

Letter to the Editor

Dear Editor:

**1998–2002 Update on “Causes of Death in Autism”**

In this journal we previously reported standardized mortality ratios (SMRs) for persons with autism in the California Developmental Disability System (DDS) over the period 1983–1997 and investigated which causes of death were elevated in this population (Shavelle, Strauss, & Pickett, 2001). To confirm these results we analyzed data for a more recent 5-year span, 1998–2002.

As before, excess mortality was observed. Table I shows an overall SMR of 2.6 for 1998–2002 compared with 2.4 in 1983–1997. The overall SMR for males was higher (2.3 compared with 1.7) but for females it was slightly lower (5.2 compared with 5.5). These differences were not statistically significant. Table II shows the number of deaths for the two time periods.

Previously we reported an SMR of 16.8 for females aged 5–10. The corresponding SMR for 1998–2002 of 3.1 is based on one reported death and is likely to be affected by random variation. However,

the overall SMR trend for females remains high and further investigation of all subject groups is needed. More than a third of Special Incidence Reports (SIR) of California subject deaths in the first 6 months of 2002 had insufficient information about the cause of death and up to 10% of deaths were ‘undetermined’ (no cause found) even after autopsy (CA DDS, 2002). In 2003 the state of California adopted more stringent criteria to track mortality using the SIR. This measure is expected to provide more detailed incidence information and a better understanding of causes of death in those individuals with autism and other developmental disorders.

In the process of investigating the 1998–2002 data we also re-examined the earlier data from 1983–1997. A key finding is that 1284 persons of the 13,111 clients diagnosed with autism went more than 3 years without receiving an additional Client Development Evaluation Report (CDER), contrary to the exclusion rule limiting exposure time to 3 years specified in point 2(c) on page 570. Correctly limiting the

**Table I.** Standardized Mortality Ratios (SMRs) for California Male and Female DDS Clients in the Initial and Later Time Period

Ages	Males		Females		Overall	
	1983–1997	1998–2002	1983–1997	1998–2002	1983–1997	1998–2002
2–5	2.3	1.8	3.0	0.0	2.4	1.6
5–10	3.5	2.1	16.8	3.1	5.4	2.2
10–20	2.3	3.3	9.2	6.2	3.0	3.6
20+	1.7	2.2	5.3	5.7	2.1	2.5
All	1.7	2.3	5.5	5.2	2.4	2.6

**Table II.** Observed Number of Deaths for California Male and Female DDS Clients in the Initial and Later Time Period

Ages	Males		Females		Overall	
	1983–1997	1998–2002	1983–1997	1998–2002	1983–1997	1998–2002
2–5	4	2	1	0	5	2
5–10	11	4	9	1	20	5
10–20	30	13	13	2	43	15
20+	98	43	36	13	134	56
All	143	62	59	16	202	78

exposure time to 3 years led to small changes in the SMRs (details available from the first author).

These studies were undertaken to understand mortality in autism as it relates health and safety issues as well as to the neuropathic study of donated brain tissue. The Autism Tissue Program continues to encourage brain donation by those with autism spectrum disorders and non-affected individuals for comparison. For information please visit [www.MemoriesofHope.org](http://www.MemoriesofHope.org) or call 1-877-333-0999.

## REFERENCES

CA DDS 2002. Biannual Summary of Community Based Client Mortality, [http://www.dds.ca.gov/mortality/mortality\\_home.cfm](http://www.dds.ca.gov/mortality/mortality_home.cfm).

Shavelle, R. M., Strauss, D. J., & Pickett, J. (2001). Causes of death in autism. *Journal of Autism and Developmental Disorders*, 31, 569–576.

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