



Australian Epilepsy Longitudinal Study

Wave 3: The Social Impact of Epilepsy

RESULTS

Report prepared by:

Christine Walker Chronic Illness Alliance

Chris L Peterson Latrobe University

December 2014

EXECUTIVE SUMMARY

- The Wave 3 survey was conducted at the end of 2013. The response rate was 324 (36.7%) of a possible 883 eligible Australian Epilepsy Research Register members.
- In Wave 3 a substantial number responded to an online version of the survey.
- Seventy five per cent of the respondents had epilepsy while the rest comprised family and carers.
- While 26% had less than Year 11 education, 34% had academic degrees.
- This did not necessarily translate into employment with only 20% of the total employed full-time, the rest either part-time or casual. The majority were unemployed though this includes older people and students. Employment rates of people with epilepsy and their carers are far lower than the Australian average.
- Of those unable to work 34.5% were unable to do so because of epilepsy or other disabilities.
- Employment patterns are reflected in income levels. The majority of the sample was of working age but 55% were on low incomes while a further 30% were on relatively low incomes in terms of average Australian weekly earnings. Where only individuals' incomes were considered half of them were on incomes below the poverty line.
- These income levels created high levels of financial distress compared to financial distress reported in the Housing Income Labour Dynamics in Australia surveys.
- Seizure activity, levels of control impact on quality of life. These impacts are comparable to the impact of chronic pain in terms of time lost from employment.
- When compared to other conditions surveyed in the HILDA study, people with epilepsy in Wave 3 demonstrated their condition had strong negative impacts in terms of their work and social relationships. Many reported a sense of powerlessness or hopelessness in the face of their epilepsy as it left them with little control over their lives.
- Injuries and trauma were part of this strong negative impact with 40% of respondents reporting injuries, some requiring hospitalisation and many being of a very serious nature.
- Having a good income did not necessarily help people with epilepsy to deal better with the social and emotional impact of their condition.

1. BACKGROUND

1.1 Establishment of the Register

In 2006 the Epilepsy Foundation of Victoria (EFV) established a Research Participants' Register (RPR) to enable it to collect data from registrants regarding the social impact of living with epilepsy.

In 2011 the Register was expanded to people in other Australian states in order to collect data from a large and representative sample of people living with epilepsy, their families and carers. Epilepsy Australia and all state and territory associations are supporting recruitment to the new register, which is now called the Australian Epilepsy Research Register (AERR). Joining the AERR is voluntary.

The Register complies with Deakin University Human Research Ethics Committee (2013-011 The Australian Epilepsy Longitudinal Study Wave 3: Health and Social Impact of Epilepsy; current from April 2013 to April 2017). All people joining the Register are informed their privacy will be respected and that their details will not be shared with anyone outside the EFV research unit. They are also informed that from time to time surveys will be sent to them, and that it remains their choice to complete the survey.

1.2 Prevalence of epilepsy in Australia

There has been substantial progress made to establish a baseline from which to better understand the social impact of epilepsy. In 2006 Brown produced for the first time evidence-based estimates of the prevalence of epilepsy in Australia ⁽¹⁾. Using the National Health Survey 2004-5 he established baseline estimates of prevalence of epilepsy in Australia. This prevalence was 0.68 % or 1 in every 147 Australians (133,700 people). Brown also explored the factor of underreporting of epilepsy, where people do not understand their condition as being epilepsy or prefer not to disclose they have epilepsy. He estimated that the prevalence could be as much as 1 in every 73 Australians (or 268,473 people). Additionally, Brown estimated that when households living with a person with epilepsy were taken into account, the combined prevalence was 2.13 % or 1 in every 47 people (or 843,000 people) either having the condition or living in a household with someone with epilepsy.

Collecting these baseline data provides researchers with the basis to establish the optimal sample size for conducting a longitudinal survey.

1.3 Sample size

The sample size required for a robust study of Australians living with epilepsy can be calculated by taking the lowest estimated prevalence point (133,700 people), then applying De Vaus' rule ⁽²⁾. Using this method, the national sample size required would be approximately 2000 people with epilepsy. This has the advantage of reducing the bias created by self-selection.

Developing the AERR as a national sample commenced in earnest in 2011 and continues with the participation of Epilepsy Australia members, Epilepsy Action and the development of Australia-wide resources.

At the time of the 2013 survey there were 883 participants eligible to receive the survey. While there are now more participants recruited from other Australian states the AERR continues to have a majority of Victorians on it.

1.4 Response rate

The AERR is the source of participants to collect data on the social impact of epilepsy longitudinal surveys. All 883 eligible participants of the AERR were mailed a paper copy in September 2013 and sent several reminders. This resulted in a response of 201 or 24%. Following this procedure an on-line survey using Survey Monkey was sent to the 245 research registrants who had supplied their email addresses as well as an additional 10 who had registered since the initial survey mail out. There were three follow ups to remind people to complete the on-line surveys. Of the 255 people sent the on-line survey, 117 or 46% completed the survey. The total number then of the 883 eligible participants to complete the survey was 324 (36.7%).

The use of Unique Identifiers demonstrates 103 people participated in both Wave 2 and Wave 3 surveys.

2 LONGITUDINAL SURVEY RESULTS

2.1 Wave 3 Survey 2013

There were 883 active registrants on the AERR when this survey was conducted in 2013. While total numbers continued to increase after 2010, the attrition rate also increased. This attrition may have been due to deaths, people changing address, or some no longer being interested in continuing.

In 2010 a large survey tool covering income, employment, educational levels, costs of caring for epilepsy, levels of depression and anxiety and attitudes towards people with epilepsy was distributed. The Wave 3 survey tool was reduced in size to explore a smaller number of variables and used validated questions in order to compare responses to other longitudinal studies representing the Australian population, including the Household, Income and Labour Dynamics in Australia Survey (HILDA).

Note: The HILDA project was initiated and is funded by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and is managed by the Melbourne Institute of Applied Economic and Social Research (Melbourne Institute). The findings and views reported in this report, however, are those of the authors and should not be attributed to either FaHCSIA or the Melbourne Institute. These data are derived from Wave 11 (2011) of the HILDA survey.

2.1.1 Characteristics of the respondents

Three hundred and twenty four persons (or 36.7% of active registrants) responded. Of these:

- 242 (75%) were people with epilepsy;
- 74 (23 %) were people who completed the survey on behalf of a person with epilepsy;
- 8 (2%) missing

Further:

- Sixty three per cent of the respondents were females and thirty per cent were males (with 7% missing data).

2.1.2 Age distribution

The mean age of the total sample was 39.8 years of age (SD =17.4; min = 2; max = 87).

Table 1: Age distribution

| 18-30 | 31-45 | 46-60 | 61+ | Total |
|----------|------------|------------|----------|------------|
| 92 (32%) | 85 (29.5%) | 73 (25.5%) | 38 (13%) | 288 (100%) |

Missing data: 36

2.2 Education profile

Table 2: Highest level of education obtained

| Year 11 or less | Year 12 | TAFE | Apprentice | Diploma | University | Post-graduate | Total |
|-----------------|----------|----------|------------|------------|------------|---------------|------------|
| 78 (26%) | 38 (13%) | 31 (11%) | 13 (4%) | 34 (11.5%) | 56 (19%) | 46 (15.5%) | 296 (100%) |

Missing data: 28

Table 2 indicates that 26 % of the total number of respondents had less than year 11 or its equivalent standard. A small number (15%) of the survey group was in trade related education possibly reflecting the restrictions relating to epilepsy.

Thirty four per cent of the participants in the survey had a Bachelor's degree or above.

In 2010, 45% of the Australian population aged between 25 and 34 had this level of education and 85% of Australians had completed secondary education ⁴.

Because of the number of younger people in the 2013 survey it is worthwhile breaking down educational attainment by age.

Table 3: Educational attainment by age

| Age | <30 | 31-45 | 46-60 | 61+ | Total |
|---------------|-------------|-------------|-------------|------------|-------|
| Yr 11 or less | 31 (36.5 %) | 10 (11.5 %) | 19 (26 %) | 15 (39.5%) | 75 |
| Yr 12 | 14 (16.5 %) | 8 (9.5 %) | 12(16.5 %) | 3 (8%) | 43 |
| TAFE/Trade | 9 (10.5 %) | 14 (16.5 %) | 11 (15 %) | 4 (10.5 %) | 56 |
| Tertiary | 31 (36.5 %) | 53 (62.5 %) | 31 (42.5 %) | 16 (42 %) | 97 |
| Total | 85 (100%) | 85 (100%) | 73 (100%) | 38 (100%) | 288 |

Missing: 36

The 36.5% of respondents under 30 with year 11 education or less is likely to contain the younger age group remaining at school or tertiary institutions. While older people over the age of 46 years had high proportions with Year 11 or less more than 40% of those in the older age brackets had gone on to tertiary education. This proportion moving to complete tertiary education is only exceeded by the 31-45 age group where nearly two thirds have tertiary education. A smaller percentage in all age groups pursued TAFE or trade qualifications.

2.3 Employment status

One hundred and forty one (43.5 %) of the 324 survey respondents were employed.

Table 4: Employment profile

| Full time | Part time | Casual | Total |
|---------------|-------------|---------------|---------------|
| 67 (47.5%) | 45 (32%) | 29 (20.5%) | 141 (100%) |

In raw numbers there are only 67 of the total number of respondents who are working full-time. This is 20% of the total number (324) of respondents.

Table 5: Employment and age distribution

| | <30 years | 31-45 | 46-60 | 61+ |
|-----------|---------------|---------------|---------------|--------------|
| Full time | 19 (47.5%) | 24 (45.3%) | 20 (57.1%) | 1 (16.7%) |
| Part time | 10 (25.0%) | 19 (35.8%) | 12 (34.3%) | 3 (50.0%) |

| | | | | |
|--------|---------------|---------------|--------------|---------------|
| Casual | 11 (27.5%) | 10 (18.9%) | 3 (8.6%) | 2 (33.3%) |
| Total | 40 (100%) | 53 (100%) | 35 (100%) | 6 (100.0%) |

All age groups except for 61 and over are represented strongly in full time work. Interestingly those aged 30 and under are less represented in part time work than the other age groups, while being comparatively over-represented in casual work.

Part time and casual work is not limited to younger people, who might generally be expected to prefer this kind of work while studying. Of those working in part-time and casual work those aged between 31 and 45 constitute the highest proportion, followed by those aged between 46 and 60. Part time and casual work has implications for quality of life with many people in these employment categories being referred to as 'the working poor' ⁵. In 2010 63.3% of all Australian employees were full-time while 36.7% of all of them were part-time including casual ⁽⁵⁾.

Table 6: Distribution of those not working

| Retired | Studying | Unable to work due to epilepsy | Unable to work due to another disability | Seeking paid work | Home duties | Total |
|---------------|-------------|--------------------------------|--|-------------------|-------------|---------------|
| 32 (12.5%) | 64 (25%) | 40 (15.5%) | 49 (19%) | 37 (14%) | 36 (14%) | 258 (100%) |

Missing: 12

Two hundred and fifty eight (80%) of the 324 respondents in the survey were not in formal employment. Thirty seven per cent of this group was retired or studying, representing both the older and younger respondents to the survey. However, of those who were unemployed, 34.5% were unable to work either due to epilepsy itself or because of another disability. This leaves a small proportion of the respondents who were of a working age but unable to work.

2.4 Income

Table 7: Weekly income levels for individuals

| <249 | 250-499 | 500-749 | 750-999 | 1000-1249 | 1250-1499 | 1500-1749 | >1750 | Total |
|--------------|--------------|--------------|--------------|---------------|-------------|------------|---------------|----------------|
| 69 (24 %) | 87 (31 %) | 34 (12 %) | 27 (10 %) | 21 (7.5 %) | 18 (6 %) | 8 (3 %) | 19 (6.5 %) | 283 (100 %) |

Missing: 41

Table 8: Total weekly household incomes for families before tax

| <249 | 250-499 | 500-749 | 750-999 | 1000-1249 | 1250-1499 | 1500-1749 | >1750 | Total |
|-------------|----------------|-------------|--------------|--------------|----------------|-------------|-------------|----------------|
| 15 (6 %) | 39 (14.5 %) | 38 (14%) | 30 (11 %) | 32 (12 %) | 31 (11.5 %) | 19 (7 %) | 65 (24%) | 269 (100 %) |

Missing: 41

A low income is defined by Centrelink in Australia as \$519 gross per week for a single person and \$899 gross per week per couple in order to qualify for a low income health care card ⁶. Table 7 shows 55% of individuals on incomes lower than \$519.00 while Table 8 shows 20.5% of families living on low incomes.

Additionally, Fair Work Australia claims the 2014 national minimum income is \$640.90 gross per week for a person over 21⁷. These tables demonstrate that the degree to which individuals and families are below this minimum.

Low income, however, is relative and all these figures should be seen in the context of full-time average weekly earnings of \$1437.70 per week in November 2013⁸. In this case nearly 85% of the 283 recording their individual incomes were on incomes below average weekly earnings, while Table 8 (above) demonstrates that more than half of the families had incomes below the average.

Further, a substantial number of respondents live below the poverty line. In 2010, the poverty line (50% of median income) for a single adult was \$358 per week and for a couple with two children it was \$752⁹.

This suggests that close to half the individuals were living below the current poverty line, while combined household incomes reduced this to under a quarter. Compare this to overall poverty statistics where it is estimated that some 13% of the Australian population lives below the poverty line and that 27% of people with a disability in Australia live below the poverty line. Those who are reliant on Centrelink payments are more likely to be living below the poverty line than any others⁶.

Despite the fact that the majority of the sample was of working age, a high proportion (55%) were on defined low incomes, while a further potential 30% were on relatively low incomes in terms of average weekly earnings. This may be partly explained by the numbers who were studying (40 or 19 %) as well as those who were retired. However, there was a large percentage (102 or 58 %) of those not working who were on disability pensions. This might include both those who were unable to work because of their epilepsy (42 people or 21 %) or those who were unable to work due to another disability. Those unable to work because of their epilepsy constitute the single greatest number apart from those who had retired (50 or 25 %) representing almost all of those over the age of 60 in the sample.

Income for people with epilepsy regardless of the reason is relatively low. If students, pensioners and retirees are all in the lowest income brackets they are well under the poverty line of \$352 for a single person or \$471 for a couple in 2010^{7,8,9}.

Lower incomes may lead to financial distress where people have difficulty affording necessary items on a regular basis. Not being able to afford food, clothes, rent or mortgages, health care as well as holidays and entertainment all indicate levels of financial distress¹⁰.

2.5 Financial distress

Table 9: Perceptions of family income and financial responsibilities

| Prosperous | Very comfortable | Reasonably comfortable | Just getting along | Poor | Very poor | Total |
|-------------|------------------|------------------------|--------------------|-------------|------------|---------------|
| 10 (3 %) | 32 (11 %) | 137 (46 %) | 104 (35%) | 12 (4 %) | 4 (1 %) | 299 (100%) |

Missing: 25

People were asked to describe their current family income and financial responsibilities. Forty per cent considered themselves to be 'just getting along', 'poor' or 'very poor'.

Each year HILDA asks this question of their survey participants. In 2009 men and women aged between 25 and 54 responded in the following manner: 52% considered the family to be 'reasonably comfortable'; 16% 'very comfortable' and only 2% considered their family 'prosperous. At the other

end of the scale, 27% said their family was 'just getting along'; 3% considered their families to be 'poor' and 1% that their families were 'very poor'¹¹.

Table 10: Indicators of financial distress

| | Could not pay utilities on time | Could not pay mortgage/rent on time | Pawned or sold item | Went without meals | Unable to heat home | Asked financial help from family/friends | Asked help from welfare/community organisations |
|-------|---------------------------------|-------------------------------------|---------------------|--------------------|---------------------|--|---|
| Yes | 66 (23%) | 38 (13.5%) | 46 (16%) | 34 (12%) | 21 (7.5%) | 75 (26%) | 32 (11%) |
| No | 219 (77%) | 241 (86.5%) | 238 (84%) | 250 (88%) | 257 (92.5%) | 212 (74%) | 250 (89%) |
| Total | 285 (100%) | 279 (100%) | 284 (100%) | 284 (100%) | 278 (100%) | 287 (100%) | 282 (100%) |

Table 10 indicates the level of financial distress that some families with epilepsy face. Most people showed a reliance on family and friends to help them out while delaying paying utility bills was another strategy to manage financial distress. These figures for people with epilepsy may be compared to the Household, Income, Labour Dynamics in Australia (HILDA) study, Wave 8 in 2010 which comprised 7495 working age individuals (aged between 21 and 64). In this study 21% of the sample reported financial distress¹². However 12.5% reported inability to pay utility bills on time; 6% reported inability to pay mortgage or rent on time; 3.7% pawned or sold something, 3% went without meals; 2% were unable to heat their homes; 12% asked friends or family for financial help and 3.5% asked for help from a welfare organization.

In the case of families with epilepsy the results are 2 to 3 times higher.

Respondents were asked a hypothetical question about raising money for an emergency, and how difficult that might be. The question asked, "Suppose you had only one week to raise \$2000.00 for an emergency. Which response best describes how hard it would be for you to get that money?"

Table 11: Suppose you only had one week to raise money for an emergency. Which response best describe how hard it would be for you to get the money?

| | |
|--|-------------|
| I could easily raise the money | 111 (36.5%) |
| I could raise the money but it would involve some sacrifices | 93 (31%) |
| I would have to do something drastic to raise the money | 38 (12.5%) |
| I don't think I could raise the money | 61 (20%) |
| Total | 303 (100%) |

Missing: 21

While more than a third of respondents could easily raise the money, more than two fifths would place themselves in graduated levels of distress. A fifth of the total would not be able to do it.

In HILDA Wave 8 nearly twice the proportion of people in this HILDA sample (61%) responded that they could easily raise the money than did people with epilepsy. Additionally twice the proportion of

people with epilepsy (20%) compared to those in the HILDA survey (10.5%) could not raise the money at all ¹².

Table 12 provides more data on the financial distress caused by the need for money in an emergency by focusing on the options respondents have to raise the money.

Table 12: raising money in an emergency

| | |
|--|------------|
| Use savings | 152 (59%) |
| Borrow from a relative who lives with you | 15 (6%) |
| Borrow from a relative who lives elsewhere | 34 (13%) |
| Borrow from a friend | 1 (.5) |
| Borrow from an financial institution or use credit | 32 (12%) |
| Sell an asset | 21 (8%) |
| Use some other method to find the money | 4 (1.5%) |
| Total | 259 (100%) |

Missing: 65

While using savings was the option open to over half of the respondents this will include some people who responded to the previous question that raising the money meant making sacrifices. By far the greater number of respondents had to borrow from family or a financial institution including credit card or sell an asset.

In comparison more than two thirds (70%) of respondents in the HILDA Wave 8 survey would use savings to raise the money while 59% of the respondents to the epilepsy survey would do so. A higher proportion of respondents (32%) in the HILDA Wave 8 were more likely to borrow from a relative than were those (19%) in the epilepsy survey, while 37% of the HILDA survey were likely to use credit or sell an asset than were respondents (9.5%) in the epilepsy survey ¹².

Table 13 explores respondents and their families' ability to save from their incomes

Table 13: Which of the following comes closest to describing you and your family's saving habits?

| | |
|--|------------|
| Don't save: usually spend more than income | 25 (8.5%) |
| Don't save: usually spend about as much as income | 61 (20.5%) |
| Save whatever is left over at the end of the month. No regular pattern | 93 (31%) |
| Spend regular income; save other income | 26 (8.5%) |
| Save regularly by putting money aside each month | 94 (31.5%) |
| Total | 299 (100%) |

Missing:25

Twenty nine percent did not save from their incomes while another 39.5% appeared to save intermittently. Whereas 5.5% of the HILDA Wave 8 survey respondents spent more than their income, 8.5% of people in the epilepsy survey were in this category. Of the respondents to the epilepsy survey 31.5% were able to save on a regular monthly basis compared to a lower proportion (26.5%) in the HILDA Wave 8 survey ¹².

Table 14 demonstrates participants' abilities to plan ahead financially.

Table 14: In planning your savings and spending, which of the following time periods is most important to you?

| | |
|--------------------------|------------|
| The next week | 69 (23.5%) |
| The next few months | 92 (31%) |
| The next year | 46 (15.5%) |
| The next 2 to 4 years | 29 (10%) |
| The next 5 to 10 years | 37 (12.5%) |
| More than 10 years ahead | 22 (7.5%) |
| Total | 295 (100%) |

Missing:29

Being able to save over a longer period time means that people are able to plan their lives adequately and do not simply have to react to crises in spending. The ability to plan ahead in terms of savings is limited amongst this group of people. More than 54% were unable to think of saving beyond the next few months, while 20% were able to think about saving in terms of more than 5 years. This is very similar to the HILDA wave 8 responses where 23.7% of participants were only able to think of this in terms of the next week; 30.5% were thinking in terms of the next few months; and 18.5% were thinking of beyond 5 years ¹².

The ability to save and plan ahead has implications for being able to access medicines and attend appointments. The following tables provide data on costs of treatments. As yet no data on the implications of these costs have been collected in the epilepsy surveys.

Table 15: Average cost of epilepsy medication per month

| Under \$10 | \$11-\$50 | \$51-\$100 | \$101-\$200 | \$201-\$300 | \$301-\$400 | Total |
|------------|-----------|------------|-------------|-------------|-------------|-----------|
| 52 (18.5%) | 129 (46%) | 70 (25%) | 27 (9.5%) | 2 (.5%) | 2 (.5%) | 282(100%) |

Missing: 42

Table 16: Average cost of treatment related travel

| Under \$10 | \$11-\$50 | \$51-\$100 | \$101-\$200 | \$201-\$300 | \$301-\$400 | Total |
|------------|-----------|------------|-------------|-------------|-------------|-------|
| | | | | | | |

| | | | | | | |
|-----------|----------|-----------|---------|--------|---------|------------|
| 146 (53%) | 77 (28%) | 26 (9.5%) | 22 (8%) | 3 (1%) | 1 (.5%) | 275 (100%) |
|-----------|----------|-----------|---------|--------|---------|------------|

Missing: 49

2.6 The impact of seizures

2.6.1 Details of seizures

Of those who responded to this question, a little less than a quarter had experienced seizures before the age of ten years with another 20% before the age of twenty-one. Numbers beyond that tended to decrease in age groups beyond that.

Table 17: Age at which experienced first seizures

| Age | Seizures first experienced | Time of diagnosis |
|------------------|----------------------------|-------------------|
| Less than 1 year | 17 (8.5%) | 8 (4%) |
| 1-4 years | 28 (13.5%) | 35 (17%) |
| 5-9 years | 28 (13.5%) | 16 (8%) |
| 10-15 years | 34 (11%) | 38 (18%) |
| 16-20 years | 28 (16.5%) | 32 (15.5%) |
| 21-25 years | 20 (10%) | 19 (9%) |
| 26-30 years | 15 (7.5%) | 18 (9%) |
| 31-40 years | 16 (8%) | 18 ((9%) |
| 41-50 years | 10 (5%) | 11 (5%) |
| 50 + | 11 (5.5%) | 12 (5.5%) |
| Total | 207 (100 %) | 207 (100%) |

Missing: 117

More than fifty per cent who responded had experienced their first seizures below the age of 20, with the majority of them experiencing first seizures below the age of 10. This table and the following table indicate that the majority were affected by epilepsy in their formative years.

Missing: 117

Table 18: Number of seizures in past twelve months

| No seizures in 12 mths | < 1 per mth | 1 or more per mth | 1 or more per week | Total |
|------------------------|-------------|-------------------|--------------------|------------|
| 106 (36%) | 88 (30%) | 53 (18%) | 48 (16%) | 295 (100%) |

Missing: 29

Two hundred and ninety five people answered the question on the number of seizures they had experienced in the last 12 months. Eighteen percent had one or more seizures per month with a further 16% having one or more per week. This suggests a small group with poorer seizure control though the number of seizures may not necessarily correlate with the severity or the type of

seizures. For this group however, levels of control have consequences for their quality of life. The following tables add to the clinical picture of the consequences of epilepsy among this group.

Table 19: Are you currently taking medicines to control epilepsy?

| | |
|-------|-------------|
| Yes | 275 (95.5%) |
| No | 13 (4.5%) |
| Total | 288 (100%) |

Missing: 36

Table 20: If not, is this because

| I am seizure free | I am following medical advice | I prefer not to take medicine | Total |
|-------------------|-------------------------------|-------------------------------|-----------|
| 6 (54.5%) | 3 (27.5%) | 2 (18%) | 11 (100%) |

Missing: 313

By far the majority of respondents were taking medicines to control their epilepsy though this does not indicate the level of control gained from the medicines. Of the 13 who were not taking medicines only 2 responded they preferred not to.

The number of medicines indicates the level of control with the large number suggesting less control¹³. Seventy per cent of the survey respondents were taking one or two medicines, in line with the generally accepted view that this proportion of the epilepsy population will achieve seizure control¹⁴.

Another 25.5 % were taking three and up to six medicines to gain some seizure control.

Table 21: Number of epilepsy drugs/medicines currently taken

| No drugs | 1 type | 2 types | 3 types | 4 types | 5 types | 6 or more | Total |
|----------|-----------|------------|----------|-----------|----------|-----------|------------|
| 12 (4%) | 114 (40%) | 87 (30.5%) | 46 (16%) | 18 (6.5%) | 5 (1.5%) | 4 (1.5%) | 286 (100%) |

Missing: 38

The following tables add to this picture of control and medicines. While 53% had frequent seizures before commencing their current treatment regime and a further 37.5% had occasional seizures (making this combined group the overwhelming majority) this changed to 39.5% having no seizures while occasional seizures remained at the same level following the commencement of current treatment. At the same time a smaller group of respondents (12.5%) reported reduced but still frequent seizures and others 93%) reported an increase in their seizures.

Table 22: Frequency of seizures before current treatment

| | |
|---------------------|-------------|
| No seizures at all | 29 (10.5%) |
| Occasional seizures | 105 (37.5%) |
| Frequent seizures | 145 (52%) |
| Total | 279 (100%) |

Missing: 45

Table 23: Frequency of seizures following commencement of current treatment

| | |
|-------------------------------------|-------------|
| Reduced to no seizures at all | 108 (39.5%) |
| Only occasional seizures | 100 (37%) |
| Reduced but still frequent seizures | 34 (12.5%) |
| Not changed | 22 (8%) |
| Increased | 22 (3%) |
| Total | 272 (100%) |

Missing: 52

2.6.2 The social consequences of epilepsy: employment and education

The next set of tables contributes to the picture of the social consequences of epilepsy in particular with regard to employment and education.

Table 24: Were you absent from work due to epilepsy during the last twelve months?

| | |
|----------------|------------|
| Yes | 75 (28.5%) |
| No | 100 (38%) |
| Not applicable | 88 (33.5%) |
| Total | 263 (100%) |

Missing: 61

Of those who answered this question, more than a quarter had missed some work in the past twelve months. If, however those for whom this question was not applicable or did not answer it are removed then the response is 43% (75:175) who missed work due to epilepsy in the last twelve months.

Of those (n=75) who were absent from work in the last twelve months, there were 34 people who missed between 1 and 365 working days and a further 11 who missed part of a day but less than one day. The remaining 30 are treated as missing responses. Total number of working days lost is 1483 days among 45 people or an average of 33 days.

Compare this with chronic pain which is widely accepted as having a strong impact on work performance and days lost ¹⁵. Working with pain was more common (on average 83.8 days over a six month period) than lost work days due to pain (4.5 days) among chronic pain participants in full time or part time employment. When both lost work days and reduced effectiveness work days were summed, an average of 16.4 lost work day equivalents occurred in a six month period, approximately three times the average number of lost work days. These figures suggest a similarity between chronic pain and epilepsy with regard to reduced effectiveness (part days in epilepsy) and lost days over a year.

Table 25: Were you absent from school due to epilepsy during the last 12 months?

| | |
|----------------|------------|
| Yes | 34 (20%) |
| No | 51 (29%) |
| Not applicable | 92 (51%) |
| Total | 178 (100%) |

Missing: 146

Of the 34 students who missed school due to epilepsy, 16 missed between 1 and 83 days. Five missed part of a day but less than 1 day. The remaining 13 did not give a number of days missing from school and consequently are reported as missing. This means that from the total of 211 school days lost among the 21 people there is an average of 10 days per student.

2.6.3 The social consequences of epilepsy: injuries and trauma

Table 26: Injuries as a result of seizures in the past three years

| | |
|-------|------------|
| Yes | 118 (40%) |
| No | 179 (60%) |
| Total | 297 (100%) |

Missing: 27

Of the 297 who responded, 40% had suffered injuries. These ranged from bruising, broken bones, dislocated joints, tongue damage and dental problems. Even more serious injuries included vehicle accidents, head trauma and an amputation. Some people reported multiple injuries such as stitches, concussion, burns and torn ligaments; spinal fracture, broken ankle, cuts and bruising; bruising and head injury and bitten tongue, car accident, whiplash and bruising.

Respondents who had been injured reported where some of these injuries took place. Most reported multiple sites with the greatest number (65) being at home. Two people reported being in a motor vehicle at the time of a seizure. There were ten reports of injuries in the street or on public transport, with one person reporting falling in front of an oncoming train. A smaller number reported seizures at hospitals, friends' houses and at work or school.

Table 27: Injuries requiring hospital treatment

| | |
|-------|------------|
| Yes | 73 (47%) |
| No | 83 (53%) |
| Total | 156 (100%) |

Missing: 168

Of the 118 people who had an injury due to a seizure 73 or 62% of them required hospital treatment. However, not attending hospital does not indicate the injuries were minor. Eight people reporting dental injuries, either saw a dentist, or did not seek treatment. Nine people reported concussion and there is some evidence that some took a 'wait and see' approach, based on previous experience. Others reported head injuries and 'bumps to the head' and there were four people who required stitches.

2.6.4 Seizures experienced by survey respondents

Table 28: Types of seizures experienced

| | Simple partial | Complex partial | Absence | Myoclonic | Tonic Clonic | Tonic | Atonic | Other |
|----------------|----------------|-----------------|-----------|-----------|--------------|----------|------------|-------|
| Yes | 102 (53%) | 131 (59.5%) | 142 (63%) | 51 (29%) | 194 (79%) | 42 (25%) | 24 (15%) | 0 |
| No | 46 (23.5%) | 50 (22.5%) | 40 (18%) | 70 (39%) | 19 (8%) | 61 (36%) | 67 (41.5%) | 0 |
| Unsure | 46 (23.5%) | 40 (18%) | 42 (19%) | 57 (32%) | 32 (13%) | 65 (39%) | 70 (43.5%) | 0 |
| Total | 194 | 221 | 224 | 178 | 245 | 168 | 161 | 0 |
| <i>Missing</i> | 130 | 103 | 100 | 146 | 79 | 156 | 163 | 324 |

Of the seven types of seizures, tonic clonic seizures were the most common with 79% (194) of all respondents experiencing this type of seizure. Absence seizures (63%), complex partial (59.5%) and simple partial (53%) were the other common types of seizure experienced. Atonic (15%) and tonic (25%) seizure were rare for the current sample. These responses also demonstrate that some people suffered several types of seizures possibly contributing to the level of uncertainty about which ones they were.

2.6.5 Medical consultations

The levels of uncertainty recorded here suggest a number of matters: that for a high proportion of the respondents the different types of seizures suffered which may be confusing; the lack of

observation of seizures so that the types are not known; health literacy of the person and the degree of communication between the consumer and the neurologist regarding diagnosis.

Table 29: Do you feel you are given adequate time and opportunity to discuss your concerns with your doctor?

| Always | Often | Sometimes | Not often | Never | Total |
|-----------|------------|------------|-----------|--------|------------|
| 119 (40%) | 70 (23.5%) | 60 (20.5%) | 38 (13%) | 9 (3%) | 296 (100%) |

Missing: 28

Despite any confusion as to the types of seizures respondents experienced, there was a strong view that there was adequate time to discuss their concerns with their doctor. Sixty three per cent responded 'always' or 'often' with only 16% considering this happened 'never' or 'not often'.

2.6.6 Surgery

Forty five people responded positively to a question about having surgery with the vast number of respondents not having had it. Mostly, surgery took place after the year 2000.

Table 30: Have you had surgery for epilepsy?

| | |
|-------|------------|
| Yes | 45 (15%) |
| No | 256 (85%) |
| Total | 301 (100%) |

Missing 23

2.6.7 Social relationships and seizures

Table 31: How much does epilepsy and its treatment affect:

| | A lot | Some | A little | Not at all | Not applicable | Total | Missing |
|-------------------------------------|------------|------------|------------|------------|----------------|------------|---------|
| Your relationship with your partner | 34 (11.5%) | 39 (13.5%) | 42 (14.5%) | 66 (22.5%) | 113 (38%) | 294 (100%) | 30 |
| Your relationship with other family | 60 (20.5%) | 62 (21%) | 61 (21%) | 99 (34%) | 11 (3.5%) | 293 (100%) | 31 |

| | | | | | | | |
|---|------------|------------|------------|------------|-----------|------------|----|
| members | | | | | | | |
| Your overall health | 81 (27.5%) | 95 (32.5%) | 66 (22.5%) | 40 (14%) | 10 (3.5%) | 292 (100%) | 32 |
| The way you feel about yourself | 86 (29.5%) | 62 (21.5%) | 78 (27%) | 56 (19%) | 9 (3%) | 291 (100%) | 31 |
| Your sense of self-esteem | 81 (27.5%) | 63 (21.5%) | 70 (24%) | 69 (23.5%) | 10 (3.5%) | 293 (100%) | 31 |
| Your plans and ambitions for the future | 100 (34%) | 61 (21%) | 57 (19.5%) | 59 (20%) | 16 (5.5%) | 294 (100%) | 30 |
| Your standard of living | 58 (20%) | 55 (19%) | 50 (17%) | 110 (37%) | 21 (7%) | 293 (100%) | 31 |
| Your confidence | 84 (26%) | 57 (17.5%) | 77 (24%) | 63 (19%) | 12 (4%) | 293 (100%) | 31 |
| Your ability to be a good parent | 26 (9%) | 33 (11.5%) | 32 (11%) | 71 (24.5%) | 128 (44%) | 290 (100%) | 34 |

Table 31 demonstrates that having epilepsy has a significant effect on relationships. A quarter of respondents felt it impacted on their relationships with partners, while more than a third recorded it impacting on their relationships with other family members. This in turn was reflected in respondents' self-esteem and the way they felt about themselves with around half of them recording the impact on these areas as a lot or some. Half the respondents recorded a higher negative impact from epilepsy on their plans for the future, a smaller number felt it impacted on their confidence, as well as standard of living. One hundred and sixty two answered the question whether epilepsy affected their ability to be a good parent, with the others in the not applicable or did not answer category. Fifty nine or 20.5% of that group considered epilepsy affected their ability to be a good parent. More than half of all the survey respondents considered that their epilepsy negatively impacted on their overall health.

The significance of epilepsy is underscored by the results from the HILDA Wave 11 survey statistics where people responded to a similar question: "During the past four weeks to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?"¹⁶ In this survey, 61% of respondents answered "not at all" whereas the epilepsy response was 22.5% for relationships with partners and more than a third for the relationship with other family members. Similarly in the HILDA survey about 17.5% felt their physical and emotional health had affected their normal social activities. This was considerably less than the effect that epilepsy had on social relationships.

Table 32: How comfortable do you feel when you talk about your epilepsy to:

| | Very uncomfortable | Somewhat uncomfortable | Not sure | Somewhat comfortable | Very comfortable | Total | Missing |
|-------------------------------|--------------------|------------------------|------------|----------------------|------------------|------------|---------|
| Your employer | 59 (24%) | 68 (28%) | 33 (13.5%) | 35 (14.5%) | 48 (20%) | 243 (100%) | 81 |
| Other people in the workplace | 40 (16.5%) | 71 (29.5%) | 35 (14.5%) | 45 (18.5%) | 51 (21%) | 242 (100%) | 82 |
| A new partner | 37 (15.5%) | 44 (18.5%) | 89 (38%) | 25 (11%) | 40 (17%) | 235 (100%) | 89 |
| A prospective partner | 43 (18%) | 42 (18%) | 93 (39%) | 21 (9%) | 38 (16%) | 237 (100%) | 87 |
| A new friend | 38 (14%) | 83 (30.5%) | 38 (14%) | 59 (21.5%) | 55 (20%) | 273 (100%) | 51 |
| A prospective new friend | 44 (16.5%) | 70 (26%) | 50 (18.5%) | 53 (20%) | 52 (19%) | 275 (100%) | 55 |

Table 32 does not consistently reflect the strong negative impact of epilepsy demonstrated by responses to the previous question. Workplace situations drew strong polarised responses with nearly as many people (127) considering they feel very/somewhat uncomfortable talking to their boss or workmates about their epilepsy as those who felt very/somewhat comfortable (129). Overall respondents felt they would be very/somewhat comfortable in personal relationships except when it came to new friendships where 40.5% considered they would be very/somewhat uncomfortable.

It is useful to compare some of these responses to another highly stigmatized condition-in this case depression. Stigma affecting employment, health insurance, and friendships was explored in 1,187 depressed patients in U.S. primary care clinics. Stigma associated with depression, HIV, diabetes, and hypertension was compared. Sixty seven per cent of depressed primary care patients expected depression related stigma to have a negative effect on employment, 59% on health insurance, and 24% on friendships. Stigma associated with depression was greater than for hypertension or diabetes but not HIV¹⁷. While exact comparisons can't be made, it is possible to argue that when the two workplace responses for people with epilepsy are combined then both people with epilepsy and people with depression expect stigma to have a similar impact on their workplace experiences, while the effect of epilepsy on friendships is far higher.

Table 33: How often do you experience:

| | Never | Not often | Some of time | Often | Very often | Total | Missing |
|---|-------------|------------|--------------|-----------|------------|------------|---------|
| People will not want to go out with me if they know I have epilepsy | 118 (43%) | 70 (25.5%) | 45 (16.5%) | 24 (8.5%) | 18 (6.5%) | 275 (100%) | 49 |
| People will not invite me to parties if they know I have epilepsy | 142 (52%) | 52 (19%) | 41 (15%) | 19 (7%) | 20 (7%) | 274 (100%) | 50 |
| I feel embarrassed about having epilepsy | 103 (37.5%) | 52 (19%) | 50 (18%) | 38 (14%) | 32 (11.5%) | 275 (100%) | 49 |
| I keep my epilepsy secret from others | 99 (36%) | 55 (20%) | 46 (17%) | 37 (13%) | 39 (14%) | 276 (100%) | 48 |
| I try to avoid talking to others about my epilepsy | 83 (30%) | 46 (17%) | 58 (21%) | 46 (17%) | 43 (15%) | 276(100%) | 48 |

The figures in Table 33 do not equate with previous views reflected in Table 26 and 27. Smaller numbers report they keep their epilepsy secret or do not talk about it and feel embarrassed about having epilepsy. This is in contrast to the responses about workplace relationships and making friends where far higher number reported negatively. Twenty seven per cent reported they avoided talking about their epilepsy, while 22.5% kept their epilepsy secret while previous responses showed that workplaces were place where people felt very/somewhat uncomfortable about these matters. Similarly far higher numbers reported problems with the impact of epilepsy on confidence, self-esteem and how they thought about themselves. Some of the response may be explained by level of seizure control. One way ANOVA showed significant differences between the effects of medication controlling epilepsy and the level of stigma experienced (see table 35). The biggest differences were between those who had no seizures at all and those who kept experiencing some seizures. Similarly with another chronic condition, asthma: in a small study of 71 people with asthma, Andrews, Jones and Mullan (2013) found that control of asthma accounted for major

differences in the stigma reported by people with asthma, where those with least control of their asthma reported experiencing the highest levels of stigma ¹⁸.

Table 34: Do the following statements reflect how you feel about your life?

| | Strongly disagree | Somewhat disagree | Slightly disagree | Neutral | Slightly agree | Somewhat agree | Strongly agree | Total | Missing |
|---|-------------------|-------------------|-------------------|----------|----------------|----------------|----------------|------------|---------|
| There is no way I can solve the problems I have | 53 (19%) | 24 (9%) | 18 (6.5%) | 41 (15%) | 38 (14%) | 35 (13%) | 65 (23.5%) | 274(100%) | 50 |
| Sometimes I feel I am being pushed around in life | 54 (19.5%) | 24 (8.5%) | 15 (5.5%) | 49 (18%) | 60 (21.5%) | 47 (17%) | 28 (10%) | 277 (100%) | 47 |
| I have little control over things that happen to me | 44 (16%) | 49 (18%) | 27 (10%) | 39 (14%) | 48 (17.5%) | 37 (13.5%) | 31 (11%) | 275 (100%) | 49 |
| I can do just about anything I set my mind to | 18 (6.5%) | 22 (8%) | 26 (9%) | 41 (15%) | 54 (20%) | 64 (23%) | 51 (18.5%) | 276 (100%) | 48 |
| I often feel helpless dealing with problems in life | 43 (15.5%) | 45 (16.5%) | 26 (9.5%) | 38 (14%) | 60 (22%) | 37 (13.5%) | 25 (9%) | 274 (100%) | 50 |
| What happens to me in future mostly | 13 (5%) | 14 (5%) | 9 (3.5%) | 38 (14%) | 48 (17.5%) | 62 (22.5%) | 89 (32.5%) | 273 (100%) | 51 |

| | | | | | | | | | |
|---|------------|------------|------------|----------|----------|------------|---------|------------|----|
| depends on me | | | | | | | | | |
| There is little I can do to change many important things in my life | 51 (18.5%) | 57 (20.5%) | 29 (10.5%) | 52 (19%) | 33 (12%) | 29 (10.5%) | 24 (9%) | 275 (100%) | 49 |

It is useful to contrast the levels of control people with epilepsy consider they have with responses from Wave 11 of HILDA. A third of HILDA respondents strongly disagreed with the statement that they could not solve their problems, while only 19% of people in the epilepsy survey strongly disagreed. While 3% of HILDA respondents strongly agreed they could not solve their problems, 23% of people in the epilepsy survey felt this reflected how they felt. There were similar results with the statement that sometimes people felt they were being pushed around in their lives, with 36.5% of HILDA respondents strongly disagreeing and 19.5% of respondents to the epilepsy survey. Three times (10%) as many respondents from the epilepsy survey considered this statement represented their feeling than did respondents (3%) to the HILDA survey. These differences in levels of control between the two surveys are reflected throughout.

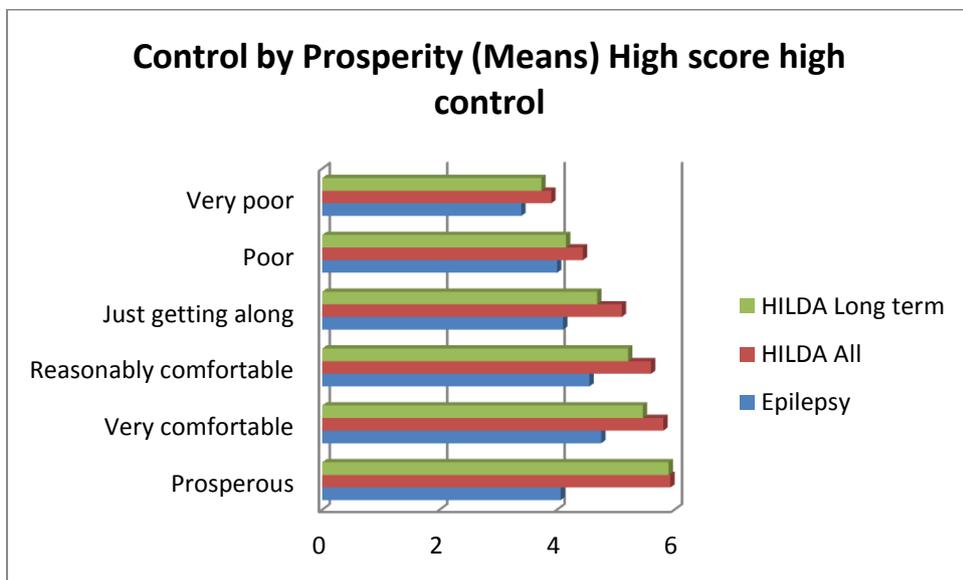
2.6.8: Epilepsy, self-perceived prosperity and personal control.

The extent to which epilepsy plays a negative role in the lives of people with epilepsy can be seen when levels of prosperity are associated with levels of personal control. In well populations there is a direct linear relationship between levels of prosperity and levels of personal control so that prosperous people feel more in control of their decisions as well as having a level of control over any future events that might impinge on their lives. This is not the case in all the domains of personal control measured above for Wave 3. In the three domains of personal control represented by the statements: 'There is no way I can solve the problems I have'; 'I have little control over things that happen to me' and 'There is little I can do to change many of the important things in my life' this linear relationship was not followed.

The following figures and tables demonstrate the relationships between level of perceived prosperity and personal control in Wave 3, comparing these relationships with HILDA Wave 11.

Overall on the scale of personal control and prosperity it can be seen in the figure (below) that Wave 3 people report a much lower level of control overall on all dimensions of perceived prosperity than people in HILDA All (Wave 11) and in HILDA Those with a long term health condition, disability or impairment. A high score represents high control and a low score, poor control.

Figure 1: Control by prosperity



In the three domains of personal control represented by the statements: 'There is no way I can solve the problems I have'; 'I have little control over things that happen to me' and 'There is little I can do to change many of the important things in my life' the diagonal linear relationship found in the two HILDA samples was not followed in Wave 3.

Table 35: There is no way I can solve some of the problems I have by prosperity: Wave 3

| | Prosperous | Very comfortable | Reasonably comfortable | Just getting along | Poor | Very poor | Total |
|-------------------|-----------------|------------------|------------------------|--------------------|-----------------|-----------------|-------------------|
| Strongly agree | 1 (11.1%) | 9 (32.1%) | 18 (14.4%) | 27 (29.7%) | 6 (50%) | 2 (50%) | 63 (23.4%) |
| Somewhat agree | 2 (22.2%) | 3 (10.7%) | 13 (10.4%) | 13 (14.3%) | 2 (16.7%) | 1 (25.0%) | 34 (12.6%) |
| Slightly agree | 4 (44.4%) | 2 (7.1%) | 18 (14.4%) | 14 (15.4%) | 0 | 0 | 38 (14.1%) |
| Neutral | 0 | 3 (10.7%) | 23 (18.4%) | 14 (15.4%) | 0 | 1 (25.0%) | 41 (15.2%) |
| Slightly disagree | 0 | 1 (3.6%) | 10 (8.0%) | 7 (7.7%) | 0 | 0 | 18 (6.7%) |
| Somewhat disagree | 0 | 2 (7.1%) | 18 (14.4%) | 2 (2.2%) | 1 (8.3%) | 0 | 23 (8.6%) |
| Strongly disagree | 2 (22.2%) | 8 (28.6%) | 25 (20.0%) | 14 (15.4%) | 3 (25.0%) | 0 | 52 (19.3%) |
| Total | 9 (100%) | 28 (100%) | 125 (100%) | 91 (100%) | 12 (100) | 4 (100%) | 269 (100%) |

The 'very poor' agree that they cannot solve the problems they have, and the 'poor' mostly do (although one third somewhat or strongly disagrees with the statement. About 60% of those 'just getting along' slightly to strongly agree they cannot solve their problems, while about only 40% of the 'reasonably comfortable' slightly to strongly agree. Surprisingly half of the 'very comfortable' slightly to strongly agree they cannot solve their problems, offering an unusual exception to other observed trends where personal control and mastery are directly linked to levels of financial comfort. Rather than the linear relationship the above table suggests a U shaped curve not linking financial prosperity with sense of personal control beyond being comfortable.

Compare this with data from all the HILDA respondents for the same question:

Table 36: There is no way I can solve some of the problems I have by prosperity: HILDA (all)

| | Prosperous | Very comfortable | Reasonably comfortable | Just getting along | Poor | Very poor | Total |
|-------------------|-------------|------------------|------------------------|--------------------|------------|------------|--------------|
| Strongly agree | 9 (3.1%) | 52 (2.3%) | 156 (2.0%) | 198 (4.7%) | 44 (10.3%) | 25 (22.9%) | 484 (3.2%) |
| Somewhat agree | 3 (1.0%) | 61 (2.7%) | 286 (3.6%) | 296 (7.0%) | 60 (14.0%) | 18 (16.5%) | 724 (4.8%) |
| Slightly agree | 11 (3.8%) | 83 (3.7%) | 446 (5.7%) | 382 (9.1%) | 67 (15.7%) | 13 (11.9%) | 3002 (6.6%) |
| Neutral | 19 (6.6%) | 135 (6.0%) | 658 (8.4%) | 590 (14.0%) | 73 (17.1%) | 19 (17.4%) | 1494 (9.9%) |
| Slightly disagree | 14 (4.9%) | 187 (8.9%) | 873 (11.1%) | 601 (14.2%) | 49 (11.4%) | 8 (7.3%) | 1732 (11.4%) |
| Somewhat disagree | 84 (29.3%) | 704 (31.3%) | 2643 (33.7%) | 1121 (26.6%) | 62 (14.5%) | 15 (13.8%) | 4629 (30.6%) |
| Strongly disagree | 147 (51.2%) | 1030 (45.7%) | 2774 (35.4%) | 1030 (21.4%) | 73 (17.1%) | 11 (10.1%) | 5065 (33.5%) |
| Total | 287 (100%) | 2252 (100%) | 7836 (100%) | 4218 (100%) | 428 (100%) | 109 (100%) | 15130 (100%) |

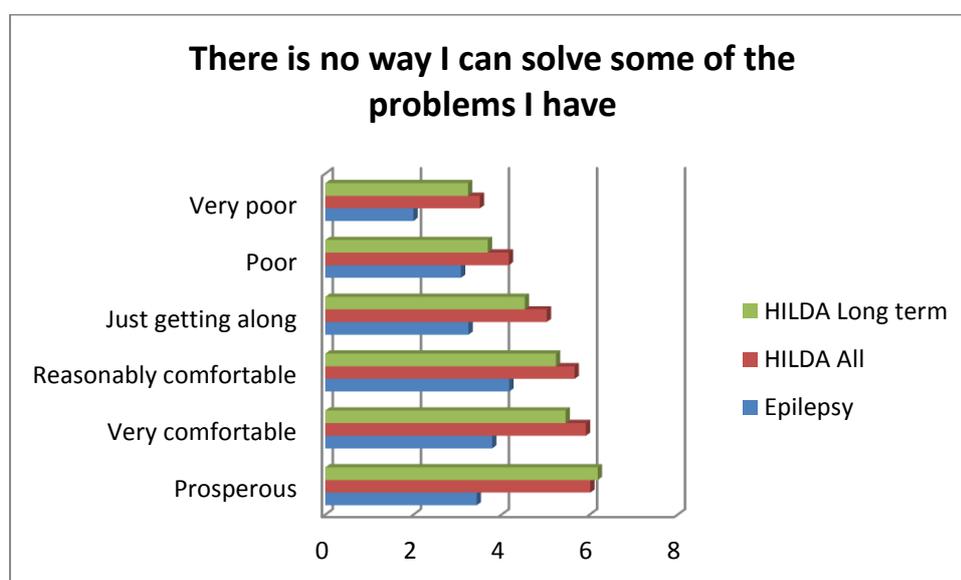
In HILDA around 50% of the very poor slightly to strongly agreed there is no way they could solve their problems. A slightly smaller proportion of the poor felt the same. Only about 21% of those just getting along felt the same while only approximately 11% of those reasonably comfortable slightly to strongly agreed there is no way they can solve their problems. Almost 9% of those very comfortable felt the same and only about 8% of those regarding themselves as prosperous slightly to strongly agreed. These results are what would be expected. There is no U shaped relationship as found with the Wave 3 sample.

It is interesting to compare the Wave 3 group with the subset of HILDA respondents who have a long term health condition, disability or impairment:

Table 37: There is no way I can solve some of the problems I have by prosperity: HILDA (long term health conditions etc.)

| | Prosperous | Very comfortable | Reasonably comfortable | Just getting along | Poor | Very poor | Total |
|-------------------|------------|------------------|------------------------|--------------------|------------|------------|-------------|
| Strongly agree | 0 | 24 (6.8%) | 78 (4.8%) | 99 (8.0%) | 35 (17.2%) | 16 (27.1%) | 252 (7.2%) |
| Somewhat agree | 0 | 14 (3.9%) | 103 (6.3%) | 132 (10.7%) | 35 (17.2%) | 10 (16.9%) | 294 (8.4%) |
| Slightly agree | 1 (3.8%) | 21 (5.9%) | 135 (8.3%) | 149 (12.00%) | 32 (15.7%) | 9 (15.3%) | 347 (9.9%) |
| Neutral | 2 (7.7%) | 27 (7.6%) | 183 (11.2%) | 209 (16.9%) | 35 (17.2%) | 8 (13.6%) | 464 (13.2%) |
| Slightly disagree | 1 (3.8%) | 39 (11.0%) | 177 (10.9%) | 172 (13.9%) | 21 (10.3%) | 5 (8.5%) | 415 (11.8%) |
| Somewhat disagree | 9 (34.6%) | 91 (25.6%) | 443 (27.2%) | 235 (19.0%) | 15 (7.4%) | 6 (10.2%) | 799 (22.8%) |
| Strongly disagree | 13 (50.0%) | 139 (39.2%) | 509 (31.3%) | 242 (19.5%) | 31 (15.2%) | 5 (8.5%) | 939 (25.8%) |
| Total | 26 (100%) | 355 (100%) | 1628 (100%) | 1238 (100%) | 204 (100%) | 59 (100%) | 3510 (100%) |

Figure 2: Problem solving and prosperity



Of the HILDA sample with long term health conditions, disability or impairment, 60% of the very poor and 50% of the poor report there is no way they can solve some of the problems they have. This compares with 4% of the prosperous, 15% of the very comfortable and 20% of the reasonably comfortable, demonstrating a linear relationship.

HILDA respondents with a long term health conditions, disability or impairment are similar in distribution to all HILDA respondents (above) and don't demonstrate a U shaped curve like the Wave 3 sample.

Table 38: I have little control over things that happen to me: Wave 3

| | Prosperous | Very comfortable | Reasonably comfortable | Just getting along | Poor | Very poor | Total |
|-------------------|------------|------------------|------------------------|--------------------|-----------|-----------|------------|
| Strongly agree | 3 (33.3%) | 2 (7.1%) | 9 (7.1%) | 10 (11.0%) | 5 (41.7%) | 1 (25.0%) | 30 (11.1%) |
| Somewhat agree | 2 (22.2%) | 2 (7.1%) | 14 (11.0%) | 18 (19.8%) | 1 (8.3%) | 0 | 37 (13.7%) |
| Slightly agree | 0 | 4 (14.3%) | 22 (17.3%) | 17 (18.7%) | 1 (8.3%) | 1 (25.0%) | 45 (16.6%) |
| Neutral | 0 | 7 (25.0%) | 20 (15.7%) | 10 (11.0%) | 1(8.3%) | 1 (25.0%) | 39 (14.4%) |
| Slightly disagree | 0 | 3 (10.7%) | 11 (8.7%) | 12 (13.2%) | 1 (8.3%) | 0 | 27 (10.0%) |

| | | | | | | | |
|-------------------|-----------|-----------|------------|------------|-----------|-----------|------------|
| Somewhat disagree | 0 | 5 (17.9%) | 28 (22.0%) | 14 (15.4%) | 1 (8.3%) | 1 (25.0%) | 49 (18.1%) |
| Strongly disagree | 4 (44.4%) | 5 (17.9%) | 23 (18.1%) | 10 (11.0%) | 2 (16.7%) | 0 | 44 (16.2%) |
| Total | 9 (100%) | 28 (100%) | 127 (100%) | 91 (100%) | 12 (100) | 4 (100%) | 271 (100%) |

In response to the statement about 'little control over things that happen to me', 55.5% of those who perceived themselves as prosperous agreed somewhat or strongly with this statement while 28% of the very comfortable and over 35% of the reasonably comfortable report low levels of control this aspect of their lives. More than half (58.5%) of those who considered themselves poor, slightly to strongly agreed with this statement. A quarter of the very poor quarter also strongly agreed. While this is not strictly U-shaped it is not linear and suggests a variation on the relationship between another aspect of personal control and levels of prosperity which is not generally seen. This is borne out with a comparison to HILDA data.

Table 39: I have little control over things that happen to me: HILDA (ALL)

| | Prosperous | Very comfortable | Reasonably comfortable | Just getting along | Poor | Very poor | Total |
|-------------------|-------------|------------------|------------------------|--------------------|------------|------------|--------------|
| Strongly agree | 12 (4.2%) | 71 (3.1%) | 220 (2.8%) | 181 (4.3%) | 39 (9.1%) | 17 (15.5%) | 540 (3.6%) |
| Somewhat agree | 9 (3.1%) | 65 (2.9%) | 322 (4.1%) | 263 (6.2%) | 50 (11.7%) | 16 (14.5%) | 725 (4.8%) |
| Slightly agree | 14 (4.9%) | 103 (4.6%) | 507 (6.5%) | 433 (10.3%) | 50 (11.7%) | 19 (17.3%) | 1126 (7.4%) |
| Neutral | 17 (5.9%) | 187 (8.3%) | 900 (11.5%) | 713 (16.9%) | 99 (23.2%) | 17 (15.5%) | 1933 (12.8%) |
| Slightly disagree | 24 (8.4%) | 233 (10.3%) | 1010 (12.9%) | 624 (14.8%) | 56 (13.1%) | 11 (10.0%) | 1958 (12.9%) |
| Somewhat disagree | 89 (31.1%) | 720 (31.9%) | 2373 (30.2%) | 999 (23.7%) | 61 (14.3%) | 16 (14.5%) | 4258 (28.1%) |
| Strongly disagree | 121 (42.3%) | 876 (38.8%) | 2517 (32.1%) | 1007 (23.9%) | 72 (16.9%) | 14 (12.7%) | 4607 (30.4%) |
| Total | 286(100%) | 2255 (100%) | 7849 (100%) | 4220 (100%) | 427 (100%) | 110 (100%) | 15147 (100%) |

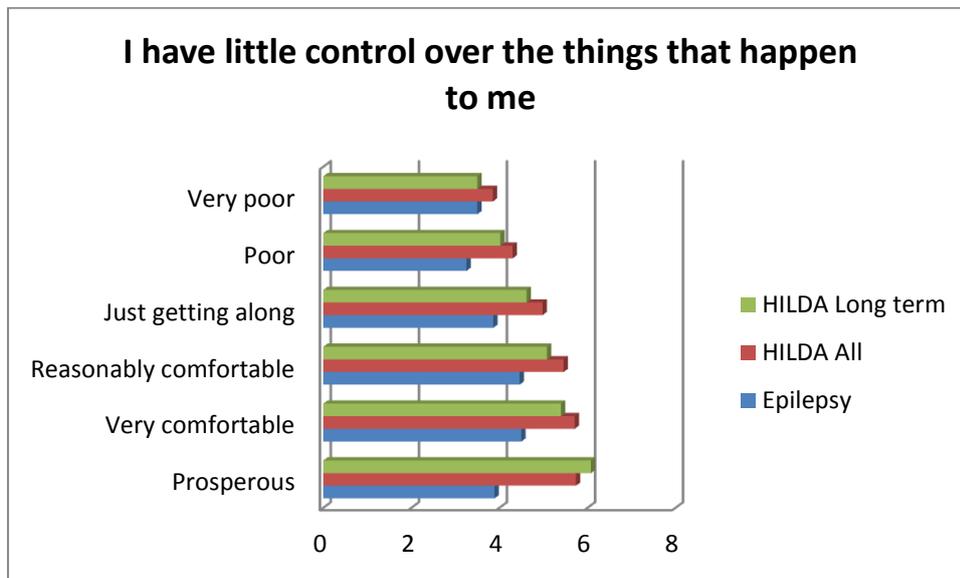
This shows a linear relationship between prosperity and levels of control with low control for the poor and very poor and high control for those who are more comfortable and prosperous.

Table 40: I have little control over the things that happen to me: HILDA Wave 11 People with a long term health condition etc.

| | Prosperous | Very comfortable | Reasonably comfortable | Just getting along | Poor | Very poor | Total |
|-------------------|------------|------------------|------------------------|--------------------|------------|------------|-------------|
| Strongly agree | 0 | 17 (4.8%) | 106 (6.5%) | 81 (6.5%) | 28 (13.8%) | 13 (21.7%) | 245 (7.0%) |
| Somewhat agree | 0 | 15 (4.2%) | 105 (6.4%) | 119 (9.6%) | 24 (11.8%) | 9 (15.0%) | 272 (7.7%) |
| Slightly agree | 0 | 24 (6.8%) | 139 (8.5%) | 156 (12.6%) | 21 (10.3%) | 13 (21.7%) | 353 (10.0%) |
| Neutral | 2 (8.0%) | 36 (10.1%) | 204 (12.5%) | 232 (18.8%) | 55 (27.1%) | 6 (10.0%) | 536 (15.2%) |
| Slightly disagree | 2 (8.0%) | 41 (11.5%) | 197 (12.0%) | 168 (13.6%) | 20 (9.9%) | 6 (10.0%) | 434 (12.5%) |
| Somewhat disagree | 13 (52.0%) | 104 (29.3%) | 420 (25.7%) | 213 (17.20%) | 27 (13.3%) | 5 (8.3%) | 782 (22.2%) |
| Strongly disagree | 8 (32.0%) | 118 (33.2%) | 464 (28.4%) | 268 (21.7%) | 28 (13.8%) | 8 (13.3%) | 894 (25.4%) |
| Total | 25 (100%) | 355 (100%) | 1635 (100%) | 1237 (100%) | 203 (100%) | 60 (100%) | 3515 (100%) |

This subset of the HILDA Wave 11 shows a stronger linear relationship compared to Wave 3 and to HILDA All. As one would expect the level of control declined steadily from the prosperous, very comfortable and reasonably comfortable so that 36% of the poor and 58% of the very poor reported having little control over the things that happened to them.

Figure 3: Control and prosperity



Respondents were asked to agree or otherwise with the statement: 'There is little I can do to change many of the important things in my life'. The following table demonstrates the relationship between prosperity and personal control over the ability to make changes in life.

Table 41: There is little I can do to change many of the important things in my life: Wave 3

| | Prosperous | Very comfortable | Reasonably comfortable | Just getting along | Poor | Very poor | Total |
|-------------------|------------|------------------|------------------------|--------------------|-----------|-----------|------------|
| Strongly agree | 2 (22.2%) | 1 (3.4%) | 9 (7.2%) | 10 (10.9%) | 1 (8.3%) | 1 (25.0%) | 24 (8.9%) |
| Somewhat agree | 2 (22.2%) | 0 | 14 (11.2%) | 10 (10.9%) | 0 | 2 (50.0%) | 28 (10.3%) |
| Slightly agree | 0 | 4 (13.8%) | 15 (12.0%) | 13 (14.1%) | 1 (8.3%) | 0 | 33 (12.2%) |
| Neutral | 0 | 3 (10.3%) | 21 (16.8%) | 22 (23.9%) | 4 (33.3%) | 0 | 50 (18.5%) |
| Slightly disagree | 0 | 3 (10.3%) | 13 (10.4%) | 10 (10.9%) | 2 (16.7%) | 1 (25.0%) | 29 (10.7%) |
| Somewhat disagree | 2 (22.2%) | 9 (31.0%) | 30 (24.0%) | 15 (16.3%) | 0 | 0 | 56 (20.7%) |
| Strongly disagree | 3 (33.3%) | 9 (31.0%) | 23 (18.4%) | 12 (13.0%) | 4 (33.3%) | 0 | 51 (18.8%) |
| Total | 9 (100%) | 29 (100%) | 126 (100%) | 92 (100%) | 12 (100) | 4 (100%) | 271 (100%) |

While the greatest agreement (75%) was amongst those who perceived themselves as very poor, 44% of those who were prosperous also agreed either 'somewhat' or 'strongly'. Thirty six per cent of those 'just getting along' slightly to strongly agreed with the statement. These responses suggest a curvilinear relationship. Comparisons with the HILDA Wave 11 data demonstrate that Wave 3 responses still demonstrate a deviation from the linear relationship.

Table 42: There is little I can do to change many of the important things in my life: HILDA Wave11 (All)

| | Prosperous | Very comfortable | Reasonably comfortable | Just getting along | Poor | Very poor | Total |
|-------------------|-------------|------------------|------------------------|--------------------|------------|------------|--------------|
| Strongly agree | 8 (2.8%) | 44 (2.0%) | 160 (2.0%) | 184 (4.4%) | 45 (10.5%) | 15 (13.5%) | 456 (3.0%) |
| Somewhat agree | 1 (0.3%) | 61 (2.7%) | 317 (4.0%) | 275 (6.5%) | 57 (13.3%) | 26 (23.4%) | 737 (4.9%) |
| Slightly agree | 9 (3.1%) | 84 (3.7%) | 454 (5.8%) | 439 (10.4%) | 71 (16.6%) | 11 (9.9%) | 1068 (7.1%) |
| Neutral | 20 (7.0%) | 176 (7.8%) | 800 (10.2%) | 711 (16.9%) | 69 (16.2%) | 20 (18.0%) | 1796 (11.9%) |
| Slightly disagree | 20 (7.0%) | 204 (9.1%) | 978 (12.5%) | 623 (14.8%) | 47 (11.0%) | 10 (9.0%) | 1882 (12.4%) |
| Somewhat disagree | 84 (29.3%) | 723 (32.2%) | 2603 (33.2%) | 1026 (24.3%) | 71 (16.6%) | 16 (13.5%) | 4522 (29.9%) |
| Strongly disagree | 146 (50.5%) | 966 (42.5%) | 2532 (32.2%) | 961 (22.8%) | 67 (15.7%) | 14 (12.6%) | 4674 (30.9%) |
| | 287 (100%) | 2247 (100%) | 7844 (100%) | 4219 (100%) | 427 (100%) | 111 (100%) | 15135 (100%) |

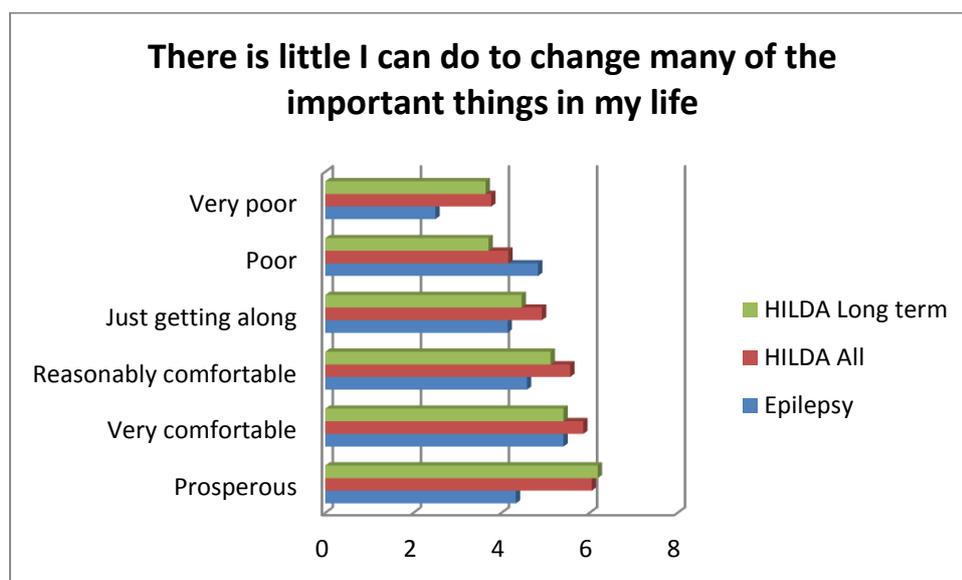
Forty eight per cent of the very poor and over 40% of the poor in this item report low levels of control. Only 6% of the prosperous and 8% of the very comfortable report poor control, thus demonstrating a strong linear relationship.

Table 43: There is little I can do to change many of the important things in my life: HILDA Long term health conditions etc.

| | Prosperous | Very comfortable | Reasonably comfortable | Just getting along | Poor | Very poor | Total |
|-------------------|------------|------------------|------------------------|--------------------|------------|------------|-------------|
| Strongly agree | 0 | 19 (5.4%) | 86 (5.3%) | 91 (7.4%) | 31 (15.3%) | 8 (13.1%) | 235 (6.7%) |
| Somewhat agree | 0 | 13 (3.7%) | 97 (5.9%) | 124 (10.0%) | 311(15.3%) | 17 (27.9%) | 282 (8.0%) |
| Slightly agree | 0 | 22 (6.3%) | 144 (8.8%) | 160 (12.9%) | 38 (18.7%) | 7 (11.5%) | 371 (10.6%) |
| Neutral | 3 (11.5%) | 40 (11.4%) | 205 (12.5%) | 249 (20.1%) | 38 (18.7%) | 9 (14.8%) | 544 (15.5%) |
| Slightly disagree | 2 (7.7%) | 33 (9.4%) | 231 (14.1%) | 196 (15.8%) | 22 (10.8%) | 5 (8.2%) | 489 (13.9%) |
| Somewhat disagree | 8 (30.8%) | 104 (29.6%) | 418 (25.6%) | 205 (16.6%) | 17 (8.4%) | 7 (11.5%) | 759 (21.6%) |
| Strongly disagree | 13 (50.0%) | 120 (34.2%) | 455 (27.8%) | 213 (17.2%) | 26 (12.8%) | 8 (13.1%) | 835 (23.8%) |
| Total | 26 (100%) | 351 (100%) | 1636 (100%) | 1238 (100%) | 203 (100%) | 61 (100%) | 3515 (100%) |

Of the HILDA people with a long term health condition, disability or impairment, 50% of the very poor and 50% of the poor report low control compared to none of the prosperous and 15% of the very prosperous. This is a stronger linear relationship compared to HILDA All.

Figure 4: Control over change and prosperity



2.6.9: Profiles of prosperous and very comfortable people with epilepsy

In light of the differences compared with both the whole HILDA survey and then with those with long term health conditions, disability or impairments the sense of personal control based on of Wave 3 respondents based on their level of prosperity is subject to other influences. What then might explain the relationship between prosperity and personal control in these three areas amongst Wave 3 respondents? To explore this we have looked at the impact of epilepsy on lives of some of the people reporting they consider themselves either prosperous or in very comfortable financial circumstances.

Prosperous people

Ten people considered they were in prosperous financial circumstances but reported a low sense of personal control. Four of the ten (40%) said epilepsy and its treatment affected their social lives and all activities greatly, including their ability to drive. Additionally their ability to work and the kind of work they could undertake was affected. Four (40%) people considered that epilepsy affected their plans and ambitions for the future. Three (30%) reported that epilepsy affected their confidence and ability to be good parents a lot. Of these ten 5 were taking 2 medicines.

Female 24: family income of \$1000-1299 per week. She has epilepsy, a rare syndrome and an intellectual disability. She had injuries due to seizures which led to hospitalisations in 2010. Has not been able to access dental care at dental hospital because staff refuses to administer a general

anaesthetic claiming patient is too hard to treat. She considers she has been subjected to discrimination due to assumptions made about her abilities and consequently her suitability for involvement in various programs. She lists her other problems as anxiety, tiredness, memory loss, weight gain and speech problems. Additionally she has comorbid problems of allergies, hearing and brain impairment.

Male 42: family income of \$1750 or more per week. Employed. No seizures at present due to current treatment.

Female 54: family income of \$1750 per week; not employed due to epilepsy. Her seizures are reduced due to current treatment but are still frequent. Have had injuries due to epilepsy in 2010 where she received burns twice as well as a head injury. In 2013 she was injured at home as well being injured at the gym as a result of a seizure which caused bruising and broken bones. This person had suffered discrimination in the workplace including bullying and an assault. She had also been refused access to public events. She considered that stigma arose from the fear other people have of her having a seizure with the consequent loss of friendships and 'being made to feel stupid'.

Additionally she listed other problems as; tiredness, memory loss, mood swings, hair problems, weight gain, speech difficulties and sexual problems. She considered that incontinence, back problems, brain impairment, migraine and blood pressure were comorbid problems.

Male 20: family income between \$1250 and \$1499 per week. This man has an acquired brain injury and intellectual disability. He is not employed due to epilepsy.

Female 59: family income of \$1750 or more. Not employed due to an unspecified illness. This person was injured in a car accident in 2010 and in 2013 suffered injuries of abrasions and cuts and a post-ictal migraine. She is on one medicine and claims to be seizure-free for the last 20 years. She has experienced stigma related to assumptions about her abilities because of her epilepsy. Other conditions are stroke, bowel problems, allergies, back problems, migraine and heart disease.

Female 40: family income of \$1750 or more per week. Not working due to epilepsy which is now reduced to occasional seizures due to current treatment consisting of 2 medicines. Also has a daughter with epilepsy. She considers that her whole life and that of the family is controlled by seizures and their unpredictability.

Female 52: family income of \$1750 or more per week. She is not working due to illness. She takes 6 or more medicines and though her seizures are reduced they are still frequent. She has suffered bruises and broken bones in 2013.

Very financially comfortable people with epilepsy

Thirty one people considered their families were comfortably off. Thirteen (42%) of them said epilepsy and its treatment affected their ability to drive a lot, 10 (32%) felt it had 'some effect' on their self-esteem. Fourteen (47%) took one type of medicine only. We profile 13 comfortably off people who reported a low sense of personal control.

Female 38: Lives with other family members. She is not working due to illness or disability. She is on one medication which effectively has stopped her seizures. She also takes medicine for a mental health issue and is intellectually disabled.

Female 34: She is awaiting surgery and is on three medicines. She was injured following a seizure when she hit her head.

Male 30: He is on two medications for epilepsy and is seizure free at present. Previously suffered from a broken nose, gashes and bruising following a car accident. He also has Hodgkin's lymphoma and is employed. He has comorbid conditions of migraine, brain impairments and memory problems.

Female 30: She is employed and takes two medications which have reduced her seizures to occasional one. She has suffered bruising but considers the emotional hardship caused by the stigma of epilepsy greater than the physical effects of seizures. Her other problems are: tiredness, memory loss, mood swings, weight problems, depressions, aggression and appetite-related issues.

Male 31: He is employed and on one medicine which has reduced his seizures to occasional ones.

Female 28: She has employment in the family business and the one medication means she is seizure free at present.

Female 19: She is studying and is on three epilepsy medicines. Over the years she has suffered epilepsy related injuries of cuts, bruises and abrasions. More recently she fractured a tooth. Her other health problems are: tiredness, memory loss, mood swings, weight gain, excess hair, irritability, and appetite issues. She lists her comorbid conditions as allergies, brain impairment and heart disease.

Female 29: She is not employed and studying. She takes four different medicines for her epilepsy which controls her seizures. She has been injured due to seizures in the past.

Female 45: she is employed but considers she is viewed as less competent because of her epilepsy which has led to discrimination in not being promoted. She takes 4 different medicines for epilepsy which has reduced her seizures to occasional ones.

She has problems of tiredness, memory loss, problems with hair, skin and weight as well as sexual function, speech, irritability, aggression and appetite, and balance problems. Other conditions are diabetes, asthma, back problems, blood pressure, heart disease, a psychiatric condition and chronic pancreatitis. She has suffered back injuries and bruising from seizures.

Male 32: He is on two different medicines for epilepsy which have led to no seizures. He is employed and has suffered no injuries due to epilepsy.

Female 62: she is not employed. She has other conditions which are incontinence, brain impairment and arthritis. She lists other problems as being memory and hair loss, tremors, speech problems irritability and aggression. She relates the memory loss and emotional issues to the side effects of her two different medicines which have led to her epilepsy being well controlled and consequently no injuries.

Female 38: Her one medication for epilepsy has reduced her seizures to occasional ones. She is employed and suffers medication related side effect of poor memory, concentration and confusion as well as poor balance and emotionalism.

Female 32: She is employed and taking 2 medicines for epilepsy which have reduced her seizures to none. In 2013 a seizure led to her breaking her nose.

3. CONCLUSION

In conclusion 324 of the 883 eligible to participate in the survey responded. This was a 36.7% response rate.

With only 20% of the survey respondents working full time it appears that despite some high levels of educational attainment, for people with epilepsy these levels of educational attainment do not automatically lead to full-time employment.

Incomes among the survey respondents remain comparatively low, reflecting that the majority of those who were employed were working in part-time or casual positions, while others who were not employed were dependent on pensions or their families.

This survey then reflects the social consequences of epilepsy. Unemployment, under-employment and lower incomes means that people with epilepsy experience financial distress. Financial distress is represented by not being able to pay mortgages, rent or utilities bills on time and relying on family and friends for financial assistance. People with epilepsy report far greater levels of financial distress than do the broader population of Australians captured by the HILDA surveys. Far more people with epilepsy consider themselves to be 'poor' and 'very poor' compared with the HILDA surveys. Levels of poverty and financial vulnerability are demonstrated by an inability to save and a tendency to spend more than the income by people with epilepsy. These levels of poverty are likely to continue as people with epilepsy report not being able to plan ahead financially.

Data on seizures show that most people found their medications assisted the control of their seizures though there is a small but significant group likely to have uncontrolled seizures. The impact of epilepsy on quality of life is shown by the days lost from work and school. Injuries and hospitalisations demonstrate the reduced quality of life for people with epilepsy as well as contributing to the cost of their care.

Personal relationships are significantly affected by poorly controlled epilepsy. People with epilepsy report that that epilepsy has a significant effect on their health, emotional and family relationships as well as the ability to socialize. These affects are far more significant for survey respondents than for the broader Australian population responding to the HILDA survey.

In the workplace there is far greater polarization about the level of comfort people with epilepsy felt in talking about their epilepsy. People with epilepsy are either very comfortable or very uncomfortable in their workplace when it comes to discussing their epilepsy with their bosses or colleagues. This may well reflect workplace cultures as much as personal feelings of people with epilepsy.

Of special note is the relationship between epilepsy and levels of prosperity. In the HILDA surveys for both the broadest group and the HILDA group with long term conditions there is a clear relationship between levels of prosperity and perceptions of control in one's life. For the HILDA respondents the greater the prosperity, the greater the feeling that one can solve one's problems and make changes in one's life. Similarly people in the HILDA surveys with long-term conditions or disabilities who are prosperous or financially comfortable have greater control over life circumstances than do those who consider they are struggling financially. High levels of prosperity provide greater protection against life's

vicissitudes including physical unwellness. This is not reflected in the lives of people with epilepsy. Being prosperous or financially comfortable does not necessarily help people with epilepsy feel they have control over their lives or can solve problems, demonstrating that the impact of epilepsy far outweighs other aspects of people's lives and has a stronger impact than other long term health conditions.

Note: This report is the first of three. The other reports undertake more extensive comparisons between Wave 2 and 3, covering both Waves as well as comparing the respondents who answered both surveys, and a report which contains analysis of PBS data across both Waves for a sample of those respondents who consented to these data being accessed.

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