

# The Mortality Issue



# Death Rates: Institution Versus Community

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- 📄 In 1996, a few researchers published a paper
- 📄 It claimed that death rates were higher in California's community homes than in the institutions
- 📄 Using a lot of complex math, they said death rate in community was 72% higher than in the institutions
- 📄 (Also 72% higher in FAMILY homes than in the institutions -- !!! No one noticed this finding. More about that later.)

# The First Study

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- 📄 Strauss, D., & Kastner, T. (1996).  
Comparative Mortality of People with  
Mental Retardation in Institutions and the  
Community. *American Journal on Mental  
Retardation*, 101, 1, 26-40.

# Impact – Courts & Media

- ☞ This paper led to later papers
- ☞ Altogether 7 published studies (Citations)
- ☞ This body of work became a “death scare”
- ☞ Tactic used in every deinstitutionalization case
- ☞ Voice of the Retarded hired and paid:
  - Lawyers (Bill Sherman, Tom York)
  - Researchers (Ted Kastner, Kevin Walsh)
- ☞ They made sure the death scare was entered into every court record
- ☞ And they sought wide media attention
- ☞ Most recently raised in a joint legislative session on closures in New Jersey (by shouting advocates)

# “Deadly Push to Discharge From State Asylums”

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- 📄 San Francisco Chronicle, front page headline, February 25, 1997
- 📄 2,000 copies in CA Senate hearing room 9am
- 📄 One researcher at UC Riverside
- 📄 45 deaths, 2.5 years, 1800 people who had moved from institution to community
- 📄 Author Lempinen did series of more than 20 anti-community stories (applied for Pulitzer with revised headline)

# The Entire Foundation of the Strauss Studies: DC Mortality

- ☞ All of the Strauss & Kastner mortality models are founded on their estimate of the Developmental Center (DC) mortality rate
- ☞ In his original 1996 study, Strauss & Kastner reported DC mortality as **16.0 per 1,000 per year**
- ☞ The California state agency (DDS) actually counted each death, by name and date, and reported **18.2 per thousand per year**
- ☞ There are more details & fine print
- ☞ But let's just take that one fact for now

# Which Figure Was Right?

☞ Lakin, K.C. (1999).

- Observations on the California Mortality Studies. *Mental Retardation*, 36, 395-400.

☞ The California state agency (DDS) counted 1,244 deaths in institutions during the Strauss & Kastner study period

☞ That was about 149 **MORE** than Strauss & Kastner “counted.”

☞ Would a state agency report MORE deaths than actually occurred?

☞ The Strauss & Kastner count was somehow incorrect.

☞ What happened?

# What Was the Cause?

- ☞ Strauss & Kastner obtained all mortality data from the California Department of Health Services
  - These Vital Statistics tapes contained all deaths in the state, including locations
- ☞ A standard practice at California institutions:
- ☞ **People who were dying were moved to local community hospitals for specialized intensive care**
- ☞ When they died in these community hospitals, Strauss & Kastner counted them as “community deaths”
- ☞ They were **not counted** as institutional DC deaths
- ☞ So Strauss & Kastner counted about 149 institutional deaths as if they were community deaths!

# The Foundation of the Work was Fatally Flawed



- By this elementary blunder...
- Strauss & Kastner made a gross underestimate of DC mortality
- This made all subsequent multiple regression models and comparisons invalid
- The true situation is likely to be the opposite of Strauss & Kastner's conclusions

# Add a Dash of Common Sense...

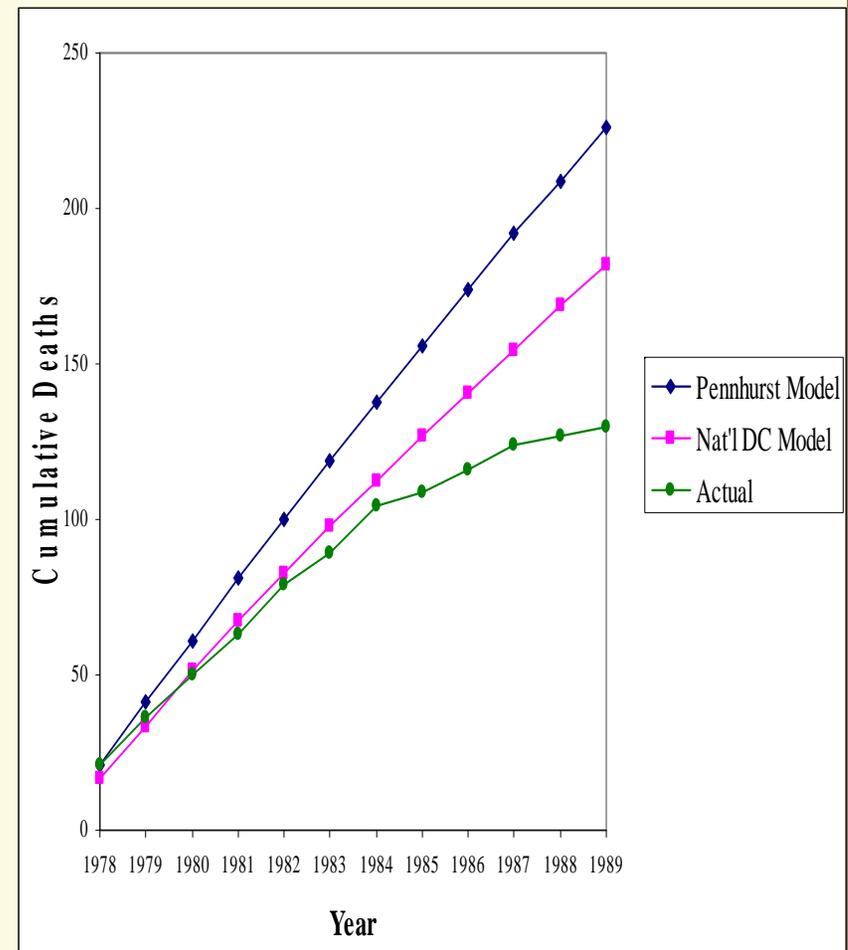
- ☞ The **absurdity** that was unacknowledged by the AAIDD journals....
- ☞ The Strauss & Kastner model of “adjusted risk of mortality” led to the conclusion that ....
- ☞ The risk of death was supposedly 72% higher in community homes than in institutions ....
- ☞ AND – also 72% higher in FAMILY HOMES than in institutions
- ☞ **So Strauss & Kastner actually claimed that people were safer in California institutions than in their own parents’ homes**
- ☞ Such a ridiculous conclusion
- ☞ Not even the Voice of the Retarded would believe such nonsense
- ☞ Yet the editors of the AAIDD journals completely missed it
- ☞ I notified the editors immediately – yet they continued to accept these obviously questionable articles
- ☞ Editorial incompetence fanned the flames of this Junk Science

# Replication?

- ☞ Strauss always claimed that publishing is the ultimate criterion of scientific validity
- ☞ It is **NOT**
- ☞ It is **replication**
- ☞ Cold fusion was **published**, but never **replicated**
- ☞ No one has replicated Strauss & Kastner
- ☞ Strauss was repudiated by his own colleagues at U of CA
- ☞ Paul Lerman, Dawn Hall Apgar, and Tameeka Jordan. Deinstitutionalization and Mortality: Findings of a Controlled Research Design in New Jersey. **Mental Retardation: Vol. 41, No. 4**, pp. 225-236.

# A Valid Study of Mortality

- ☞ A careful counting of all the people who left Pennhurst from 1978 to 1987
- ☞ The top blue line shows how many would have died if they had stayed at the institution
- ☞ (The death rate at Pennhurst had been steady for 20 years at about 16 per 1,000 per year)
- ☞ The lowest green line shows how many actually died in those years, *during the move to community*
- ☞ When “relocation stress” might have been expected to increase mortality
- ☞ But no – **about 100 people were still alive in 1990 who would have died if they had stayed at the institution**
- ☞ Conroy & Adler, 1998



# Discussion

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- How much harm has been done?
- Why have the journals not retracted?
- What is the official AAIDD position NOW?
- Will this Junk Science affect other nations?
- As they try to implement Article 19 of the United Nations Convention on the Rights of Persons with Disabilities?
- “Living independently and being included in the community”**