture
  - How do you show the impact of what didn't happen?
  - Differences in methodology show different findings
  - Changes in how we capture data?

Why These results?

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Researching the economic cost of undiagnosed neurodiversity today

Thank you

Any questions?