Possible Changes to KiwiSaver Act 2006 in relation to members with life-shortening congenital conditions

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1. Introduction

Under the KiwiSaver Act 2006, unless funds are withdrawn for the purchase of a first home, a member cannot access the funds in their KiwiSaver account until the later of reaching the age of eligibility for NZ Superannuation or completing five years membership of the fund [Clause 4(2), Schedule 1][1]. During the public consultation phase on the Taxation (Annual Rates for 2018–19, Modernising Tax Administration, and Remedial Matters) Bill, a submission was received raising the situation of Tim Fairhall.

Mr Fairhall has Down syndrome, with one effect being that he is aging prematurely, which means it is unlikely he will live to 65. Instead, his life expectancy is approximately 57 and he currently expects to retire around the age of 45-48. This means that he is not expected to live long enough to be able to access the funds in his KiwiSaver account under the current restrictions on when access is permitted.

The Ministry of Business, Innovation and Employment requested a short report to address the issues raised by Mr Fairhall, covering:

- Options for creating a new/different withdrawal category – including specific suggestions and advice on (1) how to word those options and (2) what/who it would capture.
- A recommended process for establishing whether individuals fall within the category, and other checks and balances that should apply.

2. Consultation

In preparing this report we have spoken to a number of people with an interest in KiwiSaver, as well as people able to provide guidance around congenital conditions. These include:

- KiwiSaver Trustees
- KiwiSaver Scheme providers
- Health and disability experts
- Mr Tim Fairhall, and his mother, Mrs Joan Fairhall
- Actuaries in relation to life expectancy
- IRD staff in relation to technical matters related to KiwiSaver
- A legal expert who specialises in the area of health and disability

[1] Access to KiwiSaver funds is possible in the case of serious illness or financial hardship [Clauses 10-12, Schedule 1]

In general, there was support in principle for providing earlier access than is currently permitted for KiwiSaver members with life-shortening congenital conditions. However, it is important to note that not all those spoken to were supportive of any change in access to KiwiSaver funds. During the discussions, information was provided to the authors to assist in formulating appropriate recommendations, and points raised about possible technical issues that need to be considered.

3. Background

The KiwiSaver Act 2006 came into force on 1 July 2007 to provide a government-mandated scheme to assist New Zealanders to save for their retirement. While the primary purpose of the scheme is to fund a KiwiSaver member's retirement, the scheme rules mandated by the legislation include a provision for early withdrawal in the event of serious illness, where serious illness is defined as:

> "an injury, illness, or disability—
>
> (a) that results in the member being totally and permanently unable to engage in work for which he or she is suited by reason of experience, education, or training, or any combination of those things; or
>
> (b) that poses a serious and imminent risk of death."
>
> [Clause 12(3), Schedule 1]

This provision is not suitable for the issue being considered here because it restricts the withdrawal to a point at which the KiwiSaver member is seriously incapacitated and/or facing imminent death. This means the member is unlikely to be able to utilise the funds to support an active and positive retirement, as intended by the scheme.

In some cases, KiwiSaver members face a likely death before reaching the end payment date, being the later of the age of eligibility for NZ Superannuation or five years membership, as a result of a congenital condition. If they do survive to the end payment date, their quality of life will likely have deteriorated so that access to their KiwiSaver funds will offer limited value in terms of being able to enjoy an active and positive retirement. Equity suggests that members with life-shortening congenital conditions should be able to withdraw their funds at an age when they can still expect to enjoy an active and positive retirement, as do other KiwiSaver members.

The population group of concern are people:

- with potentially life shortening conditions that are present from birth, although they may become evident or first occur in adulthood;

- who have signed up to KiwiSaver with the expectation of being able to use their savings to contribute to their financial security, standard of living and quality of life when they retire; and
- who will have to/want to stop work before 65 in order to enjoy these benefits but under current rules cannot access their savings.

In order to address the issues raised by Mr Fairhall, we need to address the following questions:

- What do we know about conditions associated with a shortened life expectancy and their prevalence?
- What are some of the criteria that could/should be considered so that individuals can apply for early access to their funds?
- What evidence would people be asked to provide to support an application?
- What further information is needed to get a better understanding of prevalence of identified impairments, premature ageing, causes of death and impact on wellbeing and functional ability?

It is important to note that this report is solely focussed on the issue of access to a member's own KiwiSaver funds, and does not give any consideration to possible changes to NZ Superannuation entitlements.

4. Context

As we consider possible changes to the KiwiSaver scheme to address the situation of members with life-shortening congenital conditions, there are a number of contextual matters that need to be considered.

4.1 UN Convention on the Rights for People with Disabilities

New Zealand is a signatory to the UN Convention on the Rights for People with Disabilities (UNCPRD). The principles of the UNCRPD include non-discrimination, full and effective participation and inclusion in society, and equality of opportunity. It is important that our obligations under the convention are met under any changes that are made.

4.2 Life expectancy

There is a difference in assessment of life expectancy for individuals and for cohorts, with average cohort life expectancy able to be measured with a reasonable level of accuracy; however, it is virtually impossible to do the same for an individual. Life expectancy can be assessed at any point in time, and is influenced by a range of factors, including genetics and lifestyle as well as socio-economic factors.

4.2.1 Increases in Life Expectancy

Advances in medicine, health, genetic and molecular research have resulted in marked increases in life expectancy. Although not as easily quantifiable, changing attitudes, greater inclusion and improved social and community care have also contributed.

As with all New Zealanders, people with intellectual impairments are living longer although their average age is still significantly lower than the general population. For people with Down syndrome there has been an extraordinary increase in age of death, particularly over the last 30 years. (Bittles & Glasson, 2004; Coppus et al 2013; Emerson & Hatton 2014; Stancliffe et al, 2012). Reported increases in age of death have gone from nine years in 1929 to an increase in the median age of death from 25 years to 49 years in the period from 1983-1997. The life expectancy of a child born with Down syndrome in the first decade of this century is predicted to exceed 60 years (Yang et al., 2002).

4.3 Life-shortening conditions

A person's life expectancy may be shortened by a range of conditions, some of which are congenital, such as cystic fibrosis, while others appear unexpectedly during their life-time, such as cancer. This report is restricted solely to the question of congenital conditions, including adult onset congenital conditions.

4.3.1 Poor Health and Earlier Mortality

Life expectancy for any one individual varies with the nature, severity and course of the condition, and related situational and environmental factors. These include the age of diagnosis of the condition and comorbidities, access to and availability of treatment and support services.

"*Our observation of excess cause-specific mortality in individuals with ASD [Autism Spectrum Disorder] may signify an increased biological vulnerability, as well as insufficient awareness, diagnoses and treatment of comorbid diseases. In other words, people may be more vulnerable to getting certain diseases that can lead to death and doctors may not be as good a diagnosing and treating these diseases in [this population group]*." (Hirvikoski et al, 2016)

The above statement applies equally to many of the conditions that fall into the group of people with conditions associated with a shortened life span. Additionally, there is growing evidence that the social determinants of health and wellbeing – education, employment, income/poverty and social supports - are strongly associated with poorer health outcomes, lower life expectancy and higher mortality rates (Rickard and Donkin, 2018; UK Trade Union paper, 2013). Many within the group of concern will have compounded and greater risk due to increased vulnerability associated with poorer social determinants of health such as inequalities in access to education, low income and low rates of employment (Rickard & Donkin, 2018).

Race and ethnicity are also critical factors with Māori and Pasifika people being over-represented in groups with high rates of potentially preventable diseases and lower life expectancy. The Social Report 2016 produced by the Ministry for Social Development explains that the lower life expectancy for Māori reflects higher death rates than for non-Māori at nearly all ages, and notes there are a number of explanatory factors including smoking rates and socio-economic factors – the report also notes that there "is a difference [in life expectancy] of 7.5 years for males and 6.1 years for females" between the most and least deprived areas of New Zealand.

4.4 Positive Retirement

Financial security, health, wellbeing, lifestyle, and adapting to change are key areas of consideration when thinking about retirement (Stancliffe, 2018; University of Otago Economics discussion paper No. 1703). Retiring voluntarily, planning for retirement, and engaging in a gradual transition to full retirement through bridge employment have all been associated with positive outcomes in general population studies (Wang & Shultz, 2010).

To understand retirement for people with the conditions that are the focus of this discussion, consideration has to be given to their employment experiences. Many of this group will have significantly lower rates of participation in employment and very different experiences to those of the general population. Despite policy initiatives to increase participation in work for particular population groups there has been little, if any, change. While there is a lack of disability and impairment specific data, recent information illustrates the gap and extent of the problem. The Household Labour Force data for the June 2017 quarter reports a labour force participation rate of 25.2% for disabled people and 72.6% for the not disabled group.

Recent research that explored retirement for individuals with intellectual and developmental impairments found that older adults with intellectual and developmental impairments do decrease their participation in paid employment as they age (Stancliffe et al., 2018). However, most adults with intellectual impairment are not in paid employment and if they are, their retirement tends to be sudden rather than a gradual reduction in work hours.

These findings indicate a need for connected and coherent policies across government, including reasonable accommodations in services, what is counted as income and possible impact on entitlements to benefits. While exact circumstances may vary for those with intellectual and developmental impairments, inherited conditions, illness, injury in adulthood and so on, many of the issues will be the same.

5. Conditions with a Potential for Shortened Life Expectancy

There are a number of conditions that have the potential to limit life expectancy or are associated with a shortened life span. How this translates for a particular individual will vary according to a number of factors. However, there are common features associated with higher rates of earlier death and premature ageing. These include:

- Greater severity of the condition (impairment/disability/disorder/disease)
- Having multiple conditions/comorbidities
- Where the condition is associated with a nervous system disorder (neurological, neurodevelopment impairment), particularly epilepsy
- Where the condition has an increased risk of respiratory aspiration and secondary disease
- Making comparisons with the right cohort/age band. The difference that this makes was illustrated earlier, as a child born with Down syndrome today has a considerably greater from birth life expectancy than of 30 years ago (see section 3.2.1 above). This applies across all the conditions discussed in this report.

The impacts of these factors are illustrated in the following sections. Many of the conditions listed are congenital (present at or before birth), however, for many people the cause of their condition is unknown.

5.1 Developmental Impairments

Available New Zealand information (MoH Health Indicators, 2011) on life expectancy from birth for people with intellectual impairments found males' average life expectancy to be 59.7 years, 18 years below that of the male general population average of 78.4 and females almost 23 years below that of the female population average of 82.4 years. This is consistent with findings in similar countries. People with an intellectual impairment die 15-20 years earlier than the average age in UK (Rickard & Donkin, 2018).

As a population group, people with an intellectual impairment have a shorter life expectancy from birth and increased age specific mortality rates across all age bands. A significant downward trend in over-time mortality rates for people with intellectual impairments was reported with an equivalent to a 1.2% year-on-year reduction. For the same period in the general population in England and Wales, the decline was 2.2% for men and 1.7% for women. As such the relative inequality in mortality rates showed a modest increase (Emerson and Hatten, 2014).

Mortality rates are higher for people with more severe impairments. In a UK sample of 247 people with intellectual impairments (Heslop et al, 2013), the average age of death varied by severity of impairment – 67.5 years for people with a mild learning impairment, 64 years for people with moderate, 59 years for severe, 46 years for people with profound and

multiple impairments. Young adults, women, people with epilepsy, people with Down syndrome and other congenital causes of intellectual impairment have also been found to have higher mortality rates.

Ageing is commonly reported as starting earlier for many people with intellectual impairment. This is seen in an earlier age of onset of medical problems related to the natural history of the specific impairment and earlier onset of some age-related diseases and frailty (Coppus, 2013). Commonly associated conditions experienced by people with intellectual impairments at higher rates than the general population include epilepsy, physical and sensory impairment, respiratory disease and dementia. People with intellectual impairment also have high rates of mental health disorders which in turn are associated with poor health and earlier death.

5.1.1 Down Syndrome

A review (O'Leary et al., 2018) of early death and causes of death for people with Down syndrome found a life expectancy 28 years younger than the general population. Congenital heart anomalies and respiratory conditions were the leading cause of death and more common than in the general population. People with Down syndrome have a greater chance of developing dementia at an earlier age than people with intellectual impairment without Down syndrome and the general population. An Irish study (McCarron et al., 2014) found that 15.8% of over 40s with Down syndrome had dementia or other serious memory impairment. This compared with 6% of over 60s in the general population. In another Irish study (McCarron et al, 2011) 26.1% had developed dementia by the age of 50, 79.6% by 60 and 95.7% by age 68.

5.1.2 Fragile X

Fragile X is the most commonly known inherited form of intellectual impairment. People with Fragile X have higher rates of epilepsy than the general population. Fragile X-associated Tremor/Ataxia Syndrome (FXTAS) is a progressive neurological impairment that can affect some male carriers over the age of 50 (Forster-Gibson & Holden, 2017). Life expectancy for people with Fragile X is normal, and therefore it is not a life-shortening congenital condition and outside the scope of this report.

5.1.3 Cerebral Palsy

For people with cerebral palsy who are able to walk and do not have complications, life expectancy is similar to that in the general population. For those who have hard to control seizures, significant respiratory difficulties, severe gastroesophageal reflux disease (GERD) and who are not ambulant, there is an increased risk of early mortality with life expectancy ranging from late 20s to early 50s. (Fehlings & Hunt 2017)

5.2 Adult Onset Conditions

5.2.1 Multiple Sclerosis

Using data from similar countries, it is estimated that one in every thousand New Zealanders has Multiple Sclerosis (MS) or approximately 4,000 people (Multiple Sclerosis Research Trust). Symptoms usually appear between the ages of 20 and 50 with a peak in the early 30's. The course of MS is unpredictable. Some people are minimally affected while others rapidly progress to being severely disabled. Most people with MS fall in between the two extremes. MS is more prevalent in people who have Northern European ancestry. MSNZ suggests that "on average, a person with MS can expect to live 7-10 years fewer than those without MS" (https://www.msnz.org.nz/prognosis/).

A small New Zealand study (Multiple Sclerosis NZ incidence study) to determine the numbers of people presenting with a first demyelinating event or new diagnosis of MS between June 1st, 2012 and May 31st, 2014 found the average age at which people developed their first symptoms was 37.8 ±11.8 years. This is older than the average age recorded in previous studies. The mean age at diagnosis was 42.2 years indicating that there is a significant delay between the onset of first symptoms and diagnosis of MS.

5.2.2 Motor Neurone Disease

Motor neurone disease (MND) is the umbrella term for a group of degenerative diseases that kill muscle nerve cells, affecting people's movement, speech and ability to breath. The incidence of MND is around 2 per 100,000 with median survival time approximately three years from symptom onset (Scotter, 2015).

The study found that New Zealand had the highest mortality rate from MND of any participating country with 2.2 deaths per 100,000 people. The mortality rate is just ahead of Australia and the United Kingdom, and while further research is needed to understand what is contributing to the high death rate, it is believed there may be links to genetic predispositions, especially among Māori and Pasifika people. Waiting times for a neurology consultation can be more than a year (Professor Valery Feigin, AUT quoted in James Ensor, Newshub, 2018).

A recent global study (Global Burden of Disease), in which New Zealand participated, reported the risk of developing the disease as one in 300 with most people dying within 15-20 months of diagnosis. As a result, the current serious illness provisions are more appropriate for someone with MND.

5.2.3 Other Relevant Conditions

Other relevant conditions that may be life-shortening and should therefore also be considered for inclusion as allowing early access to KiwiSaver funds are Huntington's chorea and Fetal Alcohol Syndrome Disorder (FASD).

There are other conditions that may result in death at an earlier age than the general population, including dementia and sequelae following different levels of severity of Spinal Cord Injury (SCI) and Traumatic Brain Injury (TBI). These are not congenital conditions and are therefore outside the scope of this report. Another condition outside the scope of this report is early onset (before 65) Parkinson's disease, as there is uncertainty as to whether it is a congenital condition or the result of environmental factors. There may be value in follow up work on conditions such as these.

6. Recommendations

6.1 Early access allowed

Some KiwiSaver members have congenital conditions that result in a shortened life span. Delaying access to their KiwiSaver funds until the legislated end payment date can be seen as inequitable since it means they are unable to enjoy the active and positive retirement available to ordinary members. As a signatory to the UNCRPD, New Zealand is expected to enable full and effective participation and inclusion in society and equality of opportunity for people with disabilities.

> **Recommendation 1:** The KiwiSaver Act 2006 should be amended to allow for an earlier end payment date for members with life shortening congenital conditions.

6.2 Consequential effects of early access

The purpose of allowing early access is to allow the KiwiSaver member with a life-shortening congenital condition to enjoy an active and positive retirement similar to an ordinary member. In practice, the member is in effect 'retiring', in the same way that an ordinary member 'retires' on reaching the age of eligibility for NZ Superannuation. This means that the changes that occur to a member's KiwiSaver scheme entitlements on reaching the end payment date should also apply in cases of early access, in particular ending the entitlement to the Member Tax Credit and Compulsory Employer Contributions.

> **Recommendation 2:** The introduction of an earlier end payment date should be accompanied by changes to remove the entitlement to Member Tax Credit and Compulsory Employer Contributions.

6.3 Life shortening congenital conditions

There are several known congenital conditions that are recognised as being associated with a shortened life-span. Enabling early access for such conditions should be made as simple as possible. However, there may be other congenital conditions, which are less common or not yet identified, that may also be associated with a shortened life span. The range of congenital conditions that may permit early access should not be limited to currently known

conditions. In addition, it should be possible to remove conditions from allowing early access where medical advances mean that the condition is no longer considered life-shortening.

Recommendation 3: The KiwiSaver Act 2006 should be amended to permit the making of a regulation that

(a) Specifies the congenital conditions that allow early access, which may be revised from time to time.
(b) Specify the end payment date associated with each condition included in the regulation.
(c) Prescribes a process for assessing other congenital conditions to determine whether the condition should be added to or removed from the list of conditions permitting early access and/or permitting early access for an individual.

A person with Down Syndrome, Cerebral Palsy, Huntington's Chorea or Foetal Alcohol Syndrome is born with it. The basis of our recommendation on Multiple Sclerosis is that no one knows for certain what causes Multiple Sclerosis and more work is being done. However, Multiple Sclerosis New Zealand reports there may a risk factor at birth (which contributes to it being congenital) and environmental factors (Vitamin D, smoking or obesity) as contributors to adult onset of the condition.

Recommendation 4: The congenital conditions that permit early access should include Down Syndrome, Cerebral Palsy, Multiple Sclerosis, Huntington's chorea, and Foetal Alcohol Syndrome Disorder. An individual with one of these conditions who is applying for early access must apply in writing to their provider.

- The application must include a medical certificate that confirms the member has a congenital condition listed in the regulation.
- The medical certificate must be from a New Zealand registered medical specialist with a relevant area of expertise that includes the member's congenital condition.
- The medical conditions included in the regulations should be verified by a medical professional.

Recommendation 5: An individual wishing to apply for early access to their KiwiSaver funds under this regulation as a result of a congenital condition that is not listed in the regulation must apply in writing to the manager (in the case of a restricted KiwiSaver scheme) or the supervisor (in the case of any other KiwiSaver scheme).

- The application must include a medical certificate from a New Zealand registered medical specialist with a relevant area of expertise that includes the member's congenital condition.
- The medical certificate must specify what the member's congenital condition is, it must confirm that the condition is associated with a shortened life expectancy, and it must detail the life expectancy from age 18 associated with the condition.
- The medical certificate should outline the existing national or international research that forms the basis for the life expectancy assessment.

- A congenital condition must reduce life expectancy by at least 15 years compared to an ordinary New Zealander of the same gender to permit early access.
- The date for early access will be calculated in line with recommendation 7 (see section 6.4 below).
- If the life expectancy associated with the condition is such that the member's death is likely to be within five years of the date of application, the member should consider whether it would be more appropriate to apply under the serious illness provision.

Recommendation 6: The list of congenital conditions which allow early access to a member's KiwiSaver funds should be reviewed every five years. At the time of the review, submissions from relevant support groups and/or medical experts should be invited and considered.

- Submissions must include a letter of support from a New Zealand registered medical specialist with a relevant area of expertise that includes the congenital condition that is the subject of the submission.
- The letter of support must confirm that the condition is associated with a shortened life expectancy, and it must detail the life expectancy from age 18 associated with the condition.
- The letter of support must outline the national or international research that forms the basis for the life expectancy assessment.
- A congenital condition must reduce life expectancy by at least 15 years compared to an ordinary New Zealander of the same gender to be added to the list.

6.4 End payment date for early access

A key consideration is the age at which early access should be permitted for KiwiSaver members with a life-shortening congenital condition. Currently the standard end payment date for an ordinary KiwiSaver member is age 65. Using the life expectancy tables produced by Statistics NZ, a male born in 1951 at age 18 had a life expectancy of 81, which equated to an expected retirement period of 16 years, or 25% of his adult life. We suggest it would be reasonable to assess the end payment date for a KiwiSaver member with a life-shortening congenital condition to provide an equivalent proportion of time in retirement. As an example, if the life expectancy of the member is 57 years, then allowing access to their KiwiSaver funds at age 47 would provide for a retirement period of 10 years, representing 26% of their adult life.

Recommendation 7: The age at which early access is permitted for any condition should be calculated to provide a retirement period that is equivalent to the expected retirement period of an ordinary member, expressed as a proportion of adult life (from age 18).

- Currently the proportion of adult life that is spent in retirement for an ordinary member should be specified as 25%.

Recommendation 8: The proportion of adult life (from age 18) that is spent in retirement for an ordinary member should be reviewed every ten years to take account of changes in life expectancy, and the end payment date for congenital conditions revised to maintain alignment if it changes.

6.5 Application process

All withdrawals from a KiwiSaver account require an application. The process associated with withdrawals for serious illness provides a foundation for a suitable process for withdrawals by members with a life-shortening congenital condition, as there is a medical element. KiwiSaver providers and trustees cannot be expected to have the requisite expertise to determine whether a member has a congenital condition that permits early withdrawal, therefore it is appropriate to require verification by an appropriate medical expert.

Recommendation 9: The process to apply for the earlier end payment date will require an application by the member, including a statutory declaration, accompanied by confirmation by an appropriate registered medical specialist that the member has a condition on the regulatory list.

6.6. KiwiSaver withdrawals are not income

KiwiSaver members with a life-shortening congenital condition who are not working may be in receipt of a government benefit to provide financial support. Some benefits are affected by income earned by the recipient. An ordinary KiwiSaver member, who reaches the end payment date, will usually receive NZ Superannuation which is a universal government payment, that is unaffected by the withdrawal of KiwiSaver funds. For equity reasons, it is appropriate that a member who has an earlier end payment date should be treated similarly.

Recommendation 10: The withdrawal of KiwiSaver funds by a member with a life-shortening congenital condition should not be treated as income.

7. Other Issues

In the course of preparing this report, we have identified a range of issues that are beyond the scope of this report, but are worth noting for possible future investigation and consideration.

7.1 Legal Capacity

In some cases, the congenital conditions that are life-shortening are associated with a degree of intellectual impairment. Article 12 of the UNCRPD, 'Equal recognition before the law', is relevant here. This article recognises that persons with disabilities should enjoy legal capacity on an equal basis with others in all aspects of life. This makes provisions for supports and safeguards for decision making, prevention of abuse and control of financial affairs.

New Zealand is in the process of reporting to the United Nations Committee on the Rights of Persons with Disabilities for our combined second and third periodic review. The UN Committee has asked the government to identify 'measures taken to ensure that responsive

and tailored supports are available and affordable to all persons with disabilities to exercise their legal capacity and to manage their financial affairs, particularly for persons with psychosocial and/or intellectual disabilities (NZ Govt. draft response current to 15 August 2018, p.32). The government has also been asked to provide information about measures taken to revise the relevant laws on supported decision making that are in full conformity with Article 12. This relates to making a shift from substitute to supported decision making and impacts on how consent, competence and mental capacity are defined and operationalised in policy and practice.

We note as an update on the government's draft response on the implementation of the UNCRPD, that the Office of Disability Issues has undertaken a stocktake to identify any legislation that is not consistent with the UNCRPD. This work yielded 59 pieces of legislation, 31 of which were identified as likely contravening the Convention.

Further work should be undertaken to

- Consider how New Zealand's commitment to the UNCRPD can be best reflected in the KiwiSaver framework, both currently and in relation to any changes
- Consider how someone with impairments affecting their mental capacity can be appropriately safeguarded in regards to informed consent and appropriately authorised legal representatives (e.g. welfare guardian or enduring power of attorney) acting on their behalf where necessary.

7.2 Provision of Information and Advice

The ability for someone like Mr Fairhall to become a KiwiSaver member under current scheme regulations raises a concern about the information and advice provided to pending and new members about the appropriateness of KiwiSaver for them. While KiwiSaver membership is generally seen as a positive option for most New Zealanders, there will always be exception. People must have sufficient information to be able to make a fully informed decision as to whether membership is the best decision for their particular circumstances. The exception to this would be if membership was compulsory for particular New Zealanders, such as those over the age of 18.

7.3 Prevalence of Different Conditions

The most common responses to questions about prevalence rates of different impairments in New Zealand reports and literature are "we don't know", "it is limited and more research is needed," "it's too old to use" or "that it is not publicly available". Most prevalence and incidence rates given are based on overseas research. As an example, there is no New Zealand data on prevalence and/or incidence of Fetal Alcohol Syndrome Disorder [FASD] but international studies suggest that around 3% of births may be affected.

Further consideration could be given to:

- What data is available that could be analysed to get a better understanding of age of death, cause of death, life expectancy from birth for different age bands (cohorts) for different impairments/population groups?
- This information may be available and could be analysed further from MoH, MSD, ACC and integrated data sets.

7.4 Serious Illness Provisions

The current provisions for early withdrawal of KiwiSaver funds include that of “serious illness”. This raises questions as to how the criteria for serious illness are defined and operationalised. For example, does ‘permanently affects your ability to work’ include unpaid/voluntary work?

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