

Recent trends in cerebral palsy survival. Part II: individual survival prognosis

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ABBREVIATION

CDER Client Development Evaluation Report

AIM The aim of the study was to determine survival probabilities and life expectancies for individuals with cerebral palsy based on data collected over a 28-year period in California.

METHOD We identified all individuals with cerebral palsy, aged 4 years or older, who were clients of the California Department of Developmental Services between 1983 and 2010. Kaplan–Meier survival curves were constructed for 4-year-old children, and the estimated survival probabilities were adjusted to reflect trends in mortality by calendar year. For persons aged 15, 30, 45, and 60 years, separate Poisson regression models were used to estimate age-, sex-, and disability-specific mortality rates. These mortality rates were adjusted to reflect trends of improved survival, and life expectancies were obtained using life table methods.

RESULTS The sample comprised 16 440, 14 609, 11 735, 7023, and 2375 persons at ages 4, 15, 30, 45, and 60 years, respectively. In 1983, 50% of 4-year-old children who did not lift their heads in the prone position and were tube fed lived to age 10.9 years. By 2010, the median age at death had increased to 17.1 years. In ambulatory children the probability of survival to adulthood did not change by more than 1%. Life expectancies for adolescents and adults were lower for those with more severe limitations in motor function and feeding skills, and decreased with advancing age. Life expectancies for tube-fed adolescents and adults increased by 1 to 3 years, depending on age and pattern of disability, over the course of the study period.

INTERPRETATION Over the past three decades in California there have been significant improvements in the survival of children with very severe disabilities. There have also been improvements to the life expectancy of tube-fed adults, though to a lesser extent than in children.

For individuals with cerebral palsy (CP), the determination of survival prognosis and life expectancy is important for medical and financial planning, including the determination of expected total lifetime care costs. Survival probabilities or life expectancies for persons with CP have been reported in several populations, including California, the UK, Australia, Canada, Sweden, and Japan.^{1–14} The most useful studies for prognosis are those that provide figures specific to children or adults of a particular age and severity of disability. In such studies, survival probabilities have been shown to be very similar across countries.^{2,13,14}

The survival figures from the published studies are based on persons with CP who were followed over the last several decades.^{2,13,14} Whether survival probabilities or life expectancy estimates computed from these historical

cohorts pertain to children and adults today is not always clear. In our companion article we documented significant improvements in mortality for children and tube-fed adolescents and adults with CP in California over the last 30 years. Survival probabilities and, by extension, life expectancies based on historical data from California should be adjusted to reflect this.

In this article we provide updated CP survival prognoses that have been adjusted to reflect the mortality trends noted in our companion article. To aid comparison with prior research, we have stratified study participants according to the same motor function and feeding skill groups used in our 1998 and 2008 studies.^{2,3} For 4-year-old children, we provide probabilities of survival to adulthood. For adolescents and adults, we update our previous estimates of life expectancy.

METHOD

Participants

The study population included all persons age 4 years and older with CP who were clients of California's Department of Developmental Services between January 1983 and December 2010.

Study participants were assessed annually with the Client Development Evaluation Report (CDER).¹⁵ This report contains over 200 medical, functional, behavioral, and cognitive items. For each client, a team headed by a physician makes medical diagnoses, including the assessment of CP, while functional items (e.g. crawling, walking, and feeding) are assessed by other professionals familiar with that aspect of the client's development. Persons who had a CDER with an International Classification of Disease (9th revision)¹⁶ code for degenerative conditions or acquired conditions (e.g. traumatic brain injury or injury resulting from near drowning) as an etiology for disability were excluded from all analyses. The severity of motor disability was recorded for the following motor skills: head-lifting in the prone position, rolling, sitting, crawling, and walking. Using this motor function data, we classified individuals into one of five levels on the Gross Motor Function Classification System (GMFCS).¹⁷ Self-feeding skills and gastrostomy interventions were also recorded. The functional skill levels recorded on the CDER describe voluntary actions that are performed on a consistent basis in typical settings. They do not represent the best level that has or may be achieved in specialized settings. The demographic and functional skill data recorded on the CDERs were consistently coded, with <1% missing values. Missing data were inputted using the last observation carried forward. The CDER assessments of these skills have been independently validated and have inter-rater reliabilities exceeding 0.85.^{18,19}

We formed five cohorts from the study population: at ages 4, 15, 30, 45, and 60 years. For example, the 4-year-old cohort comprised all children with CP who had a CDER evaluation between ages 3.5 and 5.0 years. The CDER age ranges for the 15-, 30-, 45-, and 60-year-old cohorts were 14.5–17.0, 29.0–33.0, 44.0–50.0, and 59.0–65.0 years, respectively. The age ranges were asymmetric to ensure that the average age closely matched the target age. Individuals within each cohort were classified according to their age-specific functional skills in gross motor function and feeding, and whether they had a feeding tube, at the time of their CDER evaluation.

Vital status was determined using electronic death records from the California Department of Health Services. Individuals who were not matched to a death record within 3 years of their last CDER evaluation were considered lost to follow-up at the 3-year mark. Individual survival times were censored at the date of loss to follow-up or the study end date, December 31, 2010, whichever came first.

Statistical analysis

For the 4-year-old cohort, the empirical survival probabilities were computed from the Kaplan–Meier survival curve

What this paper adds

- Documents improvements in survival probabilities for children with CP and severe disability.
- Provides updated life expectancy estimates for adolescents and adults with CP.

using data from the entire 1983 to 2010 study period. Here, the empirical hazard function at each follow-up age, x , was computed as:

$$b(x) = \frac{d(x)}{n(x)},$$

where $d(x)$ is the number of observed deaths and $n(x)$ is the number of persons still at risk (i.e. alive and not censored) at each follow-up age. The Kaplan–Meier estimate of the survival probabilities was computed as the product-limit:

$$S(x) = \prod_x(1 - b(x)) \quad (1)$$

The empirical hazard function was then adjusted to reflect mortality trends of the CP population as follows. For age x , we computed the average calendar year, $y(x)$, of the data used to compute the mortality rate at that age. The empirical hazard function was then adjusted to reflect the mortality at a given calendar year, y^* , using the formula:

$$b^{y^*}(x) = b(x) \times (1 - t(x))^{(y^* - y(x))} \quad (2)$$

where $t(x)$ is the year-over-year improvement in the mortality rate. As discussed in our companion paper this proved to be 2.5% per year for children with CP up to age 15 years and 0.9% per year for tube-fed adolescents and adults aged 15–59 years. As may be seen, $b^{y^*}(x)$ is simply the hazard function adjusted proportionally to reflect the relative improvement between years $y(x)$ and y^* . The adjusted survival curve is then the product-limit:

$$S^{y^*}(x) = \prod_x(1 - b^{y^*}(x)) \quad (3)$$

For the adolescent and adult cohorts (ages 15, 30, 45, and 60 years), the sex-, age-, and disability-specific mortality rates were estimated using a Poisson regression model.²⁰ The estimated mortality rates were then adjusted according to Equation (2) above. To be consistent with the results in our companion paper, we applied no adjustment to the estimates for orally fed teens and adults or adults over age 60. The adjusted mortality rates, together with the assumption of proportional life expectancy,²¹ were used to construct a life table for each group. Life expectancy (i.e. the mean survival time) was obtained from the life table. A bootstrap procedure with 1000 iterations was used to compute standard errors of the life expectancy estimates. As in our 2008 paper,² the life expectancies for the 'walks unaided' group assume that individuals in the group remain ambulatory until at least age 60.

RESULTS

Participant characteristics

The study population included 16 440 4-year-old children and 14 609, 11 735, 7023, and 2375 persons of ages 15, 30, 45, and 60 years, respectively. Characteristics of the participants within each age group are given in Table I. The proportion of males declined with advancing age, from 57% in the 4-year-old cohort to 53% in the 60-year-old cohort. The proportion of persons who did not walk (i.e. GMFCS level IV or V) declined from 49% at age 4 to 32% at age 30, and then increased to 37% at age 60. Conversely, the proportion of persons who walked without support, (i.e. GMFCS level I or II) increased from 34% at age 4 to 55% at age 30, and then declined to 42% at age 60. The prevalence of tube feeding was 10% in children of age 4 years, 8% at age 15, and 3 to 4% at ages 30, 45, and 60.

Survival probabilities for children

The probabilities of survival from age 4 years to ages 10, 15, 20, 25, and 30 years are presented in Table II. The survival probabilities that were adjusted to reflect mortality in 2010 indicate that most 4-year-old children with CP survive to age 20 years. An exception is children who are tube fed and who do not lift their heads when in the prone position (i.e. children with the most severe disability in GMFCS level V) of whom only 41% survive to age 20 years.

Survival probabilities were significantly higher for children with higher levels of gross motor function (Table II, log rank test for motor function alone: $\chi^2=2799$, $df=4$, $p<0.0001$). Mode of feeding was also a significant predictor of survival (Table II, log rank test for feeding skills alone: $\chi^2=2365$, $df=2$, $p<0.0001$). Children who walk without support and feed themselves have the best survival prognosis, 94% surviving to age 30 years. By comparison, 98.5% of the US general population survive to age 30 years.²²

Unadjusted survival probability estimates, which do not account for improved mortality over the study period, are lower than the adjusted-to-2010 survival estimates. The largest difference in survival probabilities calculated by these two methods was observed in the children with the most severe disabilities. For example, in tube-fed children who did not lift their heads in the prone position, the unadjusted probabilities of survival to ages 10, 20, and 30 years were 68%, 33%, and 21%, respectively, and the median age at death was 14.6 years. The adjusted-to-2010 survival probabilities were 75%, 41%, and 26%, and the median age at death increased to 17.1 years.

This comparison of the unadjusted and adjusted-to-2010 survival probabilities does not, however, fully capture the extent of improvement in survival over the course of the study period. To do so requires a comparison of the survival estimates from the beginning of the study (i.e. adjusted-to-1983 figures) with the adjusted-to-2010 figures. We have illustrated such a comparison for tube-fed children who do not lift their heads in the prone position (Fig. 1). In 1983, the median age at death was only 10.9 years, as compared with 17.1 years in 2010. Thus, the mortality improvements in this group led to a 6.2-year increase in the median survival time.

In contrast, for children who walked 10 feet unaided and fed themselves orally the adjustment to reflect trends in mortality had very little effect on the estimated survival probabilities; none changed by more than 1% between 1983 and 2010.

Life expectancy of adolescents and adults

Table III provides updated estimates of life expectancy for teens and adults with CP. The mortality rates underlying these estimates were adjusted to 2010 figures. Survival prognosis for adolescents and adults was strongly related to motor function and feeding skills. Persons who did not lift their heads in the prone position had the lowest life

Table I: Participant characteristics

Characteristic	Age (years) ^a				
	4	15	30	45	60
Sample size	16 440	14 609	11 735	7023	2375
Deaths	1795	1727	1674	1486	940
Mean follow-up years (SD)	11.4 (7.2)	11.1 (7.3)	12.8 (7.7)	10.5 (6.4)	7.9 (5.6)
Mean calendar year at beginning of follow-up	1995	1996	1994	1997	1997
Male (%)	57	55	54	53	53
Gross Motor Function Classification System					
I or II - walks unaided	34	47	55	54	42
III - walks with support	17	15	13	15	21
IV or V - does not walk					
Rolls or sits	32	25	24	25	29
Does not roll or sit, lifts head or chest in the prone position	10	7	4	4	4
Does not lift head or chest in the prone position	7	6	4	4	4
Tube fed (%)	10	8	3	3	4
Fed orally by others (%)	26	17	14	13	12
Self-feeds orally (%)	64	75	83	84	84

^aSome individuals contributed information at multiple ages.

Table II: Probability (%) that a 4-year-old child with cerebral palsy will survive to ages 10, 15, 20, 25, and 30 years

	<i>n</i>	Adjusted-to-2010					Unadjusted Kaplan–Meier				
		10	15	20	25	30	10	15	20	25	30
Does not lift head in the prone position											
Tube fed	482	75	58	41	31	26	68	48	33	25	21
Fed orally by others	615	85	73	56	47	43	80	66	51	43	39
Feeds self orally	50	97	90	90	–	–	95	88	88	–	–
Lifts head but not chest in the prone position											
Tube fed	303	79	66	55	44	34	73	58	48	38	29
Fed orally by others	795	89	80	67	54	48	85	73	61	49	44
Feeds self orally	103	97	92	86	76	76	95	89	84	74	74
Lifts head and chest, partial rolling											
Tube fed	265	82	71	65	54	40	77	65	59	48	35
Fed orally by others	962	93	86	78	66	55	90	81	73	62	52
Feeds self orally	329	97	95	92	87	77	96	93	91	85	75
Full rolling, does not walk unaided											
Tube fed	475	90	85	77	64	56	87	81	73	60	52
Fed orally by others	1643	96	93	88	84	77	95	91	86	82	76
Feeds self orally	4906	99	98	96	94	92	98	97	95	93	91
Walks unaided											
Tube fed	125	96	94	86	81	–	95	93	84	79	–
Fed orally by others	188	97	97	97	97	87	96	95	95	95	86
Feeds self orally	5199	100	99	98	96	94	99	99	98	96	94

Log rank test for the Kaplan–Meier survival curves to test whether survival varies by: motor function ($\chi^2=2799$, $df=4$, $p<0.0001$), feeding ($\chi^2=2365$, $df=2$, $p<0.0001$), or motor-feeding group ($\chi^2=3508$, $df=14$, $p<0.0001$).

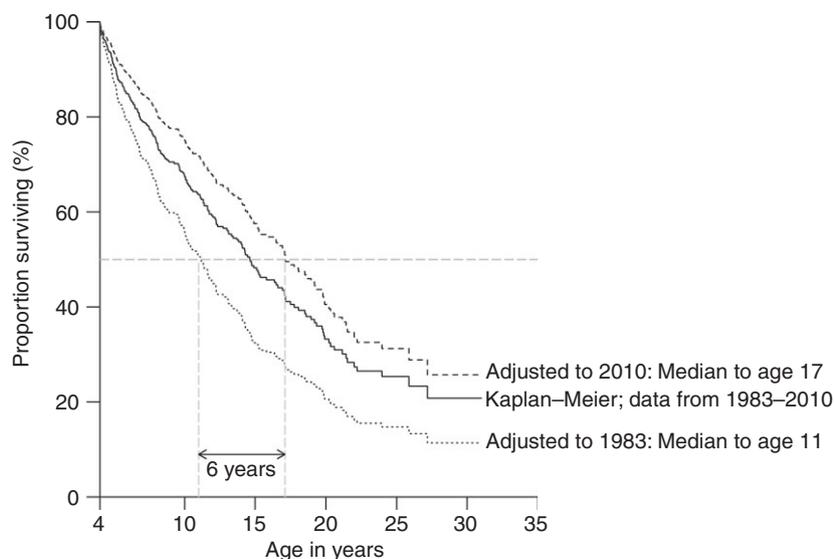


Figure 1: Survival of 4-year-old children who do not lift their heads when in the prone position and are tube fed.

expectancies, whereas those who walked unaided had the highest life expectancies. For 15 year olds who did not lift their heads in the prone position and were tube fed, the life expectancy was 14 additional years (i.e. to age 29). For those who walked unaided the life expectancies were 55 additional years for girls and 52 additional years for boys. The standard errors of the life expectancy estimates were about 1 year on average.

As in the general population, life expectancies declined with advancing age. The age-related decline was less pronounced in persons who were largely immobile, and was

most pronounced in those who walked unaided. Sex effects were also more pronounced in persons with higher levels of gross motor function. Life expectancies of women who could walk unaided were roughly 4 years longer than those of men in this group.

As noted in our companion article, the year-over-year improvement in the mortality rates of tube-fed adolescents and adults aged 15 to 59 years was 0.9%. Over the course of the 1983 to 2010 study period, the life expectancies for tube-fed 15-year-olds with CP increased by 3 to 4 years depending on the level of motor function. Similarly, the

Table III: Life expectancy: additional years (standard error) for adolescents and adults with cerebral palsy^a

Sex/Age	Cannot lift head			Lifts head or chest			Rolls/sits			Walks unaided ^b	General population
	TF	FBO	SF	TF	FBO	SF	TF	FBO	SF		
Female											
15y	14 (1.0)	18 (1.2)	–	18 (1.5)	23 (1.0)	–	27 (1.8)	37 (1.3)	48 (1.2)	55 (1.0)	66.2
30y	14 (0.9)	19 (1.2)	–	14 (0.8)	23 (1.1)	–	18 (1.8)	32 (1.2)	37 (0.8)	43 (0.7)	51.6
45y	12 (1.0)	14 (1.0)	–	12 (1.0)	17 (1.2)	–	12 (1.5)	21 (1.0)	25 (0.6)	29 (0.6)	37.4
60y	7 (0.8)	10 (1.4)	–	7 (0.8)	10 (1.1)	–	7 (0.8)	10 (0.8)	16 (0.5)	19 (0.7)	24.1
Male											
15y	14 (1.0)	18 (1.2)	–	18 (1.4)	23 (1.0)	–	27 (1.7)	33 (1.1)	45 (1.1)	52 (0.9)	61.4
30y	14 (0.9)	19 (1.2)	–	14 (0.8)	23 (1.1)	–	18 (1.7)	28 (1.1)	33 (0.7)	39 (0.6)	47.4
45y	12 (1.0)	14 (1.0)	–	12 (1.0)	17 (1.1)	–	12 (1.5)	18 (0.9)	22 (0.5)	25 (0.5)	33.5
60y	7 (0.8)	10 (1.4)	–	7 (0.8)	10 (1.1)	–	7 (0.8)	10 (0.8)	12 (0.4)	15 (0.5)	21.1

–, Results not shown because of small sample size. ^aAs noted in the text, these life expectancies do not necessarily apply to younger children. ^bLife expectancies for the ‘walks unaided’ groups assume that individuals in the group will remain ambulatory until at least age 60. FBO, fed orally by others; SF, self-feeds orally; TF, tube fed.

life expectancies of tube-fed 30-year-olds with CP increased by 2 to 3 years, and those of tube-fed 45-year-olds increased by 6 months to 1 year.

DISCUSSION

This article provides up-to-date survival probabilities and life expectancies for children, adolescents, and adults with CP. Our estimates take into account the annual mortality rate improvements documented in our companion article. Notably, the survival probabilities in Table II were adjusted to reflect mortality rates in 2010. These are more favorable than the conventional Kaplan–Meier estimates based on data from the entire study period 1983 to 2010.

As illustrated in Fig. 1, the 2.5% year-over-year mortality rate improvement implied a 6-year increase in the median survival time of 4-year-olds who did not lift their heads and were tube fed. The same 2.5% improvement made a very small difference to the probability of survival to adulthood in ambulatory children. This reflects the fact that absolute mortality rates are already very low in ambulatory children, and the 2.5% relative improvement makes only a small absolute difference.

Whether trends toward improved CP mortality have been co-occurring in other developed countries remains unclear. Several studies have reported no significant trends in mortality.^{5,6,12} However, as pointed out in our companion paper, the methods used in these studies may not have been sensitive enough to detect period effects. Further, many of the studies from other countries do not contain information on the most basic motor skills, e.g., head control, or gastrostomy feeding, which define the California subgroups that experienced the most dramatic improvements in survival probabilities and life expectancy.

The survival probabilities for young children in the present article are higher than those reported in our 1998 study.³ Although much of the difference is attributable to trends in improved mortality, the survival figures presented here and those in the 1998 study are not directly comparable. The reason is that the 1998 study considered cohorts of younger children within a broad age range of 6 months

to 3.5 years, whereas we now work with an older and also narrower age range of 3.5 to 5 years. Of course, the latter provides a better basis for long-term survival prognosis at ages 3.5 to 5. During the first 3 years of life many medically fragile children with CP die from infections or other causes, and it may not be prudent to make life-care decisions based on assessments during this high-risk period. Further, functional skills in motor function and feeding may change substantially in infants and toddlers, which is associated with higher variation in outcomes.

Nearly all of the life expectancies presented in Table III are within 1 or 2 years of those reported in our 2008 article.² The similarity reflects the fact there have been no further major trends in mortality rates for most adults with CP. Though statistically significant, the modest trend of improvement for tube-fed adolescents and adults aged 15 to 59 years over the last decade was not sufficient to dramatically alter the life expectancy estimates presented previously for these groups. Some of the minor differences may reflect sampling variability. In this regard we note that the larger sample in the present work led to increased precision, with standard errors that are in most cases about 1 year. In addition, the Poisson regression approach used here relaxes the proportional hazards assumption associated with the prior study’s Cox regression analysis and improves the numerical stability of the estimates.

One notable difference from the 2008 publication is the life expectancy for 15 year olds who roll or sit and are tube fed. The figure reported in Table III, a life expectancy of 27 additional years, is about 6 years higher than the prior figure. We note that the present life expectancy estimate for this group had a large standard error of 1.8 years, and that the standard error of the estimate in the prior study was larger still. Thus statistical imprecision may have played some role here. Closer examination of the data, however, revealed that the increase is at least partially explained by the increasing placement of feeding tubes for persons with less severe disabilities.

When survival prognosis of an individual patient with CP is of interest one can refer to Tables II and III, which

provide estimates based on age, sex, severity of motor disability, and need for feeding assistance. The figures there are appropriate for individuals whose overall condition is typical of the group. To determine whether this is the case, other factors (e.g. activities of daily living, intellectual disability and communication, comorbidities, general health, height and weight, and so on) should also be considered. For example, among persons who self-feed there is significant variation in skills such as toileting, bathing, personal hygiene, and dressing. Persons who are fed by others may be further stratified according to more basic levels of hand use, intellectual disabilities, and language skills. Among children with a particular pattern of disability, very low weight is an independent risk factor for mortality.²³ Epilepsy, severity of which may be quantified by type (e.g., generalized tonic clonic or not) and frequency of seizures, is a further mortality risk factor that may be considered.²⁴

When empirical estimates of mortality rates are not available, the qualitative assessment of an experienced clinician often proves helpful in understanding whether certain comorbidities (e.g. scoliosis, hydrocephalus, frequency of infection) and general health are better or worse than that of the average child with an otherwise similar pattern of disabilities.

Thus Tables II and III provide a starting point for a more comprehensive analysis of survival prognosis that considers more than just motor and feeding skills. The question of interest in practical work is not whether an individual's gross motor or feeding skills narrowly qualifies for a particular group in Table II or III, but whether that individual's condition as a whole is typical of the group. This is particularly important in cases where an individual's pattern of disability does not fit neatly into one of the motor-feeding categories presented there.

If the person's profile with respect to these and other predictive factors is markedly better or worse than the average then some further adjustment to the survival prognosis may be indicated. Just how much the life expectancy may be adjusted upwards or downwards is not always clear. In this context we note that the standard errors in Table III indicate the statistical precision of the estimates; they do not reflect variation in other positive or negative factors and are thus not bounds on the life expectancies of particular individuals. For example, a person with CP who is currently hospitalized for pneumonia will undoubtedly have a life expectancy lower than indicated in Table III. Conversely, someone who walks well, has no significant cognitive difficulties, and has no other significant comorbidities almost certainly has a life expectancy that exceeds the 'walks unaided' figure. Along these same lines, it should be noted that life expectancies are age specific and those given in Table III for adolescents and adults generally do not apply to children of younger ages. For young children, the survival figures given in Table II may be used, or more detailed calculations may be undertaken. For completeness, we note that the actual survival time of any particular individual may well be

longer or shorter than the medians or life expectancies reported here.

It is natural to ask whether the California CP survival probabilities and life expectancies derived in the present paper generalize to persons with CP in other countries, where general population life expectancies may differ. For example, the current general population life expectancy of the UK as a whole (80 years from birth²⁵) is about 2 years higher than that of the US (78 years from birth²²)*. Some experts attribute the difference to better access to health care in the UK. It is noteworthy, however, that the general population life expectancy in the state of California (also 80 years from birth²⁶) is equivalent to the UK figure. Furthermore, California is one of the few states that provides all medically indicated care and long-term services (housing, physical and occupational therapy, speech and language therapy, and so on) to persons with CP as an entitlement by law, regardless of personal or familial income. In this respect health care for persons with CP in California is very much like universal coverage systems in the UK, Australia, and other developed countries.

Aside from the considerations above, the most compelling argument for the use of our results for CP survival prognosis in other countries is the fact that, when the severity of disability is taken into account, the survival probabilities for persons with CP in California are remarkably similar to those from other countries.^{2,13,14} If one were to make some adjustment to the life expectancy to reflect country of residence, the 'percentage of normal' method (suggested in our 2008 paper²) remains a reasonable choice in our view. For example, if the California-based CP life expectancy estimate is 50% of the current US general population life expectancy, then 50% of the current UK general population figure may provide a reasonable prognosis in that country. Finally, as in our companion paper, we note that because our study was limited to persons who received services for CP, the extent to which the results apply to individuals with very mild CP who do not require services is not clear.

CONCLUSION

Survival prognosis for persons with CP should take into account age and severity of disability. The survival figures reported here are based on the most recent California population data from the Department of Developmental Services, and supersede those given for the same comparison groups in prior publications. These new figures

*Technical note: Some readers may find the 2-year difference between current UK and US life expectancy surprisingly small. The common perception that UK life expectancy far exceeds that of the US seems to be driven by the widespread use of 'projected' rather than current life expectancy in the UK. The 'projected' figure is based on the assumption that trends toward improved mortality observed over the last 30 years will continue indefinitely into the future.²⁵ There is an ongoing debate as to whether such projections, which are inherently subject to uncertainty, are appropriate. How to derive 'projected' life expectancy for persons with CP is a separate and complex issue.

include adjustments to reflect the observed declines in mortality rates in California. We hope that this article serves as a practical guide to prognosis to be used in planning of future care for children, adolescents, and adults with CP.

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