Tackling early death in autism
About Autistica

• The UK’s leading autism research charity

• We want to give everyone affected by autism the chance of a long, happy, healthy life

• Our research strategy is driven by the views of the autism community
Overview

- The data on mortality in autism
- New research directions
- Autistica’s report and campaign
- Policy, information and awareness
- Developing a global response
Data on mortality

• The largest ever autism mortality study (ASD n = 27,122; matched controls n = 2,672,185) was recently published, finding increased risk of early death in autism, OR:2.56 (2.38-2.76) (Hirvikoski et al., 2015).

• Autistic and intellectually disabled at highest risk of early death (OR: 5.78) with neurological conditions (epilepsy) the leading cause (OR: 40.56)

• In autistic people with no intellectual disability increased risk of death is also found (OR: 2.18) with suicide being a leading cause (OR: 9.40).

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Total n</th>
<th>Risk ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mouridsen</td>
<td>Denmark</td>
<td>341</td>
<td>1.9 (1.3-2.8)</td>
</tr>
<tr>
<td>Pickett</td>
<td>USA</td>
<td>13111</td>
<td>2.5</td>
</tr>
<tr>
<td>Gillberg</td>
<td>Sweden</td>
<td>120</td>
<td>5.6 (2.5-10.5)</td>
</tr>
<tr>
<td>Bilder</td>
<td>USA</td>
<td>305</td>
<td>9.9 (5.7-17.2)</td>
</tr>
<tr>
<td>Schendel</td>
<td>Denmark</td>
<td>20,492</td>
<td>2.0 (1.4-3.0)</td>
</tr>
</tbody>
</table>

Data from other studies on mortality
Autism and epilepsy

• 20-40% of autistic people also end up having epilepsy (Bolton et al., 2011)

• Altered developmental trajectory, often occurring later.

• Seizures may be more frequent in frontal lobe/social centres, resistant to treatment, harder to identify.
Mental Health and Suicide

• Autistic children are at increased risk of mental health problems: 70% having one; 40% having two or more (Simonoff et al., 2008). Approximately half of 5-10 year olds have an anxiety disorder.

• 80% of adults have reported having a psychiatric disorder. 57.2% reported having depression, 53.2% anxiety (Lever & Geurts, 2016)

• 66% of autistic adults with no intellectual disability have considered suicide. 35% have made plans or attempts at suicide (Cassidy et al., 2014).
Other causes of death

Autistic people experience worse physical health than the general population and are at significantly increased risk of heart disease, stroke, diabetes and respiratory conditions.

Causes are complex and poorly understood but likely to be multifactorial.

<table>
<thead>
<tr>
<th>Causes</th>
<th>Odds Risk</th>
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<tbody>
<tr>
<td>Circulatory</td>
<td>1.49 (1.27-1.75)</td>
</tr>
<tr>
<td>Congenital</td>
<td>19.10 (11.94-30.55)</td>
</tr>
<tr>
<td>Digestive</td>
<td>3.31 (2.25-4.87)</td>
</tr>
<tr>
<td>Endocrine</td>
<td>3.70 (2.34-587)</td>
</tr>
<tr>
<td>Neoplasms</td>
<td>1.80 (1.46-2.23)</td>
</tr>
<tr>
<td>Respiratory</td>
<td>2.68 (1.99-3.62)</td>
</tr>
</tbody>
</table>

*Hirvikoski et al., 2015*

<table>
<thead>
<tr>
<th>Illnesses</th>
<th>Odds Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular disease</td>
<td>2.54 (2.13-3.02)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>2.18 (1.62-2.93)</td>
</tr>
<tr>
<td>Parkinson’s</td>
<td>32.73 (7.76-137.96)</td>
</tr>
<tr>
<td>Stroke</td>
<td>2.12 (1.03-4.37)</td>
</tr>
</tbody>
</table>

*Croen et al., 2015*
We aim to raise and leverage £10m in five years to fund new research into epilepsy, suicide and the other major causes of death for autistic people.
Autistica’s scientific response

Why?
Scoping research need
The solution
Potential Research
The result

Epilepsy
Suicide
Other diseases

Full translational spectrum
Risk factors, prevention strategies
Risk factors, health services, social care

Each area: stakeholder meetings to develop research strategy

Open competition for a centre, novel treatment trials
Network, small grants aimed towards prevention
Applied health and social care research

The result

Autistic people will live longer, happier, healthier lives.
The need for a global response

We cannot tackle this enormous challenge alone.

Autistica has committed to raise awareness of this shocking situation, first in the UK and Europe and now internationally.

Our first report in March 2016 aimed to:

• Raise awareness of the hidden mortality crisis
• Increase other funders’ investment in research
• Ensure services actively reduce premature death
• Make recommendations for action by politicians
Influencing policymakers

We are calling for:
• Premature deaths in autism to be a national priority
• Better data collection and analysis
• Better support for autistic people (health checks, risk plans, screening, new therapies)
• More training for healthcare professionals
• More research
Influencing policymakers

In the UK, we have:

• Secured autism as a theme in a National Mortality Review
• Published a Parliamentary Commission report on early death and access to healthcare
• Improved autism data collection by doctors
• Integrated autism into the National Suicide Prevention Alliance and a national suicide enquiry
• Met leading politicians and civil servants
• Held a three hour debate in Parliament
Awareness

Over 120 newspapers, TV and radio stations and news websites have covered the issue

We briefed the leading UK autism charities and presented our report at Autism Europe Congress 2016

We continue to spread the word nationally and internationally
Information

This is new to the vast majority of the autism community

We must take care how and when we communicate the risks, be clear on what we do and don’t yet know, and be sensitive to autistic people’s needs

We are soon to publish new information resources for individuals and families
Driving a global response

Together, we should be aiming to give everyone affected by autism the chance of a long, happy, healthy life

- New basic, translational and epidemiological studies
- International collaborations to accelerate progress
- Open source resources for the autism community
- Coordinated policy responses