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# Mortality in Autism & Epilepsy

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# Mortality in Autism

## **Mortality in Autism: A Prospective Longitudinal Community-Based Study**

Christopher Gillberg · Eva Billstedt ·  
Valter Sundh · I. Carina Gillberg

J Autism Dev Disord (2010) 40:352–357

- 120 individuals with autism followed longitudinally
- Individuals were between 23-46 years of age
- 9/120 (7.5%) had died; expected mortality = 1.62 deaths
- Mortality rate was increased six-fold



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## Characteristics of individuals who had died:

- 8/9 had severe intellectual disability
- 1 had seizures and average intellectual abilities
- More likely to have a medical disorder, including epilepsy
- 1 accidental death due to drowning



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# Mortality in Autism & Epilepsy

## **Mortality in Individuals With Autism, With and Without Epilepsy**

Jane Pickett, PhD<sup>1</sup>, Ellen Xiu, MS<sup>2</sup>, Roberto Tuchman, MD<sup>3</sup>,  
Geraldine Dawson, PhD<sup>4</sup>, and Clara Lajonchere, PhD<sup>5</sup>

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- Previous findings suggest that co-morbidity with epilepsy is a factor in excess deaths in ASD.
- Data from Autism Speaks' Autism Tissue Program show that ~ 1/3 of brain donors with autism also had epilepsy.
- Analysis of new data from the California State Department of Developmental Services shows that there is a higher than expected rate of mortality in individuals with ASD and epilepsy than ASD alone.



# California DDS Mortality Data

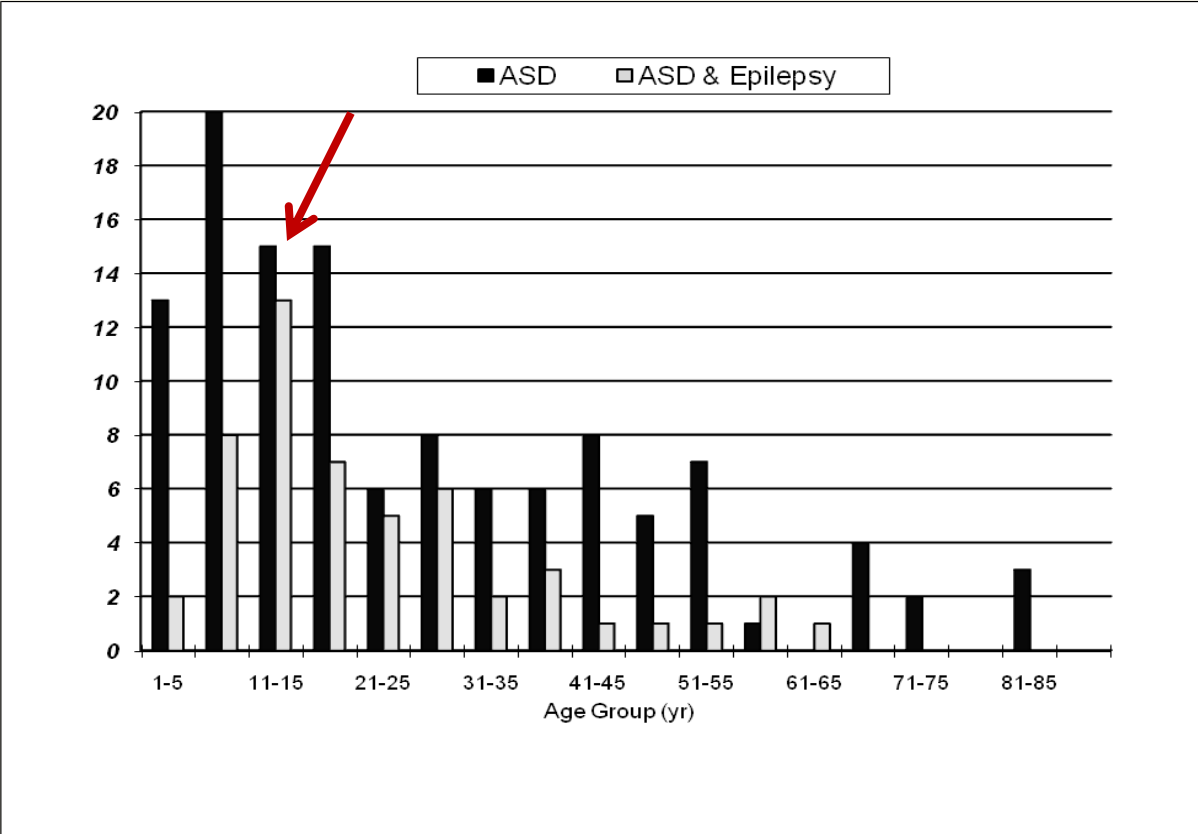
DDS SIRs (Special Incidence Reports) numbers of deceased and crude mortality rate.

	Year:	#deaths/group	Crude Death Rate
Autism:	2007	23/34,364	0.7
	2009	37/47,376	0.8
ASD-epilepsy:	2007	13/2,228	5.8
	2009	19/2,853	6.6
Epilepsy:	2007	523/35,659	14.7
	2009	533/35,134	15.2

Abbreviations: ASD: Autism Spectrum Disorder; DDS: Department of Developmental Services

# Snapshot of ASD brain donors with and without epilepsy by age

Data from ATP portal (11/2010); epilepsy rate reaches almost half by ages 11-15



# Cause of death is often unknown

CA DDS Death Type		ASD		ASD & Epilepsy		Epilepsy	
		#	%	#	%	#	%
<b>Category 1: Disease Related</b>		10	43%	7	47%	322	58%
<b>Category II: Non-Disease Related</b>	Abuse	0	0	0	0	0	0
	Accident	1	4%	0	0	22	4%
	Fire/Flood	0	0	0	0	1	<1%
	Cause Unknown	8	35%	6	40%	151	27%
	Homicide	0	0	0	0	1	<1%
	Other	3	13%	2	13%	60	11%
	Suicide	1	4%	0	0	0	0
	Substance Abuse	0	0	0	0	0	0
	Subtotal	13	57%	8	53%	235	42%
Totals Category 1&2		23	100%	15	100%	557	100%



# CONCLUSIONS

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- Mortality rates are higher in individuals with ASD and epilepsy than those with ASD alone.
- There is a need for accurate, complete and accessible records of the cause of death to increase our understanding of risk factors that contribute to early death in individuals with ASD.
- Better understanding of the factors that contribute to increased mortality rates in ASD could inform prevention efforts.
- National healthcare, state developmental disability agency and advocacy initiatives to reduce risk of mortality in people with ASD are needed.