This response appeared in the articles section of www.lifeexpectancy.com for approximately two months before it was inexplicably removed.

May 9, 2004

David Strauss, PhD, FASA
Life Expectancy Project
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Dear David;

After publishing our study concerning survival rates of children with severe neurologic disabilities[1], I was pleasantly surprised to receive a phone call from you congratulating me. In addition, you pointed out errors in the Eyman[2] statistical analysis and referred me to your letter in the Lancet.[3] You subsequently faxed me a printer's proof copy of a letter to Pediatric Neurology, which elaborated upon the Eyman mistakes, and was later published.[4]

Subsequently you contacted the editor of the Southern Medical Journal and me requesting permission to post our study on your website. We agreed and this article had been available on your website for downloading for the past several years (www.lifeexpectancy.com in the articles section), without any comments.

It was very surprising to find on February 28, 2004, your criticisms of our study posted on the website. This criticism was posted exactly six years after the publication date of our article. You claimed that "we made a serious methodologic error." These claims of supposed "errors" must be addressed.

You gave an example of a hypothetical case where in the first year of life, 90% would die, and between ages 1 and 2, 50% would die. Graphs can be generated using identical techniques to those in our publication[1] (Figure). From birth to 2 years of age results in a death rate of 95%, which is exactly what you wrote should happen. You incorrectly claimed that our cumulative death rate would have been 90.5%. Comparing the results from 1 year to 2 years of age, our graphic techniques result in a death rate of 50%. You incorrectly claimed that our methods would result in a death rate of 5%. Our techniques result in a death rate that is exactly what you wrote should take place.

Your discussion of data presented in our Figure 4 (group 4)[1] is wrong. You stated that there were 6 individuals over the age of 15. You claimed that none of them were "exposed" to death at age 4. In order

for anyone to have reached the age of 15, they would also have reached the ages 1, 2, 3, 4 etc. through 15. So, the longer surviving individuals in group 4 were exposed to death every day of their lives, including their fourth birthday.

You further claimed that we had "assumed survival to age 15" and had "guaranteed these 6 could not die prior to age 15". This claim is incomprehensible. We provided the best medical care that we could to these disabled individuals, and they lived well past their 15'th birthday. If providing good medical care results in good clinical outcomes, that is desirable and commendable, but it cannot be guaranteed. We made no "assumptions" and made no "guarantees" outside of providing the best medical care that we could. We just reported what happened. In contrast, the California data base that you have been using is seriously flawed. Please see references 5 and 6 for further details.

You corrected Eyman's "methodologic mistake" and posted these results on your website.[7] Your correction starts from 1 year of age and provides data in 5 year increments. Only information about groups 1 through 3 is provided. Comparative results can be obtained and these are presented in the Table. In generating this table we used the more extensive data base used by Eyman in his 1993 publication.[8]

The Table shows that your correction of the Eyman data results in much better survival rates. However, the results from our study continue to give better outcomes. It should be noted that in group 3, the survival rates from our study are extremely similar to those of your correction. The similarity in group 3 outcomes continues until 30 years of age. If our methodologic techniques were flawed, as claimed by your discussion of our group 4 results, then it is inconceivable that our group 3 results (a more disabled group than group 4) would be basically identical to those of your correction. This similarity in outcomes in group 3 gives independent confirmation of the reliability of our data.

Our data differs significantly from your correction for the more disabled groups 1 and 2. The greatest difference is with the most disabled group 1. In our study, we provided consistent, high quality medical care, on a continuous basis to all of our patients, in pediatric skilled nursing facilities. In contrast, the California data base, that you and Eyman have used, is based on a state-wide data collection system which includes discrepant qualities of administered medical care. In the Eyman reports, only 3.5% of severely disabled children resided in skilled nursing facilities. The vast majority resided at home, where access to acute medical care, and even access to adequate medical care, may be problematic.

Even though we collected data from three different SNFs, they all were under uniform medical and nursing direction, and continuously provided care of the highest quality. The California data base was and is collected from twenty-one regional centers located across the state. The medical care was and is provided by a very large number of different physicians and institutions. Such a large number of diverse medical care providers would necessarily produce discrepancies in the quality of medical care administered.

In Chicago's general medical community, there have been and still are many practitioners who believe these disabled children should be allowed to die. If one were to stop feeding and providing liquids to the most disabled group, life expectancy would be measured in days, not years. This attitude that espouses the neglect of disabled children has found a notable proponent, Peter Singer, Professor of Bioethics, at Princeton University. He has published several books in which he argues that the active euthanasia of disabled individuals is ethically totally acceptable. Given the prominence of his position and institution, Singer's words are being echoed in hospital ethics committees across the country. I find these attitudes to be abhorrent and, with the support of the Pediatric Long-Term Care Section, introduced a resolution to the House of Delegates of the American Medical Directors Association (AMDA) in March, 2000. The resolution, which was accepted unanimously, stated: "AMDA opposes any physician involvement in assisted suicide or active euthanasia of any person regardless of age."

As in Chicago, certainly across the state of California, there were and are many physicians with this attitude, whose practice was and is to limit access of disabled children to medical care, thus producing decreased survival rates. This important factor cannot be accounted for in the California data base. However, the consistent and uniform high-quality of medical care provided in our nursing facilities has produced better survival rate results and scientifically more valid outcomes.

Providing consistent, high quality medical care, as was done in our study, can fully account for the observed differences between your published results, and ours.

I want to take this opportunity to congratulate you and your colleagues on all of the hard work that you have done. Correcting the Eyman errors has been a tremendous step forward. I recommend that you change the way the data is collected in California. If you could address and take care of the issues in this letter, and the concerns raised in references 5 and 6, in the future you would have survival rates statistics of disabled children that would be scientifically totally accurate and irrefutable.

Also, I want to congratulate you and your colleagues in one area of your work that seems to be ignored. You have definitively shown that taking disabled children and adults from facilities, and placing them into home or group home settings, results in substantially increased mortality rates. This finding is the most important one in your body of publications. Sadly, your results are being completely disregarded. The American Academy of Pediatrics is strongly espousing the concept of The Medical Home, where the emphasis is on medically fragile children, irrespective of the severity and degree of illnesses, staying at home. In the May, 2004 issue of Pediatrics there is a special supplement which explains the AAP policies and recommendations about The Medical Home. Remarkably, and regrettably, in the entire supplement there is no mention of your work. In general principles, family based care is desirable, but when increased mortality is assured, the Academy should take your words into consideration and should be very cautious.

In addition, the government of the State of Illinois has been giving strong financial incentives for disabled children to be transferred from skilled nursing facilities to group

homes. Over the past year one of my pediatric skilled nursing facilities has undergone substantial downsizing to group homes where the quality and quantity of nursing care is less than it is was at the SNF. After personally taking care of these medically fragile children and young adults, and nursing them through illness after illness, for a full 14 years, it has been saddening and extremely disheartening to hear of deaths that have taken place after transfer. Your most important contribution is being ignored. I wish that were not the case.

Good luck with your future studies!

Sincerely,

Audrius V. Plioplys MD, FRCPC, FAAP, CMD

References

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2. Eyman RK, Grossman HJ, Chaney RH, Call TL. The life expectancy of profoundly handicapped people with mental retardation. NEJM 1990;323:584-589.

3. Strauss D. Life expectancies in children with cerebral palsy. Lancet 1997;349:283-284.

4. Strauss D, Shavelle R. Survival estimates in severely disabled children. Ped Neur 1998;19:243-244.

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7. Strauss D. Correction of Eyman et al. (1990) life expectancies. www.lifeexpectancy.com 2004.

8. Eyman RK, Grossman HJ, Chaney RH, et al. Survival of profoundly disabled people with severe mental retardation. Am J Dis Child 1993;147:329-336.

TABLE: **Survival Rate Comparison to Strauss's correction of Eyman's "methdologic mistake"**

Analysis for cases from 1 year of age to 5 years of age

	Group 1	Group 2	Group 3
Eyman et al. (1993)[8]	55%	63%	60%
Strauss (correction)[7]	66%	84%	**94%**
Plioplys et al. (1998)[1]	82%	94%	**93%**

Analysis for cases from 1 year of age to 10 years of age

Eyman et al. (1993)[8]	35%	38%	38%
Strauss (correction)[7]	41%	67%	**88%**
Plioplys et al. (1998)[1]	75%	94%	**93%**

Analysis for cases from 1 year of age to 15 years of age

Eyman et al. (1993)[8]	No data available		
Strauss (correction)[7]	27%	54%	**82%**
Plioplys et al. (1998)[1]	72%	85%	**82%**