

# Children and young people with autism

Observational study of general health status  
in a whole country population

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- Existing research
- Scotland's Census 2011
- Main findings
- Conclusions

## Examples of findings from systematic reviews of recent studies on childhood/youth prevalence of autism

Review		N of studies	Publication dates of studies	Median prevalence /1,000	Range /1,000
<b>Autistic disorder</b>					
<b>French et al., 2013</b>	Autistic disorder	26	2000-2011	2.2	0.8-9.4
	Asperger syndrome*	13	1998-2011	2.1	0.5-2.8
<b>Elsabbagh et al., 2012</b>	Northern European	16	2000-2008	1.9	0.7-3.9
	Western Pacific	12	2000-2011	1.2	0.3-9.4
	South East Asia/East Mediterranean	0	-	-	-
	Americas	7	2001-2010	2.2	1.1-4.1
	Overall			1.7	0.3-9.4
<b>Tsai, 2014</b>		43	2001-2013	2.8	0.3-19.0
<b>Pervasive developmental disorder</b>					
<b>French et al., 2013</b>		34	2000-2011	6.2	0.6-26.4
<b>Elsabbagh et al., 2012</b>	Northern Europe	14	2000-2011	6.2	3.0-11.6
	Western Pacific	4	2004-2011	-	1.6-19.0
	South East Asia/East Mediterranean	4	2007-2012	-	0.1-10.7
	Americas	13	2001-2010	6.6	1.3-11.0
	Overall			6.2	0.1-19.0
<b>Tsai, 2014</b>		59	2000-2014	7.0	0.2-26.4
<b>Adak &amp; Halder, 2017</b>		25	2005-2015	9.2	0.7-26.4

\*The authors comment on dubious quality of results

## Age of diagnosis:

- seems little investigated;
- USA study demonstrated that rates of autism diagnosis increasing with age, particularly amongst preschool children;<sup>1</sup>
- Swedish study found number of autism symptoms in children diagnosed with autism falling at age 7-12 years, but not at age 1-6 years;<sup>2</sup>
- National Survey of Children's Health, USA: 259 (24.6%) of children with autism diagnosed at <3 years of age, 479 (44.5%) at 3-5 years, and 383 (30.9%) at >5 years;<sup>3</sup>
- a critical review has suggested a considerable variation in age at diagnosis.<sup>4</sup>

1. Hertz-Picciotto I and Delwiche L. The Rise in Autism and the Role of Age at Diagnosis. *Epidemiology* 2009;20(1):84-90.

2. Arvidsson O, Gillberg C, Lichtenstein P, et al. Secular changes in the symptom level of clinically diagnosed autism. *Journal of Child Psychology and Psychiatry* 2018; doi:10.1111/jcpp.12864

3. Data Resource Center for Child & Adolescent Health. *National Survey of Children's Health; 2016*. Available at: <http://childhealthdata.org/browse/survey>

4. Daniels AM and Mandell DS. Explaining differences in age at autism spectrum disorder diagnosis: A critical review. *Autism* 2014;18(5):583-597.

## General health status of children and young people with autism:

- very little existing research
- USA study<sup>1</sup> reported parent-rated general health for 895 young people with autism aged 13-25 years at baseline, at five time points across 2001-2009:
  - no general population comparison group;
  - general health rated as excellent, very good, good, or fair/poor;
  - fair/poor ratings reported for 6.6% in 2001, 6.4% in 2003, 7.6% in 2005, 6.1% in 2007, and 6.6% in 2009.

1. National Longitudinal Transition Study 2 (NLTS2). *Data Tables NLTS2 Waves 1 – 5; 2017*. Available at: [http://www.nlts2.org/data\\_tables/index.html](http://www.nlts2.org/data_tables/index.html)

## About the Census

- held once every 10 years by the National Records of Scotland
- a snapshot of all people in Scotland on one night
- Scotland's Census 2011 was held on 27<sup>th</sup> March 2011
- autism was self/proxy-reported
- 94% response rate with remaining 6% imputed

## Analysis

- descriptive statistics for the population with and without autism
- logistic regression with odds ratios (OR; with 95% confidence intervals) of autism predicting poor health in the whole population, adjusted for age and gender
- ORs for age and gender predicting poor health within the population with autism
- two age groups of 0-15 and 16-24-year olds, with 0-15-year olds as the reference group
- gender was a binary variable, with males as the reference group
- SPSS software version 22

# How is your health in general?

- Very good
- Good
- Fair
- Bad
- Very bad



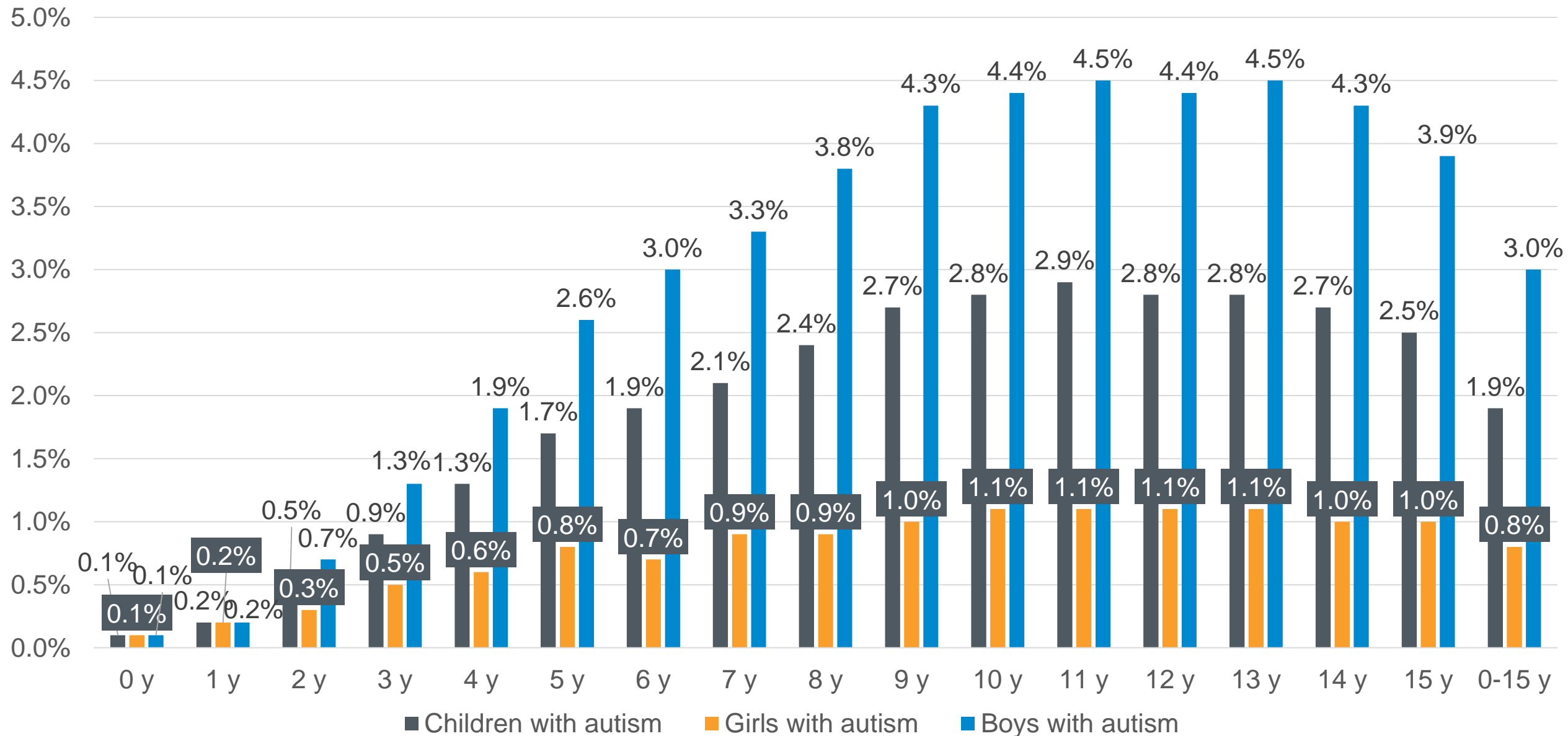
Poor health

## Study population:

- 5,295,403 people;
- 916,331 children aged 0-15 years:
  - 17,348 (1.9%) had autism;
- 632,488 young people aged 16-24 years:
  - 7,715 (1.2%) had autism;
- 25,063/1,548,819 (1.6%) of all children and young people had autism;
- 766,109 (50.3%) males and 757,647 (49.7%) females without autism;
- 19,880 (79.3%) males and 5,183 (20.7%) females with autism.

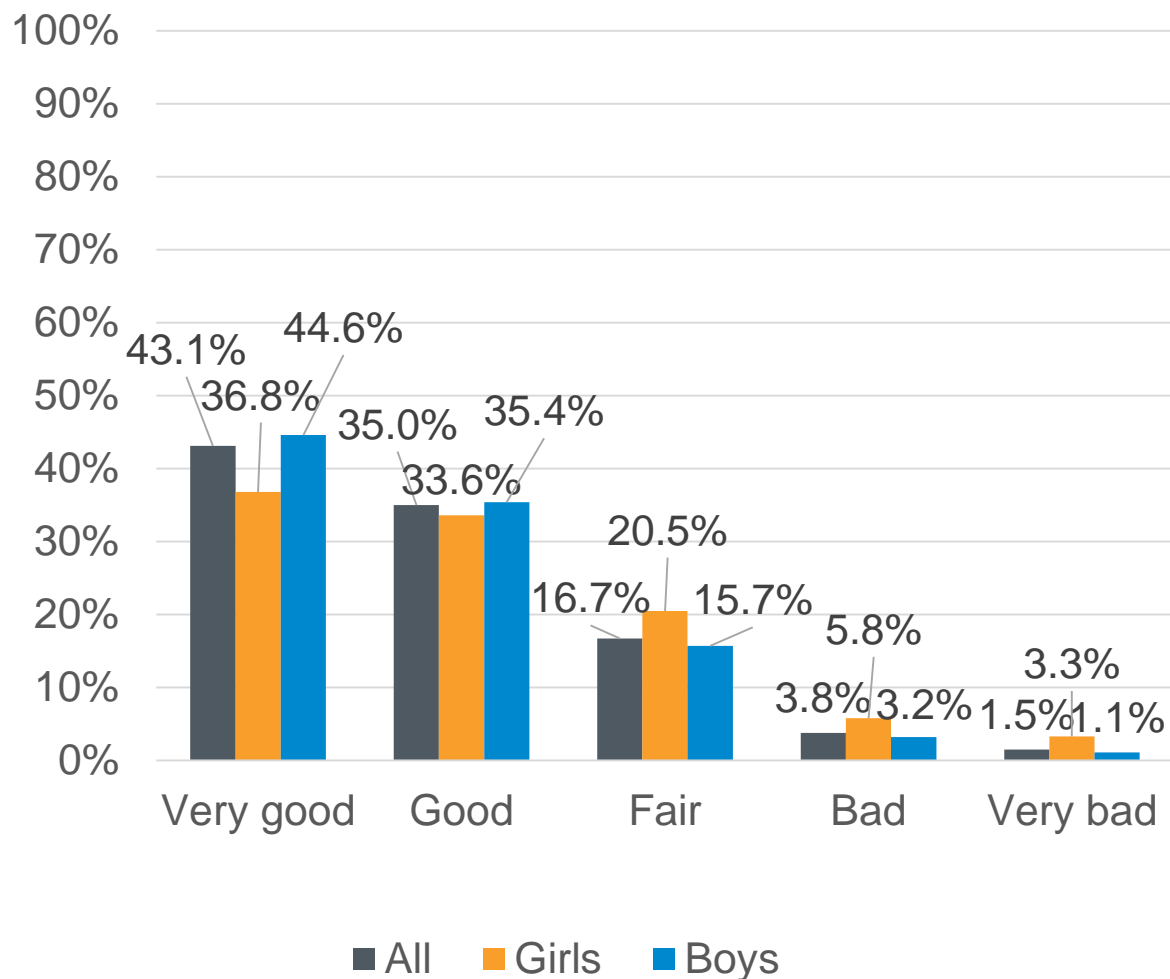


# Prevalence of autism in children

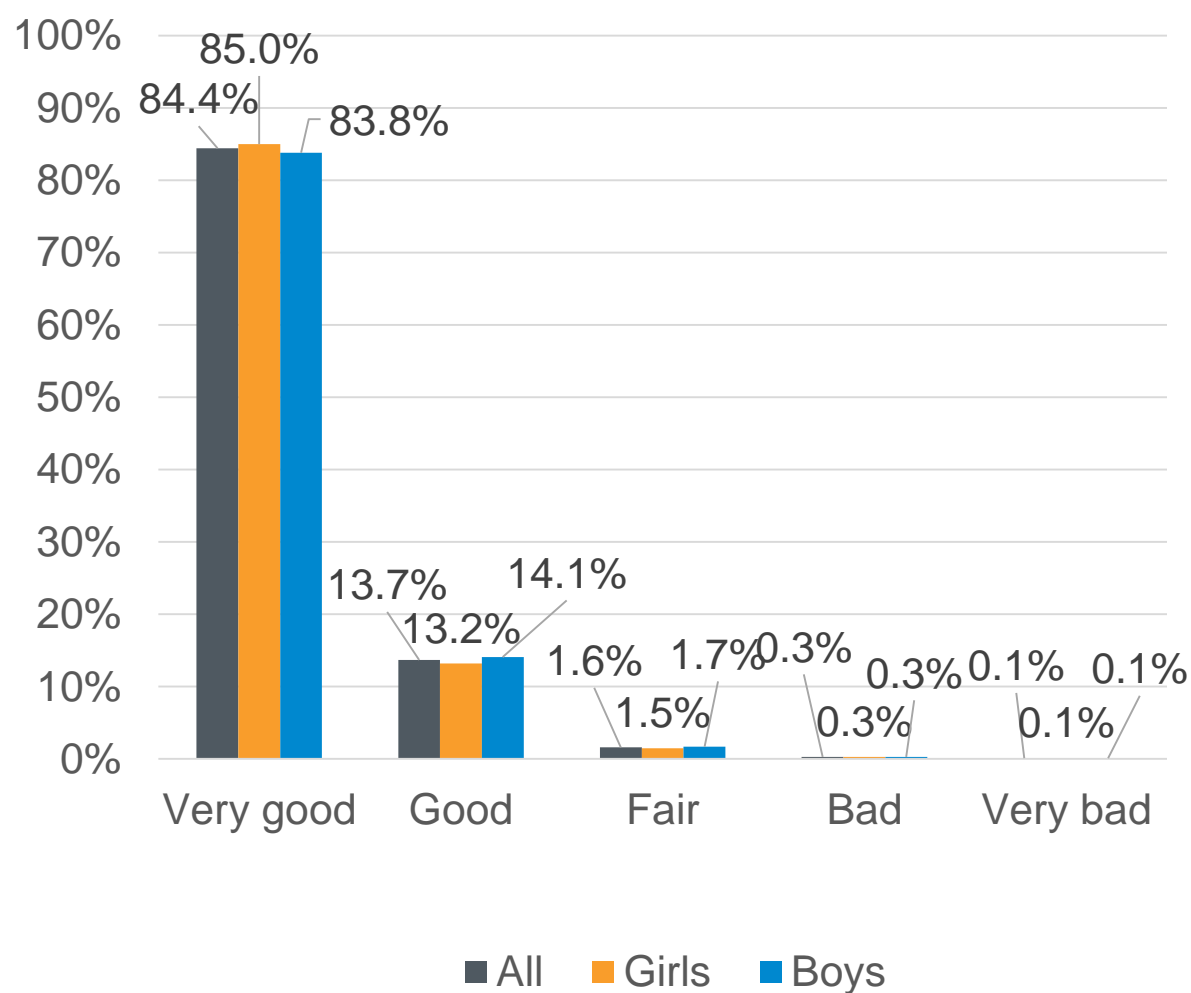


# General health status in the population of children

## Health of children with autism

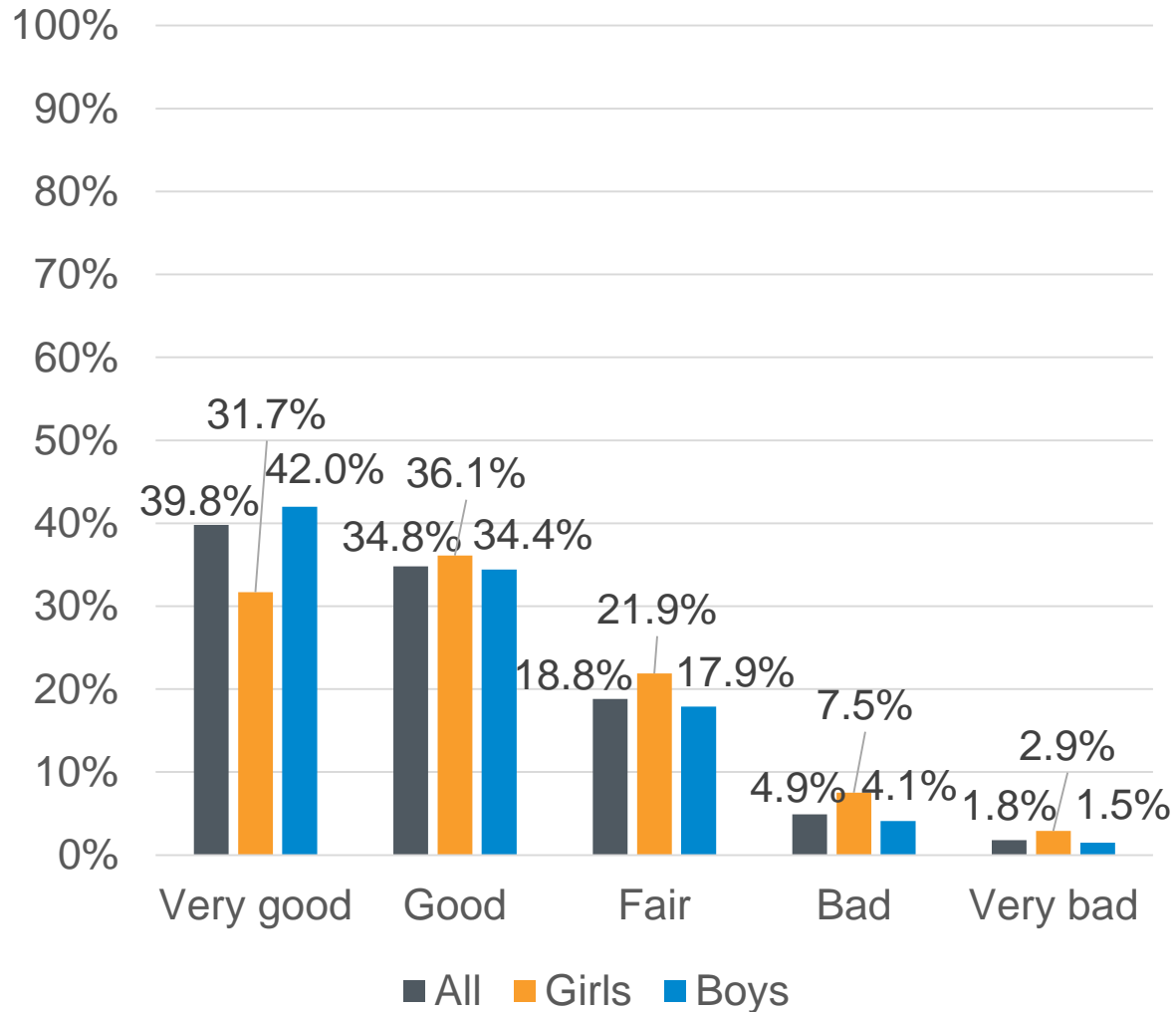


## Health of children without autism

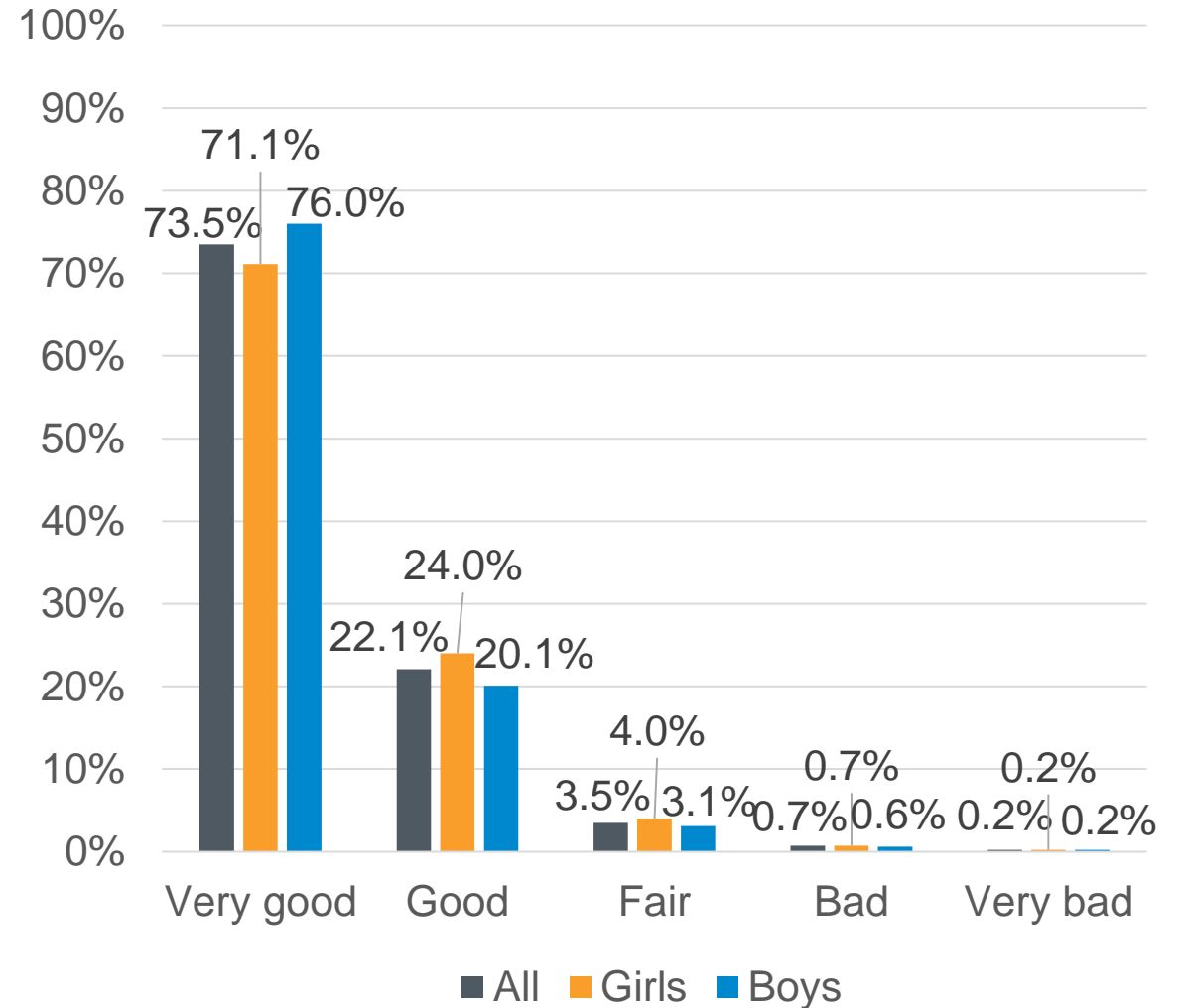


# General health status in the population of young people

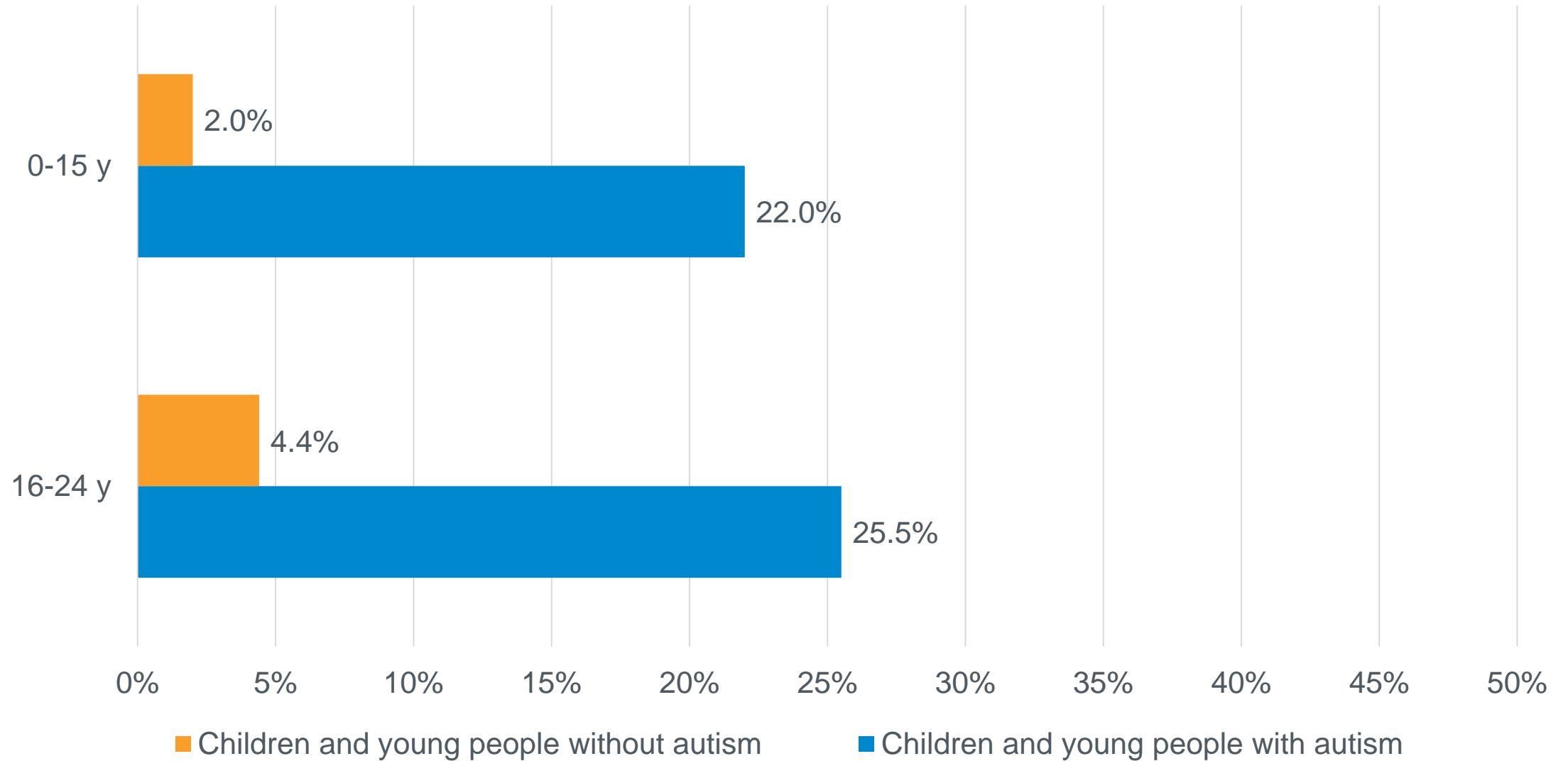
## Health of young people with autism



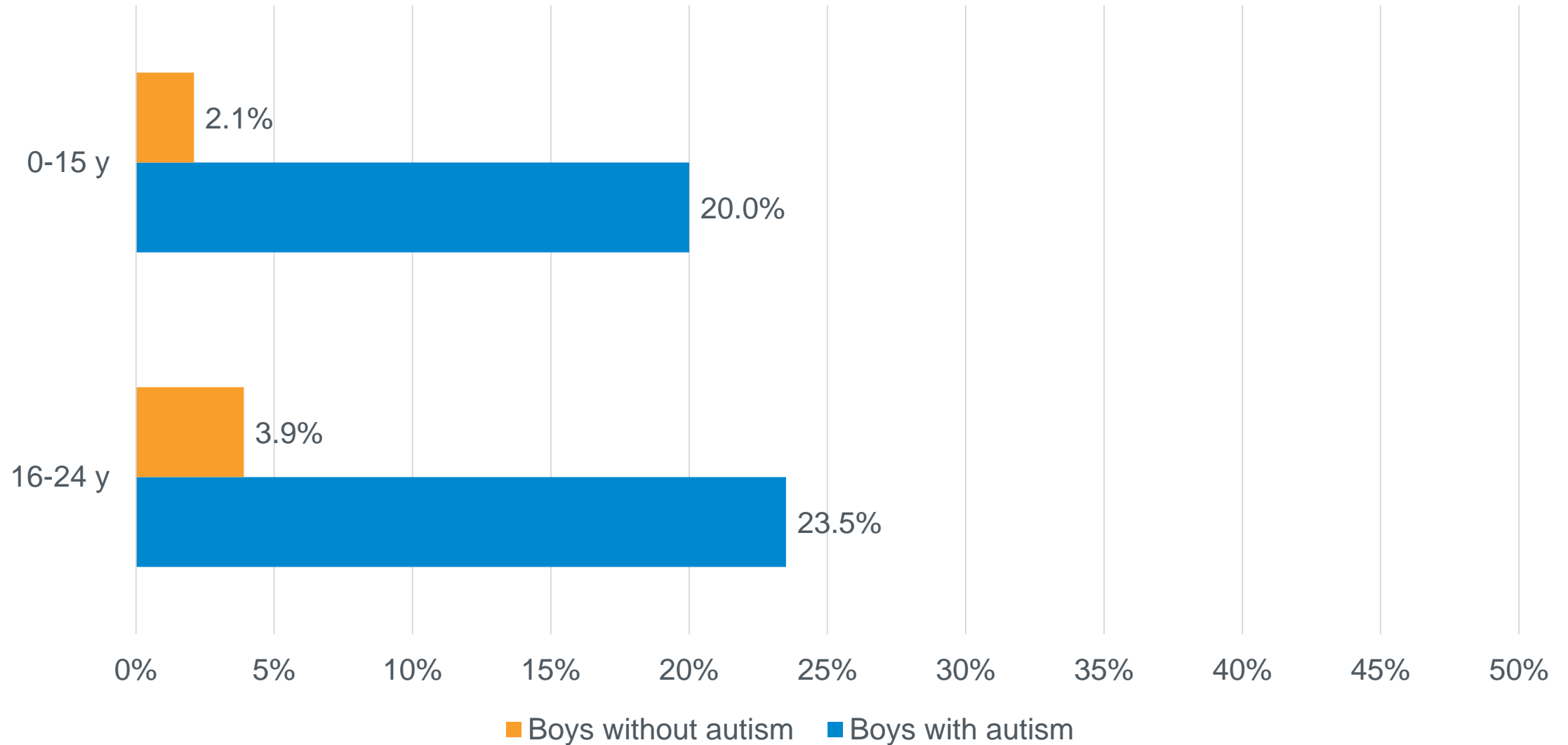
## Health of young people without autism



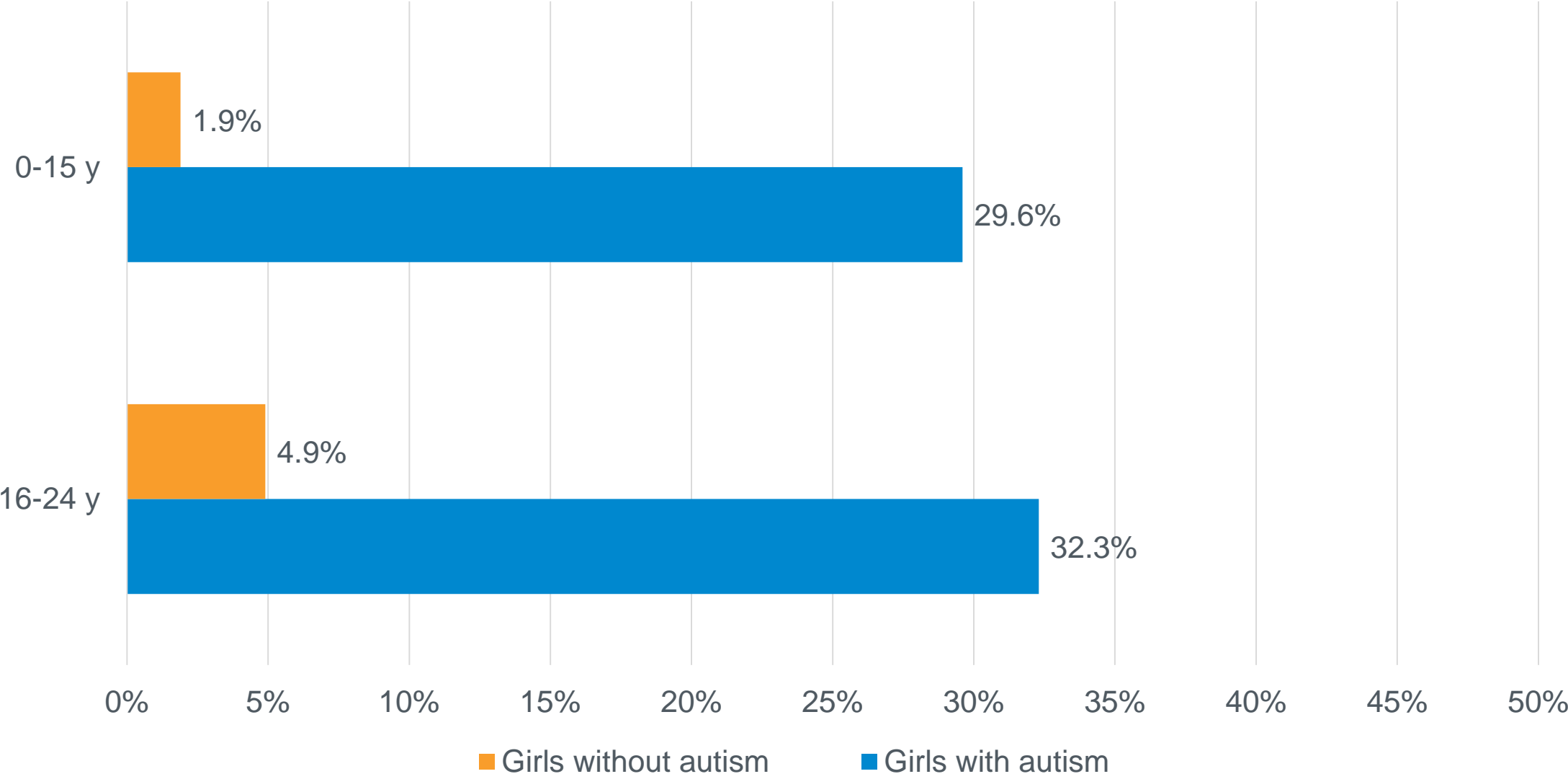
## Proportion of children and young people with and without autism reporting poor health by age



## Proportion of boys with and without autism reporting poor health by age



# Proportion of girls with and without autism reporting poor health by age



Odds ratio of autism, age, and gender in predicting poor health in the whole population of children and young people

Variable	OR	95% CI
Autism	11.339	10.983-11.707
Aged 16-24	2.137	2.098-2.176
Female gender	1.126	1.106-1.147

Odds ratios of age and gender in predicting poor health in the population of children and young people with autism

Variable	OR	95% CI
Aged 16-24	1.206	1.133-1.284
Female gender	1.635	1.527-1.750



# Conclusions

## Prevalence and age of diagnosis

- 1.9% autism prevalence in children aged 0-15 years;
- reported rate increased with age up to age 10 years in girls and 11 years in boys, reflecting the age of diagnosis;
- almost all children identified by age 9 years, with the majority before primary school;
- 2.8% prevalence at age 10 years, and 2.9% at age 11 years, so higher than rate reported for all children;
- higher rate of autism than that in the most recent systematic reviews on the subject;
- our data more recent (2011) and reported by year of age;
  - Stockholm Youth Cohort reported rates of autism in 2011 of 0.40% at age 0-5 years, 1.74% at age 6-12 years, 2.46% at age 13-17 years, and 1.76% at age 18-27 years (1.44% at ages 0-17 years);<sup>1</sup>
  - Data Resource Center for Child & Adolescent Health findings for 2014<sup>2</sup> and 2016<sup>3</sup> report higher prevalence of autism at 2.2% (n=243) and 2.5% (n=1,131) in all 3-17 year olds, but on a smaller scale;
  - autism prevalence estimates range of 1.3-2.9%, with a combined prevalence of 1.7% for 11 ADDM Network sites of 8 year old children in 2014.<sup>4</sup>

1. Idring S, Lundberg M, Sturn H, et al. Changes in prevalence of autism spectrum disorders in 2001–2011: Findings from the Stockholm Youth Cohort. *Journal of Autism Developmental Disorders* 2015;45: 1766–1773.
2. Data Resource Center for Child & Adolescent Health. *National Health Interview Survey (NHIS) – Child; 2014*. Available at: <http://childhealthdata.org/browse/survey>
3. Data Resource Center for Child & Adolescent Health. *National Survey of Children’s Health; 2016*. Available at: <http://childhealthdata.org/browse/survey>
4. Centres for Disease Control and Prevention (2018) Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *Surveillance Summaries* 2018;67(6):1-23.

# Conclusions

## General health

- health substantially poorer for children and young people with autism;
- possibly first study to directly compare general health status with the general population in a large, representative population of children and young people with autism;
- 22.0% of children and 25.5% of young people with autism and 2.0% of children and 4.4% of young people without autism had poor health;
- similar to National Health Interview Survey in 2014 which found fair/poor health for 1.6% (n=234) of children aged 0-17 years,<sup>1</sup> but no findings reported separately for children with autism;
- USA study reported fair/poor health for 6.6% in 2001, 6.4% in 2003, 7.6% in 2005, 6.1% in 2007, and 6.6% in 2009 of 895 young people with autism aged 13-25 years at baseline, but no general population comparison group and four-point scale of excellent, very good, good, and fair/poor health.<sup>2</sup>

1. Data Resource Center for Child & Adolescent Health. *National Health Interview Survey (NHIS) – Child; 2014*. Available at: <http://childhealthdata.org/browse/survey>

2. National Longitudinal Transition Study 2 (NLTS2). *Data Tables NLTS2 Waves 1 – 5; 2017*. Available at: [http://www.nlts2.org/data\\_tables/index.html](http://www.nlts2.org/data_tables/index.html)

**Thank  
You.**



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