

Tackling early death in autism

Dr James Cusack & Jon Spiers, October 2016

AUTISTICA
Building brighter futures through autism research

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

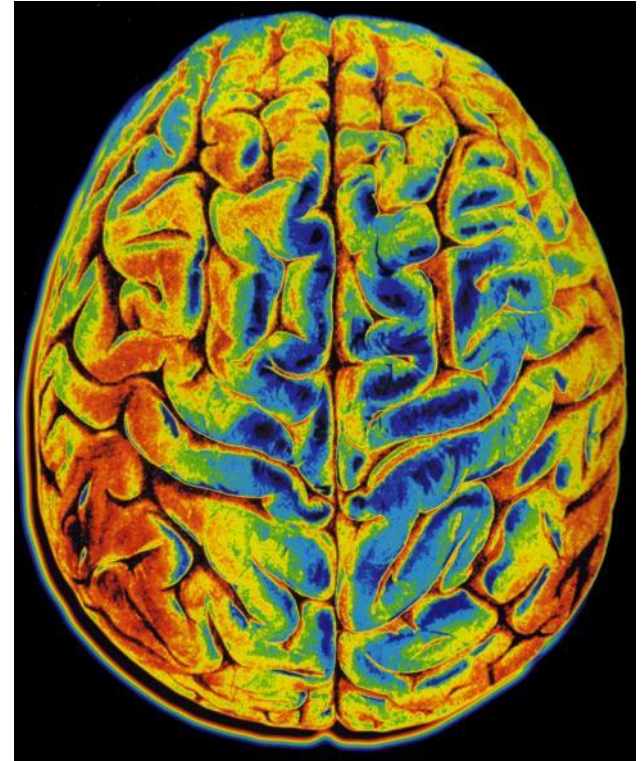
- The largest ever autism mortality study (ASD n = 27,122; matched controls n = 2,672,185) was recently published, finding increased risk of early death in autism, OR:2.56 (2.38-2.76) (Hirvikoski et al., 2015).
- Autistic and intellectually disabled at highest risk of early death (OR: 5.78) with neurological 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).

Study	Country	Total n ASD	Risk ratio
Mouridsen	Denmark	341	1.9 (1.3-2.8)
Pickett	USA	13111	2.5
Gillberg	Sweden	120	5.6 (2.5-10.5)
Bilder	USA	305	9.9 (5.7-17.2)
Schendel	Denmark	20,492	2.0 (1.4-3.0)

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 multi-factorial.

Causes	Odds Risk
Circulatory	1.49 (1.27-1.75)
Congenital	19.10 (11.94-30.55)
Digestive	3.31 (2.25-4.87)
Endocrine	3.70 (2.34-5.87)
Neoplasms	1.80 (1.46-2.23)
Respiratory	2.68 (1.99-3.62)

Hirvikoski et al., 2015

Illnesses	Odds Risk
Cardiovascular disease	2.54 (2.13-3.02)
Diabetes	2.18 (1.62-2.93)
Parkinson's	32.73 (7.76-137.96)
Stroke	2.12 (1.03-4.37)

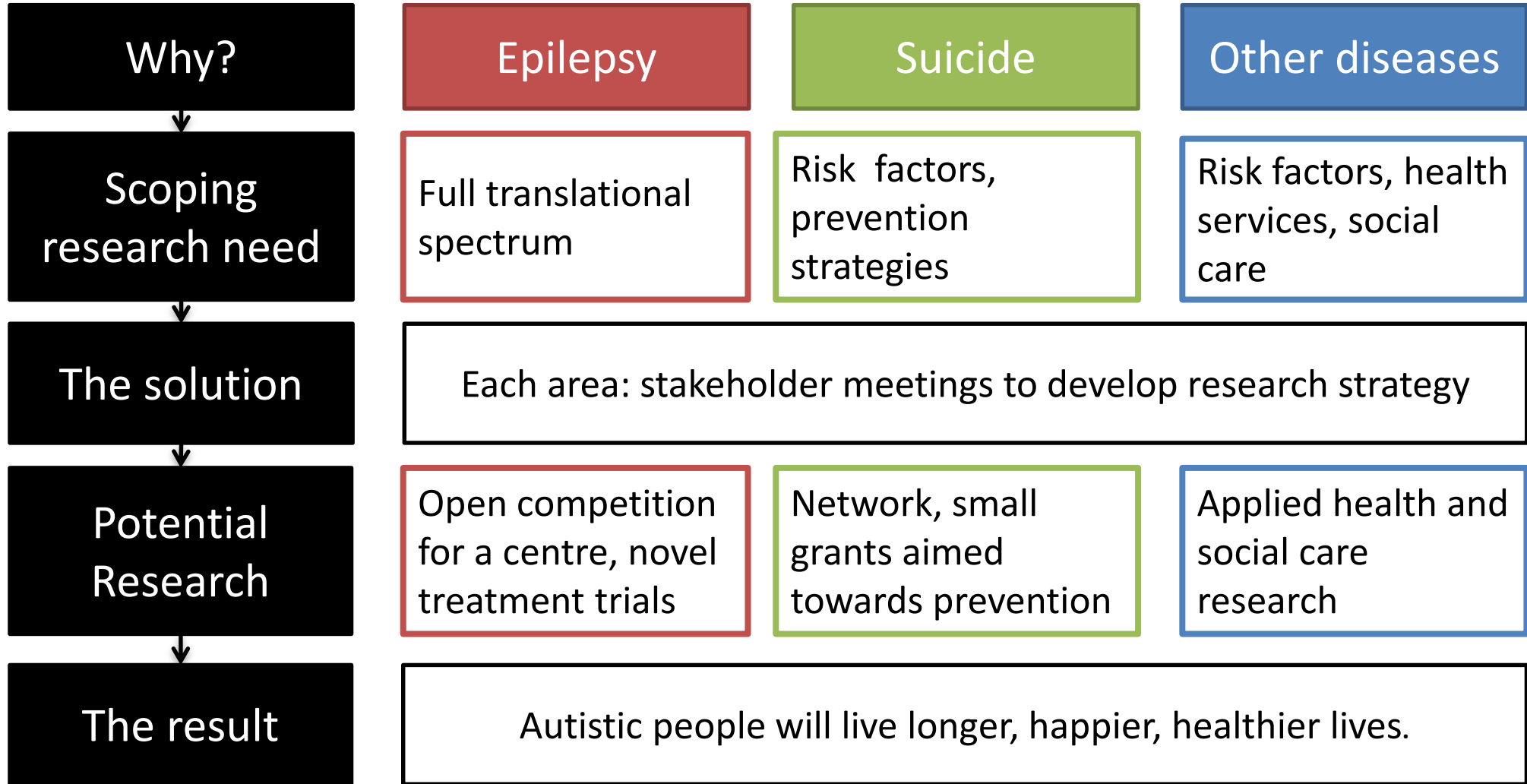
Croen et al., 2015

Autistica's scientific response



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



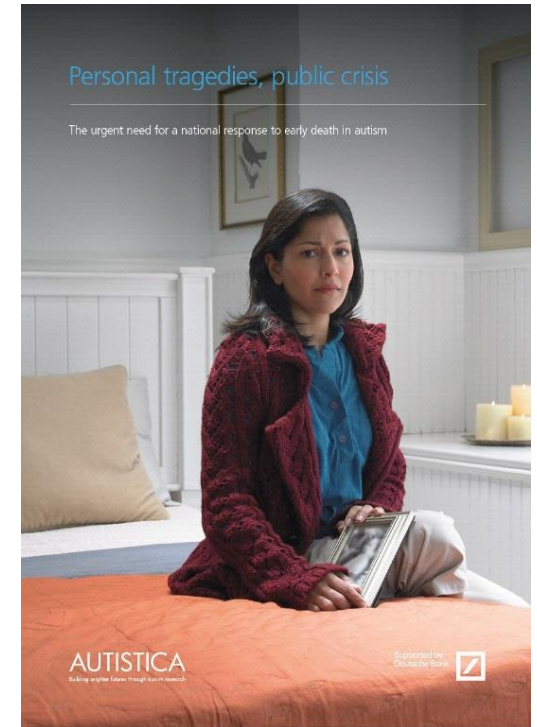
The need for a global response

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

