

INTRODUCTION

Reporting cycle

This report is the last of a three-part series on the health of children and young people in New Zealand and fits into the reporting cycle as follows:

Year 1 (2014): The determinants of health for children and young people

Year 2 (2015): The health status of children and young people

Year 3 (2016): The health of children and young people with chronic conditions and disabilities

Chronic conditions and disabilities

This report aims to assist district health boards to plan to meet current and future demands in order to improve the quality of life for children with disabilities and chronic conditions by providing:

1. Information from a range of routinely collected data on children and young people's disability and chronic conditions, including prevalence of conditions arising in the perinatal period
2. Information about children's and young people's use of secondary health services
3. Evidence for good practice derived from current policies, guidelines and evidence-based interventions for each of the indicators presented

Chronic conditions and disabilities often affect people for life. Having a good quality of life and flourishing to your best ability is dependent, at least in part, on what happened as you were growing up. Understanding the dimensions of chronic conditions and disabilities among children and young people is essential to planning and developing good quality health services for New Zealand's children and young people.

About 11% of children aged 0–14 years have a disability according to the 2013 New Zealand Disability Survey.¹ Of these children, the survey identified that 49% of children with impairments that limited daily activity were affected by conditions that existed at birth, while for a third of the children, the reason was one of a range of 'other causes', not usually diagnosed at birth, which include autism spectrum disorder, attention deficit hyperactivity disorder, developmental delay, dyslexia and dyspraxia. Learning difficulty was the most common impairment with 6% of children surveyed, and 52% of disabled children having difficulty learning. Boys had a disability rate of 13% compared with the girls' rate of 8%, with boys having higher rates in psychiatric/psychological, speaking and learning impairments. Māori children had a disability rate of 15% compared with 9% for non-Māori children. Twenty five percent of disabled children had impairments that were caused by a disease or illness, and 3% by an injury.¹

The New Zealand Health Survey (NZHS) also indicates chronic conditions and disabilities that affect children and young people in New Zealand. The majority of 2–14 year olds have a BMI category of healthy weight, however, an estimated 11% prevalence of obesity was found among 2–14 year olds in the 2014/15 NZHS. This is of concern because there are implications for future health, given the association with type 2 diabetes and the risk of high blood pressure, coronary heart disease and stroke later in life.² The unadjusted prevalence rate of childhood obesity in the 2014/15 NZHS was significantly higher than that in the 2006/07 survey. The rate for type 2 diabetes among 15–24 year olds is less than 1% and has been much the same in recent years.

The prevalence of children being diagnosed with autism spectrum disorder varies with age, with the 2014/15 NZHS rate being about 0.5% among those aged 2–4 years and 1.5% among the 10–14 year olds. Rates have increased over the years, reflecting similar trends overseas not fully understood but possibly influenced by increased recognition of the condition.

The NZHS 2014/15 indicated that prevalence rates for eczema have been increasing, especially among those aged 0–4 years. Hospitalisations of 0–24 year olds has risen from below 100 to over 200 per 100,000 population for eczema and dermatitis as the primary diagnosis, while the rates rose from about 540 to 790 per 100,000 population for cases where eczema and dermatitis were reported but were not the primary reason for the hospitalisation. These are often for the 0–4 year olds. The presence of such conditions for children and young people in hospital has implications for health services.

New indicators and new thinking have been taken into consideration in presenting data in this report. While obesity has traditionally been viewed as separate from eating disorders, increasingly they are being considered as parts of a continuum with common risk factors and scope for integrated prevention. Musculoskeletal conditions have been included reflecting an increasing rate of hospitalisations for the suite of conditions that includes juvenile arthritis, juvenile osteochondrosis, and scoliosis.

A major limitation of this report is that it cannot address questions that require outpatient data. These data are not available at a national level. While the inclusion of the New Zealand Health Survey data provides a little more detail about estimated population prevalence for a few indicators, the full picture of outpatient and primary health care data is required for planning nationally and by district health boards.

A further limitation in this report is the lack of data on the transition of children and young people into adult services, particularly in health, a process that those with chronic conditions and disabilities almost inevitably face. And a transition into adults able to reach their potential by achieving in education, gaining meaningful employment, and participating in their community is an aim that many children and young people with chronic conditions and disabilities aspire to.

Review topics

Two issues were selected by participating DHB for review and inclusion in this report: Fetal alcohol spectrum disorder (FASD) by Judith Adams, and the Health needs of children and young people in State care by Mavis Duncanson.

Fetal alcohol spectrum disorder (FASD) contributes to many poor outcomes for New Zealand's young people including early mortality, abuse and neglect, poor educational achievement, engagement with the criminal justice system, benefit dependence, and mental health and alcohol and drug problems. This chapter provides information on the features of FASD, the life course consequences of FASD and the comorbidities of FASD. It discusses international studies on the epidemiology of FASD. Diagnosis of FASD is not straightforward therefore methods of diagnosis are reviewed along with the findings from a review of the Hawke's Bay DHB's FASD assessment pathway. Subsequent sections look at the evidence base for interventions to address the difficulties faced by people with FASD and their families. The final sections review what is known about New Zealand women's drinking habits, the patterns of drinking that are associated with the greatest risk of FASD and the evidence regarding the effectiveness of interventions to prevent the harm resulting from prenatal exposure to alcohol.

In New Zealand there have consistently been around 5,000 children and young people in the custody of the Chief Executive of Child, Youth and Family (in CYF care) each year. Many children and young people referred to Child, Youth and Family have high levels of long-term need and disadvantage. Health and educational assessments (Gateway Assessments) of children and young people in CYF care have identified multiple health needs for most children. Internationally it is well recognised that children and young people in State care often present with complex and serious health problems. This chapter uses published reports to describe the group of children in CYF care in New Zealand and to outline key characteristics of the current and proposed new care and protection systems, particularly those relevant to health services. The chapter also provides a rapid review of New Zealand and international literature regarding the health needs of children and young people in State care and guidelines for best practice in providing care to them.

In addition, the content of the appendices may be helpful when interpreting information in this report. Error! Reference source not found. provides an overview of the methods used to develop the reviews of evidence for good practice which appear at the conclusion of most indicator chapters. Error! Reference source not found. describes the statistical methods used, including a description of rates calculated within the data. Error! Reference source not found. contains information on the data sources used to develop each indicator and discusses data limitations. Error! Reference source not found. deals with the measurement of ethnicity and also provides an overview of the NZ Deprivation Index; NZDep 2013 is used where data relate to the 2013 Census. Error! Reference source not found. displays the tables of clinical codes referred to.

Conclusion

This report reviews the prevalence of a range of disabilities and chronic conditions experienced by children and young people living in New Zealand. These conditions place demands on health and disability support services needed to provide all children with quality of life. This report provides information on the secondary health service utilisation patterns of children and young people with chronic conditions and disabilities. It is unable to provide data on all health service use as these data are not collated nationally. It does, however, aim to provide

some insights into two quite different perspectives of disability and chronic conditions: the consequences and management of children with fetal alcohol syndrome, and a review of the health needs of children in care.

While the data presented are at times imperfect, and at best only provide a glimpse of the health needs of these diverse groups of children and young people, the current paucity of data should not preclude DHBs reviewing the health and disability support services available locally (including those with a public health focus), with a view to considering whether further improvements are required within the region.

Increasingly high quality evidence is becoming available to direct future initiatives for a number of the conditions included here. The number of systematic reviews has risen exponentially in many of these fields. Some of these will inform the development of integrated services to benefit the children and young people with chronic conditions and disabilities, and those who care for them.

Table 1 to Table 5 present an overview of children and young people in the South Island DHBs hospitalised with chronic conditions between 2011 and 2015, babies born with congenital anomalies and babies who died as a result of congenital anomalies between 2009 and 2013, and cancer notifications of children and young people between 2010 and 2014. Congenital anomaly rates are per 1,000 total births and cancer notification rates are age standardised rates per 100,000 population. Details for indicators with small numbers are suppressed. New Zealand data are presented for comparison.

Table 1. Summary of data for 0–24 year olds with chronic conditions Nelson Marlborough DHB vs. New Zealand

| Indicator | Nelson Marlborough DHB | | | New Zealand | | |
|------------------------------------|------------------------|-------------------|-----------|---------------------|-------------------|-----------|
| | Unique individuals* | Hospitalisations† | | Unique individuals* | Hospitalisations† | |
| | | Primary diagnosis | All cases | | Primary diagnosis | All cases |
| Cystic fibrosis | 18 | 142 | 157 | 336 | 2122 | 2625 |
| Diabetes | 124 | 234 | 427 | 4137 | 6466 | 12308 |
| Eating disorders | 29 | 49 | 77 | 1012 | 1509 | 2301 |
| Autism spectrum disorder | 71 | 18 | 137 | 1853 | 485 | 3015 |
| Cerebral palsy | 51 | 44 | 162 | 1678 | 2458 | 5852 |
| Epilepsy | 94 | 147 | 212 | 4336 | 7440 | 9876 |
| Chronic lower respiratory diseases | 539 | 546 | 889 | 29184 | 37909 | 48433 |
| Inflammatory bowel disease | 49 | 172 | 206 | 1447 | 5168 | 5999 |
| Constipation | 303 | 208 | 415 | 14578 | 7805 | 18723 |
| Eczema and dermatitis | 253 | 81 | 311 | 15331 | 5022 | 18950 |
| Musculoskeletal disorders | 39 | 79 | 101 | 1506 | 2431 | 3016 |

| | <i>n</i> | DHB rate | 95% CI | <i>n</i> | NZ rate | 95% CI |
|--|----------|----------|-------------|----------|---------|-------------|
| Babies with one or more congenital anomalies | 450 | 55.07 | 50.10–60.40 | 21219 | 67.56 | 66.66–68.48 |
| Infant mortality with congenital anomalies | 9 | 1.11 | 0.51–2.10 | 439 | 1.41 | 1.28–1.55 |
| Cancer notifications 0–14 year olds | 17 | 12.69 | 7.39–20.32 | 699 | 14.67 | 10.53–19.91 |
| Cancer notifications 15–24 year olds | 20 | 26.59 | 16.24–41.07 | 821 | 26.34 | 24.57–28.21 |

Unique individuals* were identified as being hospitalised at least once from 2011–2015; †all relevant hospitalisations 2011–2015

Table 2. Summary of data for 0–24 year olds with chronic conditions South Canterbury DHB vs. New Zealand

| Indicator | South Canterbury DHB | | | New Zealand | | |
|------------------------------------|----------------------|-------------------|-----------|---------------------|-------------------|-----------|
| | Unique individuals* | Hospitalisations† | | Unique individuals* | Hospitalisations† | |
| | | Primary diagnosis | All cases | | Primary diagnosis | All cases |
| Cystic fibrosis | <5 | 34 | 42 | 336 | 2122 | 2625 |
| Diabetes | 64 | 167 | 226 | 4137 | 6466 | 12308 |
| Eating disorders | 17 | 25 | 32 | 1012 | 1509 | 2301 |
| Autism spectrum disorder | 14 | <5 | 29 | 1853 | 485 | 3015 |
| Cerebral palsy | 11 | 10 | 29 | 1678 | 2458 | 5852 |
| Epilepsy | 43 | 51 | 69 | 4336 | 7440 | 9876 |
| Chronic lower respiratory diseases | 157 | 154 | 214 | 29184 | 37909 | 48433 |
| Inflammatory bowel disease | 21 | 50 | 59 | 1447 | 5168 | 5999 |
| Constipation | 142 | 71 | 187 | 14578 | 7805 | 18723 |
| Eczema and dermatitis | 115 | 49 | 146 | 15331 | 5022 | 18950 |
| Musculoskeletal disorders | 16 | 19 | 19 | 1506 | 2431 | 3016 |

| | <i>n</i> | DHB rate | 95% CI |
|--|----------|----------|-------------|
| Babies with one or more congenital anomalies | 215 | 68.45 | 59.60–78.24 |
| Infant mortality with congenital anomalies | 7 | 2.24 | 0.90–4.62 |
| Cancer notifications 0–14 year olds | <10 | s | s |
| Cancer notifications 15–24 year olds | <10 | s | s |

| | <i>n</i> | NZ rate | 95% CI |
|--|----------|---------|-------------|
| | 21219 | 67.56 | 66.66–68.48 |
| | 439 | 1.41 | 1.28–1.55 |
| | 699 | 14.67 | 10.53–19.91 |
| | 821 | 26.34 | 24.57–28.21 |

Unique individuals* were identified as being hospitalised at least once from 2011–2015; †all relevant hospitalisations 2011–2015

Table 3. Summary data for 0–24 year olds with chronic conditions Canterbury DHB vs. New Zealand

| Indicator | Canterbury DHB | | | New Zealand | | |
|------------------------------------|---------------------|-------------------|-----------|---------------------|-------------------|-----------|
| | Unique individuals* | Hospitalisations† | | Unique individuals* | Hospitalisations† | |
| | | Primary diagnosis | All cases | | Primary diagnosis | All cases |
| Cystic fibrosis | 59 | 310 | 397 | 336 | 2122 | 2625 |
| Diabetes | 457 | 577 | 1121 | 4137 | 6466 | 12308 |
| Eating disorders | 188 | 222 | 443 | 1012 | 1509 | 2301 |
| Autism spectrum disorder | 140 | 69 | 277 | 1853 | 485 | 3015 |
| Cerebral palsy | 214 | 253 | 705 | 1678 | 2458 | 5852 |
| Epilepsy | 427 | 645 | 935 | 4336 | 7440 | 9876 |
| Chronic lower respiratory diseases | 2698 | 3721 | 4519 | 29184 | 37909 | 48433 |
| Inflammatory bowel disease | 204 | 583 | 725 | 1447 | 5168 | 5999 |
| Constipation | 1574 | 701 | 2010 | 14578 | 7805 | 18723 |
| Eczema and dermatitis | 1598 | 393 | 1865 | 15331 | 5022 | 18950 |
| Musculoskeletal disorders | 155 | 246 | 294 | 1506 | 2431 | 3016 |

| | <i>n</i> | DHB rate | 95% CI |
|--|----------|----------|-------------|
| Babies with one or more congenital anomalies | 2035 | 64.49 | 61.72–67.36 |
| Infant mortality with congenital anomalies | 28 | 0.89 | 0.59–1.29 |
| Cancer notifications 0–14 year olds | 81 | 17.13 | 13.60–21.29 |
| Cancer notifications 15–24 year olds | 85 | 23.99 | 19.16–29.66 |

| | <i>n</i> | NZ rate | 95% CI |
|--|----------|---------|-------------|
| | 21219 | 67.56 | 66.66–68.48 |
| | 439 | 1.41 | 1.28–1.55 |
| | 699 | 14.67 | 10.53–19.91 |
| | 821 | 26.34 | 24.57–28.21 |

Unique individuals* were identified as being hospitalised at least once from 2011–2015; †all relevant hospitalisations 2011–2015

Table 4. Summary of data for 0–24 year olds with chronic conditions West Coast DHB vs. New Zealand

| Indicator | West Coast DHB | | | New Zealand | | |
|------------------------------------|---------------------|-------------------|-----------|---------------------|-------------------|-----------|
| | Unique individuals* | Hospitalisations† | | Unique individuals* | Hospitalisations† | |
| | | Primary diagnosis | All cases | | Primary diagnosis | All cases |
| Cystic fibrosis | <5 | <5 | 11 | 336 | 2122 | 2625 |
| Diabetes | 35 | 49 | 90 | 4137 | 6466 | 12308 |
| Eating disorders | 9 | 14 | 21 | 1012 | 1509 | 2301 |
| Autism spectrum disorder | 12 | <5 | 15 | 1853 | 485 | 3015 |
| Cerebral palsy | 12 | 13 | 32 | 1678 | 2458 | 5852 |
| Epilepsy | 29 | 37 | 49 | 4336 | 7440 | 9876 |
| Chronic lower respiratory diseases | 139 | 144 | 206 | 29184 | 37909 | 48433 |
| Inflammatory bowel disease | 11 | 26 | 30 | 1447 | 5168 | 5999 |
| Constipation | 80 | 39 | 98 | 14578 | 7805 | 18723 |
| Eczema and dermatitis | 80 | 6 | 92 | 15331 | 5022 | 18950 |
| Musculoskeletal disorders | 6 | 6 | 7 | 1506 | 2431 | 3016 |

| | <i>n</i> | DHB rate | 95% CI |
|--|----------|----------|-------------|
| Babies with one or more congenital anomalies | 134 | 63.12 | 52.88–74.76 |
| Infant mortality with congenital anomalies | <5 | s | s |
| Cancer notifications 0–14 year olds | <10 | s | s |
| Cancer notifications 15–24 year | <10 | s | s |

| | <i>n</i> | NZ rate | 95% CI |
|--|----------|---------|-------------|
| | 21219 | 67.56 | 66.66–68.48 |
| | 439 | 1.41 | 1.28–1.55 |
| | 699 | 14.67 | 10.53–19.91 |
| | 821 | 26.34 | 24.57–28.21 |

Unique individuals* were identified as being hospitalised at least once from 2011–2015; †all relevant hospitalisations 2011–2015

Table 5. Summary of data for 0–24 year olds with chronic conditions Southern DHB vs. New Zealand

| Indicator | Southern DHB | | | New Zealand | | |
|------------------------------------|---------------------|-------------------|-----------|---------------------|-------------------|-----------|
| | Unique individuals* | Hospitalisations† | | Unique individuals* | Hospitalisations† | |
| | | Primary diagnosis | All cases | | Primary diagnosis | All cases |
| Cystic fibrosis | 27 | 167 | 200 | 336 | 2122 | 2625 |
| Diabetes | 338 | 743 | 1187 | 4137 | 6466 | 12308 |
| Eating disorders | 105 | 144 | 221 | 1012 | 1509 | 2301 |
| Autism spectrum disorder | 91 | 34 | 180 | 1853 | 485 | 3015 |
| Cerebral palsy | 103 | 62 | 340 | 1678 | 2458 | 5852 |
| Epilepsy | 275 | 505 | 662 | 4336 | 7440 | 9876 |
| Chronic lower respiratory diseases | 1488 | 2038 | 2503 | 29184 | 37909 | 48433 |
| Inflammatory bowel disease | 136 | 422 | 534 | 1447 | 5168 | 5999 |
| Constipation | 1109 | 778 | 1504 | 14578 | 7805 | 18723 |
| Eczema and dermatitis | 903 | 264 | 1100 | 15331 | 5022 | 18950 |
| Musculoskeletal disorders | 113 | 123 | 167 | 1506 | 2431 | 3016 |

| | <i>n</i> | DHB | 95% CI |
|--|----------|-------|-------------|
| Babies with one or more congenital anomalies | 1242 | 67.41 | 63.71–71.26 |
| Infant mortality with congenital anomalies | 18 | 0.98 | 0.58–1.55 |
| Cancer notifications 0–14 year olds | 41 | 14.67 | 10.53–19.91 |
| Cancer notifications 15–24 year olds | 47 | 19.89 | 14.61–26.45 |

| | <i>n</i> | NZ rate | 95% CI |
|--|----------|---------|-------------|
| | 21219 | 67.56 | 66.66–68.48 |
| | 439 | 1.41 | 1.28–1.55 |
| | 699 | 14.67 | 10.53–19.91 |
| | 821 | 26.34 | 24.57–28.21 |

Unique individuals* were identified as being hospitalised at least once from 2011–2015; †all relevant hospitalisations 2011–2015

References

1. Statistics New Zealand. 2014. Disability Survey 2013 http://www.stats.govt.nz/browse_for_stats/health/disabilities/disabilitysurvey_hotp2013.aspx accessed November, 2014.
2. Ministry of Health. 2015. Annual update of key results 2014/15: New Zealand Health Survey. Wellington: Ministry of Health. <http://www.health.govt.nz/publication/annual-update-key-results-2014-15-new-zealand-health-survey>

