Mortality and Life Expectancy in Dutch Residential Centres for Individuals with Intellectual Disability, 1991–1995

Marian A. Maaskant
Governor Kremers Center of the University of Maastricht and Pepijn Centre, the Netherlands

Jan P. M. Gevers
VGN, the Netherlands

Henk Wierda
Prismant, the Netherlands

Background   **Several studies showed that the individuals with intellectual disability have a shorter life expectancy than their intellectually average peers. To gain insight in the present life expectancy of people with intellectual disability, a study with recent data was performed.**
Methods   **We used data of the National Case Register (LRZ) with data of almost all residents of residential centres in the Netherlands for the period 1991–1995 ($N = 29\,290$). Approximately 40% of all people with intellectual disability in the Netherlands reside in such centres.**
Results   **Results showed that 5-year-old people with intellectual disability in Dutch residential centres have a life expectancy of 41 years. The life expectancy of their peers with Down's syndrome in the centres is 46. At the age of 30 years, the respective figures are 36 and 26 years. No statistically significant differences in mortality were found between women and men and between levels of intellectual disability.**
Conclusions   **Due to prolonged longevity, the client population in residential centres will continue to age and thus the numbers of older individuals will increase. This ageing process has implications for the care for elderly individuals, because they need other care than before due to physical, psychological and social changes and spiritual challenges.**

Introduction

Several studies showed that individuals with intellectual disability have a shorter life expectancy than their intellectually average peers. However, the life expectancy of individuals with intellectual disability has increased substantially in the past decades (e.g. Record & Smith 1955; Carter 1958; Collman & Stoller 1963; Fabia & Drolette 1970; Balakrishnan & Wolf 1976; Freyers & MacKay 1979; Elwood & Darragh 1981; Masaki *et al.* 1981; Baird & Sadovnic 1987; Baird & Sadovnick 1988; Malone 1988; Bell *et al.* 1989; Eyman *et al.* 1990; McGrother & Marshall 1990; Eyman *et al.* 1991; Eyman *et al.* 1993; Kastner *et al.* 1993; McGuigan *et al.* 1995; Puri *et al.* 1995; Hayden 1998; Hollins *et al.* 1998; Jagger *et al.* 1998; Janicki *et al.* 1999; Patja *et al.* 2000).

Several subgroups of individuals with intellectual disability showed to have increased mortality at a relatively young age. Known examples of such subgroups are: people with

Down's syndrome; people with severe/profound intellectual disability; people with additional physical problems (e.g. epilepsy, cerebral palsy, tube-fed, bedridden people) (Kastner *et al.* 1994; Forsgren *et al.* 1996; Strauss *et al.* 1997; Sullivan 1998; and see also reference list above).

Lately, discussions as to whether placement from institutions to community placement influence mortality rates have been published. Not only methodological aspects were discussed, but ethical questions as well (Strauss & Kastner 1996; Strauss *et al.* 1996, 1998a, b, c; Blacher 1998; Borthwick-Duffy *et al.* 1998; Conroy & Adler 1998; Decouflé *et al.* 1998; Fujiura 1998; Lakin 1998; O'Brien & Zaharia 1998; Strauss & Shavelle 1998; Shavelle & Strauss 1999). This study unfortunately does not contain data of people with intellectual disability living in the community, except from those who live in the community-based group homes of the centres (see Methods), so this study cannot contribute to these discussions by means of analysing such data. Therefore, it lies beyond the scope of this article to go into further details, but it is of interest to read such debates.

In the early eighties, 5-year-old Dutch clients of residential settings for individuals with intellectual disability could expect to live approximately another 54 years. The respective life expectancies for their peers in the general population were then 72 years (Maaskant *et al.* 1995). At the moment, Dutch newborn in general, can expect to live 81 (women) and 75 (men) years (CBS 2001).

Information about the life expectancy of individuals with intellectual disability in general and clients of residential centres specifically is relevant. On the one hand, this is relevant because increased longevity will result in an increase in persons reaching middle age and old age. As in the general population, individuals with intellectual disability will also develop infirmities of old age (e.g. Janicki & Wisniewski 1985; Hogg *et al.* 1988; Maaskant 1993; Day & Jancar 1994; Janicki & Deb 1994; Hogg 1997; Suttie & Heller 1997; Cooper 1998; World Health Organization 2000; Hammel & Nochajski 2001).

Therefore, it has been stated that elderly residents need different care than in the past, so the provision of care should be made to fit their needs.

On the other hand, in the Dutch residential care of individuals with intellectual disability, only a limited number of places are available. Because of increased longevity, the turnover rate in residential centres is low. This low turnover rate will lead to an even larger proportion of aged than expected from the natural ageing of the population (Maaskant 1993). As in other countries, the Dutch government promotes deinstitutionalization to a great extent. In recent years and in years to come, the large residential centres have created and will create small community-based houses. However, also in smaller community-based houses, the increasing longevity of clients leads to aged populations.

Keeping this in view, it is needed to update the information about life expectancy of individuals with intellectual disability.

As stated before, people with Down's syndrome have increased mortality at a relatively young age, mainly due to the early onset of dementia (e.g. Masaki *et al.* 1981; Baird & Sadovnic 1987; Malone 1988; Bell *et al.* 1989; McGrother & Marshall 1990; Eyman *et al.* 1991). Mortality is related to the level of intellectual disability (people with lower level of intellectual disability have shorter life expectancies than those with higher level of intellectual disability (e.g. Eyman *et al.* 1990; Strauss & Eyman 1996; Patja *et al.* 2000).

Therefore, we analysed and compared the mortality data of people with Down's syndrome and people without Down's syndrome. We also analysed the mortality data regarding the level of intellectual disability. Women in general have a higher life expectancy than men (CBS 2001). In an earlier Dutch study regarding mortality in people with intellectual disability (Maaskant *et al.* 1995), no significant differences were found in mortality rates between women and men. Nevertheless, we also compared the mortality data of women and men separately.

Aim of the study

The aim of the study is to calculate the age-specific life expectancy of clients of residential centres for individuals with intellectual disability in total, and (because of their proven specific mortality patterns) subdivided for Down's syndrome, level of intellectual disability and gender.

Materials and methods

Study population

Since 1971, most of the residents of Dutch residential centres for individuals with intellectual disability[1] are included in National Case Register [Landelijke Registratie Zorg en dienstverlening aan mensen met een verstandelijke handicap (LRZ)]. The LRZ contains data of, for example, date of birth, gender, level of intellectual disability, physical handicaps, aetiological diagnosis, mobility, date of admission, date of discharge and date of death. At present, approximately 40% of all Dutch people with intellectual disability reside in residential centres, either in small-scaled houses on the grounds of the centres or in small-scaled community-based group homes, as organizational units of the centres.

For the analysis of data for this article, data of 5 years (1991–1995) were used. Data of a more recent period of 5 years could not be used due to a significant technical change in the registration in 1996. Therefore, combining the data from the period till 1996 and data of 1996 and later could not be realized. At present, not all data from 2001 are available yet. So, the most recent period we could analyse was the period 1991–1995.

[1]In 1991, the Netherlands counted 94 general centres for people with intellectual disability. At present, there are 106 centres. These centres accommodate almost 31 000 persons in total. The Netherlands still have a relatively large population in residential centres, compared to other European countries (Walsh 1997). However, in contrast to other countries, these centres accommodate clients in small (on average eight persons) separate housing units. Besides, almost 30% of the residents of these centres do not live on the grounds of the centres, but in group homes in the community. Since they still formally are clients of the centre, they are counted as residents of the centres. The percentage clients living in such group homes increases substantially, due to 'community-care-projects', stimulated by the Dutch government. Besides these group homes owned by the residential centres, the Netherlands count more than 16 000 people with intellectual disability who live in group homes. These group homes are more or less are independent organizational organizations. This perhaps confusing situation is a result of historical developments in the care for people with intellectual disability in the Netherlands.

In the LRZ-database, data of 96% of the clients from the period 1991–1995 were available ($N = 29\,290$). For the remaining 4% of the clients, no data were available. There are no indications that these 4% non-response have caused selection-bias regarding the mortality rates.

From those present in the database and living in one of the centres at 1 January 1991, 57% were male and 43% were female. A borderline or mild intellectual disability was diagnosed in 14% of the clients. The percentages for persons with moderate, severe and profound intellectual disability were 28, 31 and 27%, respectively. Almost 16% were diagnosed as having Down's syndrome. Eleven per cent were younger than 20 years, 22% were older than 50 years.

Calculating life expectancy

The life expectancy is an important measure used to compare mortality patterns between two or more populations. The age-specific life expectancy is the additional number of years a person of a certain age can expect to live.

The life expectancy is calculated with the help of so-called 'life tables'. A life table gives insight into the 'extinction' of a (fictitious) population of for example 100 000 children, who were born on the same day, given the age-specific mortality rates. These life tables are constructed on the basis of obtained age-specific mortality rates on a certain moment, under the assumption that the mortality rates do not change during the life of the cohort. As a consequence of this assumption, the calculated life expectancy is estimated too low, when age-specific mortality rates decrease in the course of time (Sturmans 1982). This is almost always the case. In Appendix 1, an extensive description of the calculations is given.

In the Netherlands, only data of clients of the 94 residential centres are available in the National Case Register LRZ. Data of individuals with intellectual disability who live with their parents/family or who live in semiresidential settings are not collected and thus not available.

A problem inherent to calculating mortality rates of clients of residential centres is the relatively small number of persons 'at risk' and the number of deceased in some age groups. The obtained 1-year mortality rates therefore can be somewhat unstable. In view of the small numbers, we calculated 5-year mortality rates (1991–1995) per 5-year age groups (0–4, 5–9, 10–14, ..., 95+) instead of 1-year mortality rates.

The aim of the study is to calculate the age-specific life expectancy of clients of residential centres for individuals with intellectual disability in total, and subdivided Down's syndrome, level of intellectual disability and gender. This adds to the afore-mentioned problem of small numbers. In the oldest age groups, the numbers at risk were very small. Therefore, the average mortality risk of the age groups 80–84, 85–89 and 90–94 were combined, and then calculated and regarded as the mortality rate for these age groups. For people with Down's syndrome this was done for the age groups of 60 and above. The age-specific mortality of persons aged 95 years or older was fixed at 100%; for people with Down's syndrome a 100% mortality rate was fixed for all persons aged 75+. In order to construct a regular life table, the mortality rates were re-calculated per 1-year age-interval per year. For example, it showed that 2.67% of the residents, aged 30–34, died within 5 years. It was assumed to be an even distribution within each year and within each age (30, 31, 32, 33, 34). So, 0.53% (2.67 : 5) of the residents aged 30, 31, 32, 33 and 34 years died within 1 year. These mortality rates were the basis of the life table.

Table 1 People with intellectual disability in Dutch residential centres (1991–1995), according to age-group, numbers present, deceased, censored and mortality rates (including standard error)

Age-group	Present at 1 January 1991 p_x	Deceased 1991–1995 d_x	Censored 1991–1995 c_x	Five-year mortality rate	SE	One-year mortality rate
0–4	72	16	14	0.281[1]	0.066	0.056[2]
5–9	326	22	65	0.078	0.016	0.016
10–14	956	54	136	0.063	0.009	0.013
15–19	1672	77	240	0.051	0.006	0.010
20–24	2787	65	244	0.025	0.003	0.005
25–29	3551	107	231	0.032	0.003	0.006
30–34	3507	90	171	0.027	0.003	0.005
35–39	3391	96	129	0.029	0.003	0.006
40–44	3218	128	107	0.041	0.004	0.008
45–49	1826	121	53	0.070	0.006	0.014
50–54	1612	139	50	0.092	0.008	0.018
55–59	1429	166	37	0.125	0.010	0.025
60–64	1179	194	21	0.181	0.012	0.036
65–69	768	177	18	0.264	0.020	0.053
70–74	482	139	9	0.341	0.029	0.068
75–79	291	122	2	0.533	0.047	0.107
80–94[3]	223	147	2	0.990	0.085	0.198
95+[4]				1		1
Total	27290	1860	1529			

[1]$m_x = d_x/[p_x - (0.5d_x + 0.5c_x)] = 16/[72 - (0.5*16) + (0.5*14)]$, see Appendix 1 for the explanations. In this table, the rounded numbers are presented. In the calculations, however, the exact numbers are used.
[2]0.281/5.
[3]Numbers for the age-groups 80–84, 85–89, 90–94 are combined, due to small numbers in the separate age-groups.
[4]95+: mortality rate fixed at 100%.

Results

Table 1 shows the 5-year age-specific mortality rates for people with intellectual disability in residential centres (see Appendix 1 for calculations in more detail).

With the data of Table 1, it is possible to calculate the age-specific life expectancy. Table 2 shows the results in summary (also see Appendix 1).

Table 1 shows the mortality rates of the total population. It showed that 28% of the young children (0–4 years old) died within a period of 5 years. Less than 10% of the children between 5 and 19 years and less than 5% of those aged 20 and 44 year died between 1991 and 1995. After the age of 65 years, the mortality rates increased substantially. Further calculations (Table 2) showed that 5-year-old children in residential setting can expect to live another 49 years, whereas for example, 35-year-old persons have an additional longevity of almost 32 years.

Of the total group, 15.6% ($n = 4272$) were diagnosed as having Down's syndrome. For persons with Down's syndrome (Table 3), the mortality rates in young children (0–5 years old) were lower than for the whole group: no children with Down's syndrome in the residential centres under the age of 10 died between 1991 and 1995. However, the number of children in the Down's syndrome group is small.

Table 2 Age-specific life expectancy of people with intellectual disability in Dutch residential centres (1991–1995)

Age, x	One-year mortality rate, m_x	Life expectancy, le_x
0	0.056	41.3
5	0.016	49.4
10	0.013	48.2
15	0.010	46.2
20	0.005	43.5
25	0.006	39.5
30	0.005	35.7
35	0.006	31.6
40	0.008	27.5
45	0.014	23.5
50	0.018	20.1
55	0.025	16.8
60	0.036	13.7
65	0.053	11.0
70	0.068	8.7
75	0.107	6.3
80	0.198	4.4
85	0.198	4.1
90	0.198	3.2
95	1	0.5

Table 3 People with Down's syndrome in Dutch residential centres (1991–1995), according to age-group, numbers present, deceased, censored and mortality rates (including SE)[1]

Age-group	Present at 1 January 1991	Deceased 1991–1995	Censored 1991–1995	Five-year mortality rate	SE	One-year mortality rate
0–4	3	0	2	0.000	0.000	0.000
5–9	15	0	6	0.000	0.000	0.000
10–14	69	6	7	0.096	0.039	0.019
15–19	187	3	18	0.017	0.100	0.003
20–24	395	4	22	0.010	0.005	0.002
25–29	606	15	35	0.026	0.007	0.005
30–34	675	19	26	0.029	0.007	0.006
35–39	718	16	12	0.023	0.006	0.005
40–44	675	41	18	0.064	0.010	0.013
45–49	335	42	8	0.135	0.209	0.027
50–54	245	51	6	0.236	0.033	0.047
55–59	191	58	3	0.361	0.047	0.072
60–74[2]	154	96	5	0.934	0.084	0.186
75+[3]	0	0	0	1		1
Total	4272	354	168			

[1]In this table, the rounded numbers are presented. In the calculations however, the exact numbers are used.
[2]Numbers for the age-groups 60–64, 65–69, 70–74 are combined, due to small numbers in the separate age-groups.
[3]75+: mortality rate fixed at 100%.

Table 4 Age-specific life expectancy of people with Down's syndrome in Dutch resident centres (1991–1995)

Age, x	Mortality rate, m_x	Life expectancy, le_x
0	0.000	50.8
5	0.000	45.8
10	0.019	40.8
15	0.003	39.7
20	0.002	35.4
25	0.005	30.7
30	0.006	26.4
35	0.005	22.2
40	0.013	17.6
45	0.027	13.6
50	0.047	10.3
55	0.072	7.4
60	0.186	4.7
65	0.186	4.3
70	0.186	3.3
75	1.000	0.5

As could be expected, after the age of 45 the 5-year mortality rates in people with Down's syndrome were much higher compared to the whole group. The age-specific life expectancies of the people with Down's syndrome are presented in Table 4. It showed that 5-year-old children with Down's syndrome in residential centres had a life expectancy of 46 years, and those aged 35 years have a longevity of 22 years. The numbers of persons with Down's syndrome are rather small in some age groups, so some calculations can be somewhat unstable.

Figure 1 shows a summary of the life expectancies of the total group and those with Down's syndrome graphically. Except for the youngest group, those clients with Down's
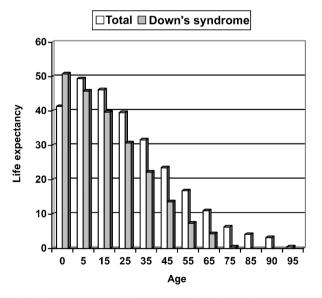

Figure 1 Age-specific life expectancies of clients in Dutch residential centres (total and clients with Down's syndrome).

syndrome have a shorter life expectancy than the group in total. From the age of 15, the total group has a life expectancy that is between 5 and 10 years higher than their peers with Down's syndrome.

Additional analyses showed no statistically significant relations between mortality and the level of intellectual disability (mild vs. moderate/severe/profound). Other analyses showed that there were no systematic differences in mortality rates between women and men. The results of these additional analyses therefore are not presented in this article.

Discussion

As could be expected, this study showed that people with intellectual disability in Dutch residential centres still have a shorter life expectancy than their peers without intellectual disability in the general population. The life expectancy of people with Down's syndrome is – as could be expected – still lower than their people with intellectual disability with other aetiological diagnoses, mainly due to the high prevalence of dementia in people with Down's syndrome over 40 (e.g. Janicki & Wisniewski 1985; Aylward *et al.* 1997; Wilkinson & Janicki 2001).

The results are in line with results of other (recent) studies regarding longevity of people with intellectual disability (see Introduction), albeit that the populations of the studies are not always directly comparable.

The results showed no significance difference in mortality between men and women. This finding was in line with the earlier study in the Netherlands (Maaskant *et al.* 1995). It was surprising that no systematic and statistical significant differences in mortality were found between the levels of intellectual disability (mild vs. moderate/severe/ profound). An explanation might be that the numbers (and especially the numbers of deceased persons) in the several groups were too small to detect significant differences.

Compared to a similar study with data from the early eighties (Maaskant *et al.* 1995), the life expectancy did not increase, but was in fact a bit lower. This result may be unexpected. Mainly the young persons (−20 years) and the elderly (60+ years) had a higher 5-year mortality rate. However, there are several reasons that can explain this finding. Comparing the data of both studies, it showed that this study contained much more elderly clients and thus the results of these age groups are more stable than the results of the earlier study. In the earlier study, a relatively small number of elderly died, at least in comparison with this study. This did influence the mortality rates and thus the life expectancy. Perhaps the elderly in the first study could be regarded as very healthy survivors, whereas a part of the elderly in this study can be regarded as more vulnerable. Another explanation could be related to the changed admission policy. Since the early eighties, the admission policy in Dutch residential centres has changed. Nowadays there are much more alternatives for the residential care for people with intellectual disability, e.g. respite care, day care and home care. People with borderline or mild intellectual disability will not be admitted to residential centres anymore, unless they have severe behavioural problems. and only few young persons will be admitted to residential centres, unless they require specific nursing care because of physical conditions or show severe challenging behaviour. Many of the people who nowadays are admitted to residential centres have – beside their intellectual disability – physical handicaps as well, and thus are more fragile. This is especially true for teenagers and young adults.

Since these young persons have a relatively high mortality rate because of their physical fragility, they can influence the longevity substantially.

It is hard to compare the results of studies regarding mortality in people with intellectual disability. When comparing the results of mortality studies (either or not living in residential centres), unfortunately it is (almost) impossible to determine whether discrepancies in outcomes are due to differences in the study populations or to real differences in mortality rates. This is not only true for this study (with an undoubtedly select study population), but in fact for all research studying mortality in people with intellectual disability. When comparing results, thorough attention has to be paid to the comparability of populations, data sources and results.

Albeit that the life expectancy of clients in Dutch residential settings has not increased during the past decade, the increased longevity of people with intellectual disability in the past century still has its implications. The client population will continue to age and thus the numbers of older individuals will increase. A recent study (Bernard, Maaskant, Gevers, & Wierda 2001) showed that presently 25% of the clients of Dutch residential centres are 50 years or older. In 2011, this percentage of older individuals will have increased to 39–46% (depending on the chosen model). The relative number of persons aged 65 years or more will rise from 8 to 11–16% (depending on the chosen model). This ageing process has implications for the care for individual elderly, because they need other care than before due to physical changes (e.g. sense impairments, declining motor skills, declining ADL-functions), psychological changes (e.g. depression, dementia), social changes (loss of work, decreasing social network) and spiritual challenges (e.g. death of friends and nearing own death).

The issue of life expectancy in people with intellectual disability has been studied for a long time, but repeating such studies every decade still is worthwhile, because the implications of changing longevity in people with intellectual disability is much more far-reaching than having recent figures only.

Acknowledgments

Correspondence

Any correspondence should be directed to Marian Maaskant, Pepijn Centre, PO Box 40, NL-6100 AA Echt, the Netherlands (e-mail: m.maaskant@pepijn.nl).

References

Aylward E. H., Burt D. B., Lai F. & Dalton A. J. (1997) Diagnosis of dementia in individuals with intellectual disability. *Journal of Disability Research* **41**, 152–164.

Baird P. A. & Sadovnic A. D. (1987) Life expectancy in Down's syndrome. *Journal of Pediatrics* **110**, 849–854.

Baird P. A. & Sadovnick A. D. (1988) Causes of death to age 30 in Down's syndrome. *American Journal of Human Genetics* **43**, 239–248.

Balakrishnan T. R. & Wolf L. C. (1976) Life expectancy of mentally retarded persons in Canadian institutions. *American Journal of Mental Deficiency* **80**, 650–662.

Bell J. A., Pearn J. H. & Firman D. (1989) Childhood death in Down's syndrome. Survival curves and causes of death from a total population study in Queensland, Australia, 1976–1985. *Journal of Medical Genetics* **26**, 764–768.

Bernard S., Maaskant M. A., Gevers J. & Wierda H. (2001) Voorspellingen ten aanzien van het aantal oudere mensen met een verstandelijke handicap in algemene woonvoorzieningen 1996–2011. *Nederlands Tijdschrift Voor Zorg Aan Verstandelijk Gehandicapten* **27**, 166–177.

Blacher J. (1998) Much ado about mortality: debating the wrong question. *Mental Retardation* **35**, 412–415.

Borthwick-Duffy S. W., Widaman K. F. & Grossman H. J. (1998) Mortality research, placement, and risk of death: basic research, the media, and public policy. *Mental Retardation* **36**, 416–422.

Carter C. O. (1958) A life-table for mongols with the causes of death. *Journal of Mental Deficiency Research* **2**, 64–74.

CBS (2001) *Sterfte: Kerncijfers Vanaf 1950*. Centraal Bureau voor de Statistiek, Voorburg.

Collman R. D. & Stoller A. (1963) A life table for mongols in Victoria, Australia. *Journal of Mental Deficiency Research* **7**, 53–59.

Conroy J. W. & Adler M. (1998) Commentary on the mortality issue. *Mental Retardation* **36**, 410–411.

Cooper S. A. (1998) Clinical study of the effects of age on the physical health of adults with mental retardation. *American Journal on Mental Retardation* **102**, 582–589.

Day K. & Jancar J. (1994) Mental and physical health and ageing in mental handicap: a review. *Journal of Intellectual Disability Research* **38**, 241–256.

Decouflé P., Hollowell J. & Flanders W. D. (1998) Is community placement an independent risk factor for increased mortality? Comments on two recent reports. *Mental Retardation* **36**, 403–405.

Elwood J. H. & Darragh P. M. (1981) Prevalence of mongolism in Northern Ireland. *Journal of Mental Deficiency Research* **25**, 157–160.

Eyman R. K., Call T. L. & White J. F. (1991) Life Expectancy of Persons with Down's syndrome. *American Journal on Mental Retardation* **95**, 603–612.

Eyman R. K., Grossman H. J., Chaney R. H. & Call T. L. (1990) The life expectancy of profoundly handicapped people with mental retardation. *New England Journal of Medicine* **323**, 584–589.

Eyman R. K., Grossman H. J., Chaney R. H. & Call T. L. (1993) Survival of profoundly disabled people with severe mental retardation. *American Journal of Diseases of Children* **147**, 329–336.

Fabia J. & Drolette M. (1970) Life tables up to age 10 for mongols with and without congenital heart defect. *Journal of Mental Deficiency Research* **14**, 235–242.

Forsgren L., Edvinsson S. O., Nyström L. & Blomquist H. K. (1996) Influence of epilepsy on mortality in mental retardation: an epidemiologic study. *Epilepsia* **37**, 956–963.

Freyers T. & MacKay R. I. (1979) Down's syndrome: prevalence at birth, mortality and survival. A 17-year study. *Early Human Development* **3**, 29–41.

Fujiura G. T. (1998) Commentary on the meaning of residential mortality research. *Mental Retardation* **36**, 400–403.

Hammel J. & Nochajski S. M. (2001) *Aging and Developmental Disability: Current Research, Programming, and Practice Implications*. The Haworth Press, Binghamton.

Hayden M. F. (1998) Mortality among people with mental retardation living in the United States: research review and policy application. *Mental Retardation* **36**, 345–359.

Hogg J. (1997) Intellectual disability and ageing: ecological perspectives from recent research. *Journal of Intellectual Disability Research* **41**, 136–143.

Hogg J., Moss S. & Cooke D. (1988) *Ageing and Mental Handicap*. Chapman & Hall, London.

Hollins S., Attard M. T., Von Fraunhofer N., McGuigan S. & Sedgwick P. (1998) Mortality in people with learning disability: risks, causes, and death certification findings in London. *Developmental Medicine and Child Neurology* **40**, 50–56.

Jagger C., Raymond N. & Morgan K. (1998) Planning for the future; the effect of changing mortality, incidence, and recovery rates on life expectancy with visual disability. *Journal of Aging and Health* **10**, 154–170.

Janicki M. P. & Deb S. (1994) Ageing: our continuing challenge. *Journal of Intellectual Disability Research* **38**, 229–232.

Janicki M. P. & Wisniewski H. M. (1985) *Aging and Developmental Disabilities, Issues and Approaches*. Paul H. Brookes, Baltimore.

Janicki M. P., Dalton A. J., Henderson C. M. & Davidson P. W. (1999) Mortality and morbidity among older adults with intellectual disability: health services considerations. *Disability and Rehabilitation* **21**, 284–294.

Kastner T., Nathanson R. & Friedman D. L. (1993) Mortality among individuals with mental retardation living in the community. *American Journal of Mental Retardation* **98**, 285–292.

Kastner T., Criscione T. & Walsh K. (1994) The role of tube feeding in the mortality of profoundly disabled people with severe mental retardation. *Archives of Pediatrics and Adolescent Medicine* **148**, 537–538.

Lakin K. C. (1998) Observations on the California mortality studies. *Mental Retardation* **36**, 395–400.

Maaskant M. A. (1993) *Mental Handicap and Ageing*. Kavanah, Dwingeloo.

Maaskant M. A., Sturmans F., Haveman M. J. & Frederiks C. M. A. (1995) Life expectancy of institutionalised people with mental handicap in the Netherlands. *European Journal on Mental Disability* **2**, 5–13.

Malone Q. (1988) Mortality and survival of the Down's syndrome population in Western Australia. *Journal of Mental Deficiency Research* **32**, 59–65.

Masaki M., *et al.* (1981) Mortality and survival for Down's syndrome in Japan. *American Journal of Human Genetics* **33**, 629–639.

McGrother C. W. & Marshall B. (1990) Recent trends in incidence, morbidity and survival in Down's syndrome. *Journal of Mental Deficiency Research* **34**, 49–57.

McGuigan S. M., Hollins S. & Attard M. (1995) Age-specific standardized mortality rates in people with learning disability. *Journal of Intellectual Disability Research* **39**, 527–531.

O'Brien K. F. & Zaharia S. (1998) Is it life threatening to live in the community? Commentary. *Mental Retardation* **36**, 408–410.

Patja K., Iivanainen H., Oksanen H. & Ruoppila I. (2000) Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of Intellectual Disability Research* **44**, 591–599.

Puri B. K., Lekh S. K., Langa A., Zaman R. & Singh I. (1995) Mortality in a hospitalised mentally handicapped population: a 10-year survey. *Journal of Intellectual Disability Research* **39**, 442–446.

Record R. G. & Smith A. (1955) Incidence, mortality, and sex distribution of mongloid defectives. *British Journal of Preventive Social Medicine* **9**, 10–15.

Shavelle R. & Strauss D. (1999) Mortality of persons with developmental disabilities after transfer into community care: a 1996 update. *American Journal on Mental Retardation* **104**, 143–147.

Strauss D. & Eyman R. K. (1996) Mortality of people with mental retardation in California with and without Down's syndrome, 1986–1991. *American Journal on Mental Retardation* **100**, 643–653.

Strauss D. & Kastner T. A. (1996) Comparative mortality of people with mental retardation in institutions and the community. *American Journal on Mental Retardation* **101**, 26–40.

Strauss D. & Shavelle R. (1998) What can we learn from the California mortality studies? *Mental Retardation* **36**, 406–408.

Strauss D., Eyman R. K. & Grossman H. J. (1996) Predictors of mortality in children with severe mental retardation: the effect of placement. *American Journal of Public Health* **86**, 1422–1429.

Strauss D., Kastner T., Ashwal S. & White J. (1997) Tube-feeding and mortality in children with severe disabilities and mental retardation. *Pediatrics* **99**, 358–362.

Strauss D., Anderson T. W., Shavelle R., Sheridan F. & Trenkle S. (1998a) Causes of death of persons with developmental disabilities: comparison of institutional and community residents. *Mental Retardation* **36**, 386–391.

Strauss D., Kastner T. A. & Shavelle R. (1998b) Mortality of adults with developmental disabilities living in California institutions and community care, 1985–1994. *Mental Retardation* **36**, 360–371.

Strauss D., Shavelle R., Baumeister A. & Anderson T. W. (1998c) Mortality in persons with developmental disabilities after transfer into community care. *American Journal on Mental Retardation* **102**, 569–581.

Sturmans F. (1982) *Epidemiologie; Theorie, Methoden En Toepassing*. Dekker & van de Vegt, Nijmegen.

Sullivan P. B. (1998) Is tube-feeding in disabled children associated with excess mortality? *Journal of Journal of Pediatric Gastroenterology and Nutrition* **27**, 240–241.

Suttie J. & Heller T. (1997) *Proceedings of the Eighth International Roundtable on Aging and Intellectual Disabilities: Emerging National and Global Perspectives on Aging with Developmental Disabilities*. Rehabilitation Research and training Center on Aging with Mental Retardation, Institute on Disability and Human Development, University of Illinois at Chicago, Chicago.

Walsh P. N. (1997) Old world-new territory: European perspectives on intellectual disability. *Journal of Intellectual Disability Research* **41**, 112–119.

Wilkinson H. & Janicki M. P. (2001) *The Edinburgh Principles*. University of Stirling, Stirling.

World Health Organization (2000) *Ageing and Intellectual Disabilities – Improving Longevity and Promoting Healthy Ageing: Summative Report*. World Health Organization, Geneva.

Appendix 1

Calculation of life expectancy

How is a life table constructed? The actual construction is demonstrated by means of Table A1. The first column (x) represents the age (0–95); column 2 gives the age-specific mortality rate (m_x); column 3 the (fictive) start cohort (l_x) of 100 000 persons and its 'extinction' is given; column 4 presents the number of deceased persons (d_x); and finally, the age-specific life expectancy (le_x) is given in column 5.

So in the first age category the mortality rate of infants (age 0), being 0.05614 and with a cohort of 100 000 persons, the number of deceased persons is 5614 (100 000 × 0.05614). After 1 year, 94 386 (100 000–5614) persons are still alive, 5299 persons (0.05614 × 94 386) will die, etc. At age 95 the cohort is totally extinct. Now the life expectancy of a person at a certain age × (le_x) can be calculated from the persons alive at the beginning of each year

Table A1 Life table (abbreviated), people with intellectual disability in Dutch residential centres 1991–1995 (except for m_0: rounded numbers, in the calculations exact numbers are used)

Age, x	Mortality rate, m_x	Alive, l_x	Deceased, d_x	Life expectancy, le_x
0	0.05614	100000	5614	41.3
1	0.056	94386	5299	42.8
2	0.056	89087	5001	44.3
3	0.056	84086	4721	45.9
4	0.056	79365	4456	47.6
5	0.016	74910	1167	49.4
6	0.016	73743	1149	49.2
7	0.016	72594	1131	48.9
8	0.016	71464	1113	48.7
9	0.016	70351	1096	48.5
10	0.013	69255	869	48.2
11	0.013	68386	858	47.8
12	0.013	67528	847	47.4
⋮	⋮	⋮	⋮	⋮
24	0.005	60655	299	40.3
25	0.006	60267	381	39.5
26	0.006	59886	379	38.8
⋮	⋮	⋮	⋮	⋮
89	0.198	1381	273	3.5
90	0.198	1108	219	3.2
91	0.198	888	176	2.9
92	0.198	713	141	2.5
93	0.198	571	113	1.9
94	0.198	458	91	1.3
95	1.000	368	368	0.5

by the formula:

$$le_x = \frac{\sum (l_{x+1} \ldots l_n)}{l_x} + 0.5$$

The deceased persons on average lived 0.5 years in the year of death, therefore half a year is added. For example: the formula of le_{24} is:

$$le_{24} = \frac{l_{25} + l_{26} + l_{27} + \cdots + l_{94} + l_{95}}{l_{24}} + 0.5 = \frac{60267 + 59886 + \cdots + 458 + 368}{60566} + 0.5 = 40.3$$

In order to calculate age-specific mortality rates, data about the number of persons of age × alive at the beginning of a period (i.e. 1 year) (p_x), and the number of persons of age × deceased in that year (d_x) are needed. Age-specific mortality rate is then calculated as follows:

$$m_x = \frac{\text{number of persons of age} \times \text{deceased in a certain year}}{\text{number of persons alive in the middle of that year}}$$

Assuming that the number of deceased persons is evenly distributed, the formula of age-specific mortality rates is:

$$m_x = \frac{d_x}{p_x - 0.5d_x}$$

When calculating age-specific mortality rates of e.g. people with intellectual disability in residential centres, one has to take into account that some of the persons will be lost to follow-up in a certain period. The assumption is that the persons who were lost to follow-up (censored data) are a random group, i.e. these censored data are supposed to have similar mortality rates as the non-censored data. In this study the numbers 'at risk' are corrected for the time that censored persons (c_x) have been part of the group. The persons lost to follow-up are assumed to be dispersed evenly over the period so the persons at risk are:

$$m_x = \frac{d_x}{p_x - 0.5d_x - 0.5c_x}$$

Given the mortality rates for all ages in a population, it is possible to follow the populations 'extinction' and to determine age-specific life expectancies.