The use of oral health services by adults with intellectual disability. A mixed methods study.

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ABSTRACT

Objectives
The intent of this study was to explore the use of oral health services by a group of adults with an intellectual disability.

Methods
The study was an explanatory mixed-methods design. It consisted of an initial collection and analysis of quantitative data, and a second qualitative phase. In the quantitative phase of the study, a clinical audit of oral health services provided for adults with intellectual disabilities was carried out for individuals who underwent a general anaesthetic for dental treatment at Christchurch Hospital during the period of 1 January 2005 to 31 December 2009.

The second, qualitative phase was then conducted to investigate the experience and perceptions of individuals with an intellectual disability (and caregivers and guardians) relating to their oral health care. Fifteen semi-structured interviews were carried out with participants for 13 individuals with an intellectual disability who had a GA for dental treatment at Christchurch Hospital between 1 January 2009 and 31 December 2009.

Ethical approval for this study was obtained from the Upper South A Regional Ethics committee in July 2009. Quantitative data were entered onto a database and analysed using SPSS version 17.0 (SPSS Inc, Chicago, USA). Qualitative data were analysed by manual coding and labelling of the data in order to identify patterns and themes that were expressed by the participants.
Results
The majority of individuals with intellectual disability who had dental treatment under GA at Christchurch Hospital in the 5-year period lived in care and many had severe medical issues. Most of the individuals had both restorative treatment and tooth extractions carried out under GA.

The major concern for individuals with an intellectual disability was anxiety related to dental visits. Support people/guardians shared this concern, and played a vital role in helping to manage this anxiety. Many support people/guardians had difficulty identifying dental problems in those with an intellectual disability, and often relied on detection of changes in the individual’s behaviour or demeanour. While the majority of feedback on encounters with dental and medical staff was positive, problems with continuity of care were a concern. The time spent waiting in waiting rooms for check-ups or treatment was a frequently reported cause of stress to the respondents. In addition, some problems were identified with the way in which waiting areas were set up for this patient group.

Conclusions
As a group, these individuals present challenges for the provision of oral health care, given the severity of disability and the presence of systemic disease, and many require a high level of support for daily activities. When dental treatment is required, a GA is often necessary in order to carry out the treatment.

There is potential to improve the service with a multidisciplinary approach to coordinate other health services during treatment episodes, the delivery of preventive oral health care, and the utilisation of satellite clinics. Interview participants were particularly concerned with anxiety related to dental visits and identified potential improvements that could help to alleviate this anxiety.
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1. Introduction

In 2006, people with intellectual disabilities were identified as one of the priority groups in the ‘Good oral health for all for life’ document, which highlighted that little is known about the oral health of patients with special needs, or of their experiences of oral health services (Ministry of Health 2006).

The Christchurch Hospital Dental Service employs a number of registered dental specialists including two registered specialists in Special Needs Dentistry, as well as specialists in Oral Medicine, Orthodontics, Periodontics, Prosthodontics, and Oral and Maxillofacial Surgery. In addition, there are five dental house surgeons and six part-time senior dentists.

The Special Needs Dental Service provides regular primary oral health care for adults with intellectual disabilities in supported living care, adults with psychiatric illness in supported living care, and adults who are medically compromised who cannot safely access dental care in the community. This service is provided at dental clinics located at Christchurch Hospital, Burwood Hospital and Hillmorton Hospital. General Anaesthetic facilities for adults with special needs are located within the Oral Health Centre and at the Day Stay Unit at Christchurch Hospital. There is one half-day list allocated for dental care for adults with special needs each fortnight, with additional capacity available through the paediatric dental lists (there are five half-day lists per week) for urgent cases.

With the arrival of a second registered specialist in Special Needs Dentistry in 2005 and the establishment of regular general anaesthetic lists for adults with special needs at the Day Stay Unit in 2008, there have been changes in the way the service has been provided in recent years. Given this, and the identification of this patient
group as a priority group in the ‘Good oral health for all for life’ document, there is a need to investigate their experiences of oral health services.

The intent of this study was to explore the use of oral health services by a group of adults with an intellectual disability. An explanatory mixed methods design was used to collect statistical quantitative results from a sample of adults with an intellectual disability, and then follow up with some individuals with an intellectual disability (and their caregivers /guardians) to explore those results in more depth. In the first, quantitative phase of the study, a clinical audit of oral health services provided for adults with intellectual disabilities was carried out for individuals who underwent a general anaesthetic for dental treatment at Christchurch Hospital during the period of 1 January 2005 to 31 December 2009. This was to provide information on frequency of recalls, frequency and type of dental treatment provided, use of sedation or general anaesthetics for dental treatment, and occurrence of acute episodes requiring urgent treatment. The second, qualitative phase was then conducted to investigate the experience and perceptions of individuals with an intellectual disability (and caregivers and guardians) relating to their oral health care. The reason for the exploratory follow-up was to help build on, add depth to and explain the initial quantitative results.
2. Literature Review

Prior to investigating the experiences of adults with intellectual disabilities in obtaining oral health services at Christchurch Hospital, it is important to first consider what knowledge exists in the New Zealand and overseas literature. A literature review was carried out to investigate definitions and classifications of intellectual disability, oral health status of adults with intellectual disability, and how normalisation policies and the role of caregivers affect their oral health. In addition, qualitative studies were identified which investigated the opinions and attitudes of people with intellectual disabilities, caregivers, and dental professionals.

A search was conducted using the PubMed and Medline databases, in order to identify literature reporting on the oral health status of people with intellectual disabilities (PID), and the opinions and attitudes of PID, and the people involved in their care. Key words and phrases used in the database searches were “accessibility”, “dental care”, “disabled”, “special needs”, “intellectual disability”, “mental retardation”, and “health services”.

In New Zealand, the preferred term ‘intellectual disability’ is used in policy and the provision of services (Bray, 2003a). However, older terms such as ‘intellectual handicap’ or ‘mental retardation’ have been used both overseas and in New Zealand until relatively recently. For this reason, a search of the literature needed to include all of these terms.
2.1 Definitions and classification of Intellectual disability

2.1.1 Definitions

The World Health Organization defines the word ‘disability’ as an “umbrella term, covering impairments, activity limitations, and participation restrictions” and thus “a complex phenomenon reflecting an interaction between features of a person’s body and features of the society in which he or she lives”. The National Health Committee report ‘To have an ordinary life; kia whai oranga noa’ was published in 2003 and examined issues of community membership for adults with an intellectual disability. The definition of intellectual disability that was used in this report was “a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood with a lasting effect on development” (National Advisory Committee on Health and Disability, 2003).

One of the most influential groups in the field is the American Association of Intellectual and Developmental Disabilities (AAIDD), which published its definition in 2010. This was the organisation’s first official definition of the term ‘intellectual disability’ and replaced the former term ‘mental retardation’ and its definition. The AAIDD definition is as follows: “Intellectual disability is characterised by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18” (The AAIDD Ad Hoc Committee on Terminology and Classification, 2010).

The key points with these definitions are that the diagnosis of intellectual disability relies not only on the outcome of an intelligence test (IQ score), but also on observations of adaptive behaviour, including skills such as reading, writing and language, social skills, and activities of daily living. The definition specifies that the
age of onset was prior to adulthood in order to distinguish intellectual disability from other forms of disability that may occur later in life (The AAIDD Ad Hoc Committee on Terminology and Classification, 2010).

2.1.2 Classification and aetiology of intellectual disability

Historically, intellectual disability was classified as being due to either biological or environmental causes. However, the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) focuses on the impact of disability rather than its cause. The system considers both physical and social factors within the context of the individual’s environment (WHO, 2001).

The American Association of Intellectual and Developmental Disabilities (AAIDD) describe the complex interaction of multiple risk factors in a model that consists of four categories of risk factors (biomedical, social, behavioural, and educational). They propose that these factors interact across time to affect the individual directly, or across generations via their parents (The AAIDD Ad Hoc Committee on Terminology and Classification, 2010). Table A from the AAIDD manual ‘Intellectual Disability: Definition, Classification, and Systems of Supports (11th ed)’ outlines how biomedical, social, behavioural and social factors can affect an individual during the prenatal, perinatal, or postnatal periods. Any of these risk factors can be implicated individually, or in combination, in the development of an intellectual disability. It is clear that this model considers a wide range of social, parental, and societal causes, rather than focusing on the limited scope of historical models which solely considered medical/biological and environmental causes. However, it is important to remember that a risk factor may be present but, in fact, not cause impaired functioning, and therefore not result in an intellectual disability. This was pointed out by Anne Bray using Down syndrome as an example:
“Intellectual disability in an individual may have a specific aetiology, such as Down syndrome, but it is not synonymous with that aetiology. All people with Down syndrome are different and function within a wide range of strengths and difficulties. Some individuals with Down syndrome may not meet the criteria of a functional definition of intellectual disability” (Bray, 2003b).

The most common medical conditions that are associated with intellectual disability are epilepsy, Down syndrome, cerebral palsy, and musculoskeletal problems (Bray, 2003b; Krahn et al., 2006).
<table>
<thead>
<tr>
<th>Timing</th>
<th>Biomedical</th>
<th>Social</th>
<th>Behavioural</th>
<th>Educational</th>
</tr>
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</table>
| Prenatal | 1. Chromosomal disorders  
2. Single-gene disorders  
3. Syndromes  
4. Metabolic disorders  
5. Cerebral dysgenesis  
6. Maternal illness  
7. Parental age | 1. Poverty  
2. Maternal malnutrition  
3. Domestic violence  
4. Lack of access to prenatal care | 1. Parental drug use  
2. Parental alcohol use  
3. Parental smoking  
4. Parental immaturity | 1. Parental cognitive disability without supports  
2. Lack of preparation for parenthood |
| Perinatal | 1. Prematurity  
2. Birth injury  
3. Neonatal disorders | 1. Lack of access to prenatal care | 1. Parental rejection of caretaking  
2. Parental abandonment of child | 1. Lack of medical referral for intervention services at discharge |
| Postnatal | 1. Traumatic brain injury  
2. Malnutrition  
3. Meningoencephalitis  
4. Seizure disorders  
5. Degenerative disorders | 1. Impaired child-caregiver interaction  
2. Lack of adequate stimulation  
3. Family poverty  
4. Chronic illness in the family  
5. Institutionalisation | 1. Child abuse and neglect  
2. Domestic violence  
3. Inadequate safety measures  
4. Social deprivation  
5. Difficult child behaviours | 1. Impaired parenting  
2. Delayed diagnosis  
3. Inadequate early intervention services  
4. Inadequate special education services  
5. Inadequate family support |

Table from the AAIDD manual ‘Intellectual Disability: Definition, Classification, and Systems of Supports (11th ed)’, 2010 pg 60.

(The AAIDD Ad Hoc Committee on Terminology and Classification, 2010)
2.2 Intellectual disability in New Zealand
It is estimated that 33,700 New Zealanders had an intellectual disability in 2006, making up just less than 1% of the total population in New Zealand. Some 31,700 adults (94%) with intellectual disabilities lived at home, while the remaining 2,100 (6%) lived in residential care (Statistics New Zealand, 2006). Of those living in residential care in 2001, 98% were considered severely disabled (Ministry of Health, 2005). People with intellectual disabilities were identified as one of the priority groups in the ‘Good oral health for all for life’ document, which highlighted that little is known about the oral health of patients with special needs, or of their experiences of oral health services (Ministry of Health, 2006).

2.3 Studies of oral health of adults with Intellectual disability
Individuals with intellectual disability experience poorer health than those without an intellectual disability in terms of the prevalence of adverse health conditions, attention to care needs by support people, preventive care, health promotion, and access to health care (Krahn et al., 2006). These disparities exist in both general and oral health care.

Much of the literature on the oral health of people with intellectual disabilities relates to children rather than adults. A study in France found that the prevalence of poor oral health was greater in older age groups, with adolescents and young adults with disabilities having greater oral health care needs than children (Hennequin et al., 2008). People with intellectual disabilities may require assistance from caregivers to maintain their oral health, and may engage in behaviour that can adversely affect their oral health, such as lip biting and tongue thrusting (Pezzementi et al., 2005). It has been hypothesised that oral disease can have a psychological impact on individuals with intellectual disabilities, with poor oral
appearance and halitosis potentially adding to the rejection and isolation of an individual by society (Wilson, 1992).

The international literature reports that adults with intellectual disabilities experience poor oral health, with more untreated dental caries, worse oral hygiene, and more gingival inflammation and periodontal disease than the general population (Cumella et al., 2000; Gallagher et al., 2007; Gizani et al., 1997). In addition, they have more missing teeth, and it has been suggested that they are more likely to have experienced extractions rather than restorations in response to caries (Cumella et al., 2000). In 2010, Anders and Davis published a systematic review of studies looking at the oral health of adults with intellectual disabilities. Twenty-five of the 27 studies which met the authors’ criteria found that people with an intellectual disability had poorer oral hygiene (with more visible plaque) than the general population. In addition, people with intellectual disabilities had a higher prevalence and greater severity of periodontal disease than the general population. While caries prevalence in people with intellectual disability did not differ from the general population, people with intellectual disabilities had more untreated caries (Anders et al., 2010).

An Australian study found that adults who were developmentally disabled were more likely than the general population to have visited a dentist in the preceding 12 months, and were more likely to have used public dental services rather than a private dentist. Despite these frequent dental visits, the individuals with developmental disabilities were found to have more undetected dental disorders requiring specialist treatment. In particular, they were more likely to have oral mucosal pathology, periodontal disease, or malocclusion (Scott et al., 1998).

Data on the oral health of New Zealanders with intellectual disabilities are scarce. In a New Zealand study of people with intellectual disability or psychiatric illness...
who were long-term hospital residents, it was reported that there were fewer filled teeth, and more decayed and missing teeth, than the general population. Oral hygiene was poor, with 83.5% of individuals requiring scaling and cleaning, and 17.7% requiring complex periodontal therapy. One-third of the population required a general anaesthetic for most dental treatment (Whyman et al., 1995).

The severity of intellectual disability is an important factor in caries experience. Gabre et al carried out a longitudinal study of oral health in a group of adults with intellectual disability who were enrolled with a hospital dental clinic over eight-and-a-half years. Individuals with severe intellectual disability had a lower caries incidence and prevalence than those with milder disability, even when the number of teeth present were taken into account (Gabre et al., 2001a). This was interesting given that those with severe intellectual disability received less preventive treatment than individuals with less severe disability. Those with poor cooperation had lost more teeth, and consequently had a lower number of remaining teeth than those who cooperated well.

2.4 Studies of specific groups of individuals with intellectual disabilities

Some studies have reported on the oral health of specific groups of people with intellectual disabilities. Special Olympics athletes, for example, are a group that has had numerous papers published on their oral health status. Other studies have focused on individuals with a specific medical diagnosis such as Down syndrome or Autism Spectrum Disorder. Although the results of these studies are limited to the group investigated, they add valuable information to the overall body of literature on the oral health of individuals with intellectual disabilities.
2.4.1 Special Olympics

Participants in the Special Olympics are offered health screening as part of the ‘Healthy Athletes’ programme. This screening includes a dental check. Some studies have reported on the select population of Special Olympic athletes, and while the results may be interesting, they cannot be generalised to the population as a whole. A survey of participants in the United Kingdom Special Olympics National Games in 2005 (Turner et al., 2008) found that they enjoyed relatively good oral health, particularly in the younger age groups. Participants were more likely to have no restorations than the same age groups in the general population, and were more likely than the general population to be free of untreated caries in the 16-24 and 25-34 age groups. Older participants did not fare so well, and were more likely to have lost teeth, have untreated dental caries, and have more restorations than younger participants.

A similar study of Special Olympics athletes in North America reported oral health inequalities associated with poverty. Athletes from poorer states were more likely to have had restorations, and less likely to have received preventive treatment, than athletes from more wealthy states (Pezzementi et al., 2005).

In an Italian study, Dellavia et al examined participants in the Italian Special Olympics over a 3-year period. They found that individuals without Down syndrome had significantly more decayed or filled teeth than those with the condition. In addition, the Special Olympics participants enjoyed better oral health than other Italian adults with an intellectual disability who lived in institutions (Dellavia et al., 2009).

It is acknowledged that athletes in the Special Olympics tend to be younger, experience less severe disability, and are likely to have better support systems and integration in society, and therefore cannot be considered representative of all
people with intellectual disability (Reid et al., 2003). Nevertheless, the data are informative because they demonstrate that poor oral health among individuals with an intellectual disability is not inevitable.

2.4.2 Individuals with Down syndrome

Down Syndrome is the most commonly diagnosed learning disability (Bradley et al., 2004), and there is often an associated greater prevalence of congenitally missing permanent teeth (Boyd et al., 2004; Russell et al., 1995). This may present difficulty when using the DMF index because it is necessary to determine whether a missing tooth was congenitally absent or lost as a result of dental caries. Fung and Allison compared a group of individuals with Down syndrome to an age-matched control group. They found that, after adjusting for the number of teeth, there was no difference in caries experience between people with Down syndrome and those without it (Fung et al., 2005). While this study was small (128 controls, and 44 with Down syndrome) and used a convenience sample, a similarly designed Norwegian study reported similar findings: Ulseth et al examined a group of institutionalised adults with intellectual disability and found that there was no difference in caries experience between adults with Down syndrome and other adults with intellectual disability. In addition, more individuals with Down syndrome were edentulous than the control group, and the prevalence of periodontitis was higher (Ulseth et al., 1991).

However, Gabre et al found that individuals with Down syndrome differed from those with other types of intellectual disability. They had lower caries incidence and prevalence, and a lower number of remaining teeth, but they lost the same number of teeth over the course of the study as other participants. In addition, those with Down syndrome had lost more alveolar bone over the study period (Gabre et al., 2001a). It has been suggested that individuals with Down Syndrome
may be more susceptible to periodontal disease due to a different immunological response (Barr-Agholme et al., 1998).

2.4.3 Individuals with Autism Spectrum Disorder

The prevalence of autism has been estimated to be approximately 5.5 per 10,000. It affects males more frequently than females, with a ratio of 4.8:1, and around 71% of individuals with autism have some intellectual impairment, with 42% being severely impaired (Fombonne, 1999). Autism spectrum disorder encompasses a broader range of conditions and includes Asperger Syndrome, and pervasive developmental disorders not otherwise specified (PDD-NOS) (Newschaffer et al., 2003).

There is little literature available on the oral health of individuals with autism spectrum disorder. Most of the information that is available relates to the oral health of children. Loo et al carried out a cross-sectional study of the dental caries experience of patients with autism spectrum disorder (ASD) who had attended a hospital dental clinic in Boston, USA. They were compared with a random sample of patients without ASD who attended the same clinic. The patients ranged in age from 3-28 years, and, of those with ASD, 12.4% (49 patients) had an intellectual disability. After adjusting for age, individuals with ASD were 70.5% less likely to have experienced caries, and had lower caries severity than the individuals without the condition. When treatment was required, significantly more patients with ASD were considered uncooperative for dental treatment and required a general anaesthetic to enable treatment to be carried out (Loo et al., 2008).

Pradhan et al found that individuals with autism were 3.0 times more likely to have had caries experience, and 2.5 times more likely to have a missing tooth than those with a physical disability (Pradhan et al., 2009).
These studies suggest that the oral health of individuals with intellectual disabilities differs among groups within that population. Special Olympics athletes appear to enjoy better general and oral health than other groups with intellectual disabilities. This is likely to be related to lesser severity of disability and a high degree of social support. Likewise, the patterns of oral disease experienced by individuals with Down syndrome differ from others with intellectual disability.

2.5 Contributing factors

A number of studies have reported on factors that contribute to the oral health of individuals with intellectual disabilities. Recent policies that involve the move away from institutional-based living to a more integrated living arrangement in the community have presented new challenges in the oral health care for individuals with intellectual disabilities. In addition, the role that caregivers play in influencing the oral health of people with intellectual disabilities may be another contributing factor.

2.5.1 The effect of normalisation policies

There has been an international trend away from the institutionalisation of individuals with intellectual disabilities, and towards integration into the general community (Scott et al., 1998). This policy allows individuals to live in more ‘normal’ surroundings and enjoy an improved quality of life. But on the other hand, the change from institutional living to community-based arrangements may result in barriers to care (Pezzementi et al., 2005), and may be associated with changes in dental attendance and treatment patterns. Individuals living in institutional residences have been found to be more likely to receive regular dental examinations, and operative dental treatment than those living in the community (Stanfield et al., 2003). However, a study that investigated changes in oral microbiological flora among adults with moderate or severe intellectual disabilities
(as indicators of oral disease) who moved from institutions to community-based living showed that there was no deterioration in oral health after moving to community-based living (Gabre et al., 2001b), at least with respect to their oral microflora.

Another study reported that, despite changing from institutional to community-based living, individuals continued to have a significantly lower caries prevalence than other intellectually disabled individuals, and suggested that stable habits were formed in individuals with prolonged experience of restricted living (Gabre et al., 2001a). But this did not take into account the greater number of missing teeth in individuals who had been in institutions. An Australian study of adults with physical and intellectual disabilities found that, after adjusting for the confounding effects of carer and care-recipient characteristics, the type of residential setting was not associated with caries experience. However, factors such as diet, frequency of dental visits, receipt of oral hygiene assistance, and carer contact hours were associated with caries experience (Pradhan et al., 2009).

Rodriguez Vazquez et al examined all individuals aged between 20 and 40 in one institution for people with intellectual disability in Madrid, and compared them with a national survey of the general population. They found a lower prevalence of caries and attributed this to the strict dietary control within the institution (Rodriguez Vazquez et al., 2002).

A Swedish study (Gabre et al., 1997) found that, when looking at community-residing adults with an intellectual disability (as opposed to those living in an institution), individuals with a mild intellectual disability had higher caries experience than those with a severe disability. It was hypothesised that the latter were more reliant on the decisions of their caregivers—even when living in the community—than the former, who may have greater freedom in lifestyle choices.
(such as diet and oral hygiene habits). The authors concluded that living arrangement was not an important factor in caries experience for individuals with moderate or severe intellectual disability.

### 2.5.2 The role of caregivers

The role that caregivers have in influencing the general and oral health of people with intellectual disabilities is a commonly reported factor. A Belgian study found that children with intellectual disabilities had poor oral hygiene, with approximately one in three having heavy plaque accumulation (Gizani et al., 1997). Interestingly, children with moderate or severe intellectual disabilities had lower DMFT scores, were more likely to have sealants present, and brushed their teeth more regularly than children with less severe intellectual disabilities. It was hypothesised that the difference was related to caregiver support. While 56% of children with moderate or severe disability received help from their parents or carers for tooth brushing, those with mild intellectual disability almost never received help. In addition, children with more severe disabilities tended to spend more time in institutions, and participated in a systematic medical follow-up programme that often included dental care, while children with mild disabilities (who spent less time in institutions) relied on their parents or caregivers to seek dental care (Gizani et al., 1997). A lack of perceived need on behalf of the carers has been identified as a barrier to an individual receiving dental care while living in the community, and this indicates perhaps that the importance of oral health care is under-appreciated among some care staff (Stanfield et al., 2003). Pradhan et al suggested that, while carers may meet with resistance from care-recipients when providing daily oral hygiene care, diet was a factor that may be easily modified by carers (Pradhan et al., 2009).

Given the policy changes with regards to the living arrangements of individuals with intellectual disabilities, and the apparent challenges this poses in oral health
care, it is important that oral health services are adapted to cater for these changes. Likewise, the role of caregivers in influencing the oral health of individuals with intellectual disabilities should not be underestimated.
2.6 Qualitative studies of dental care for individuals with intellectual disabilities

Qualitative studies can provide valuable insight into oral health care for individuals with intellectual disabilities. They allow us to understand the opinions and attitudes of participants towards their oral health care from their own perspective. For this reason, qualitative methods have been used for a number of studies investigating the opinions and attitudes of individuals with intellectual disabilities, their caregivers, and dental professionals with respect to the provision of oral health care.

2.6.1 Opinions and attitudes of individuals with intellectual disabilities and their care-givers/support people

A qualitative study that explored positive oral health outcomes achieved with people with intellectual disabilities, used semi-structured interviews with ‘key-players’ supporting the oral health of the people with disabilities. These ‘key-players’ included dental professionals, direct support workers, and other professionals who played a care role. They identified factors that may have contributed to the success, which included participation in decision making, communication, allowing adequate time, and teaching skills (Grant et al., 2004). Similarly, responses of caregivers in interviews in another study indicated that avoidance of pain, the friendliness of the dentist, and their familiarity with the needs of people with an intellectual disability were all important (Cumella et al., 2000). Similar themes were identified when Vos Horrell et al interviewed adults with intellectual disabilities (and their parents or guardians) investigating the experiences and satisfaction they had with the delivery of primary health care services. The themes that were apparent with the adults with intellectual disabilities were dissatisfaction with unpleasant medical procedures and decisions, and the degree to which the physician was friendly, likeable and showed care and
concern for their well-being. Parents and guardians, however, were most concerned with issues of advocacy, insurance, specialist care, attention to specific health conditions, and the degree of agency support (Voss Horrell et al., 2006).

In a UK study in North Warwickshire (Cumella et al., 2000), individuals with an intellectual disability were interviewed in order to obtain their opinions and attitudes to oral health; they were also offered a dental examination. The authors noticed that there were some problems in interviewing them, as most respondents found it difficult to respond to questions which asked them to give reasons or express opinions. Similarly to other studies, the participants were more likely than the general population to have experienced extractions rather than fillings in response to caries. Respondents were largely unaware of the presence of caries and gingival problems in their mouths, and relied on appearance and the absence of pain to judge the condition of their teeth. Individuals with poor oral condition expressed embarrassment about their appearance, and reported trouble with eating. Many individuals with an intellectual disability were aware of their appearance and were concerned about how other people perceived them. Caregivers shared this concern about the way people with an intellectual disability are perceived by society and were eager to remove any additional barriers to acceptance. There were some problems related to the high turnover of staff in some residential homes, which meant that some carers were not informed about the respondent’s dental needs. Carers found it difficult to identify a dental problem; although they could identify that there was discomfort, they could not pinpoint the nature of the problem. This may indicate that dental problems are often undetected and untreated in this group.

Care managers in residential homes in London were interviewed in order to investigate their experiences and opinions of obtaining dental services for adults with a learning disability (Pratelli et al., 1998). Many managers felt that individuals
may be unwilling to accept care, and that forcing treatment under a general anaesthetic could be an infringement on an individual’s rights unless pain or gross need was present. They also felt that it was important to have continuity of care with the dentist, and that there should be a partnership approach between the carer and dental professional. While some managers felt that on-site care improved the cooperation of the individual with dental treatment, and reduced the drain on staff resources, others felt that home visits by the dental professional would be an invasion of privacy, and contrary to normalisation policies (Pratelli et al., 1998).

In summary, while qualitative methods have been used successfully in studies investigating the opinions and attitudes of individuals with intellectual disabilities and their caregivers, some difficulties have been reported when individuals have more severe disabilities and may not be able to answer open-ended questions. It is evident that caregivers play an important role in facilitating access to oral health care, but they may have difficulty identifying that a dental problem exists. This may contribute to dental problems being undetected and untreated in this group. Issues of advocacy, autonomy, and the removal of barriers to care were of primary concern for caregivers. This was an issue that was also expressed by the individuals with intellectual disabilities who participated in these studies.

2.7 Summary

It is clear that individuals with intellectual disabilities have poor oral health and high levels of unmet need for general medical and dental care. In addition, when
they receive dental treatment, the nature of that treatment appears to differ from
that provided for the general population, resulting in more tooth extractions. The
pattern of oral disease in individuals with Down syndrome (which is the most
commonly diagnosed learning disability) differs from people with other diagnoses
of intellectual disability. The movement of people with intellectual disabilities from
institution-based living to more integrated community-based living, while
allowing a better quality of life for individuals, also poses new challenges for the
provision of general and oral health services in the community.

Caregivers are vital in the maintenance of oral health care of people with
intellectual disabilities, as they play an important part in both the day-to-day oral
care and in facilitating access to oral health services. Qualitative studies have
found that caregivers may have difficulty identifying dental problems, which
could result in problems being undetected and untreated in the people they care
for. Caregivers were concerned with issues of advocacy, and the maintenance of
the autonomy of the people for whom they cared. In addition, they were
concerned with how people with intellectual disabilities are perceived by society,
and were eager to remove additional barriers to acceptance. This was an issue that
was also expressed by the individuals with intellectual disabilities who
participated in qualitative studies. Qualitative studies which sought to investigate
the opinions and attitudes of people with mild intellectual disabilities were
relatively successful. However, this form of study is not likely to be useful for
individuals with more severe disabilities, who may not be able to answer open-
ended questions.

While many quantitative studies have been published internationally on the oral
health status of people with intellectual disabilities, many have used small sample
sizes, and lack control groups for comparison. A number of overseas studies have
outlined the effect of poverty on the oral health of individuals with intellectual
disabilities. These countries have various health insurance schemes for the provision of health care. It is unclear what effect poverty has on the oral health of people with intellectual disabilities in the New Zealand health system. While dental care is free for all New Zealand children until they reach the age of eighteen, it is unknown how the transition from childhood dental services to adult services affects individuals with intellectual disabilities. Data from 2001 found that most adults with intellectual disabilities had low personal incomes, with 63% having annual incomes of $15,000 or less. There is a need for contemporary data on these issues for people with intellectual disabilities in New Zealand society, given the recent changes in living arrangements for many of them.
3. Methods

The study was an explanatory mixed-methods design. It consisted of two parts: an initial collection and analysis of quantitative data, and a second qualitative phase. This design allows for qualitative data to help build on, add depth to, and explain the initial quantitative findings (Creswell et al., 2007).

Ethical approval for this study was obtained from the Upper South A Regional Ethics committee in July 2009 (Appendix i).

3.1 Quantitative – Clinical audit

3.1.1 Participants
General anaesthetic lists for the period 1 January 2005 to 31 December 2009 were obtained from the dental department at Christchurch Hospital. From these lists, adults with an intellectual disability, who had had a general anaesthetic for dental treatment, were identified. All individuals aged 18 or over with an intellectual disability who underwent a general anaesthetic for dental treatment during the 5-year period were included in the audit.

3.1.2 Data collection
Clinical notes were reviewed for all individuals who met the inclusion criteria. Paper and computer records were included. Clinical notes of recall and emergency appointments, and general anaesthetics carried out in the dental department, were
stored in the department. Paper files had been used until April 2008, after which a computer system was introduced and clinical notes were recorded electronically. Where an inpatient general anaesthetic had been carried out in the day-stay unit or main operating theatres at Christchurch Hospital, clinical notes were recorded in the medical notes and stored in the clinical records department of Christchurch Hospital.

An identification number was assigned to each individual to ensure anonymity. The date of birth was used to calculate the age of each individual. Ethnicity and living situation was recorded as stated in the patient notes. Medical diagnoses were also recorded.

For each recall visit, the nature of the visit (whether routine recall or as a result of a presenting problem) was recorded. The use of premedication was also noted, as well as whether scaling or oral hygiene advice was given or topical fluoride applied. In addition, the number of radiographs taken was recorded, together with any treatment provided (such as restorations or extractions). Restorations were recorded as being one-surface, two-surface, or three-or-more surfaces. Amalgam restorations were counted separately from glass ionomer and composite restorations; the latter were grouped together and recorded as being in either anterior or posterior teeth. This was consistent with the information routinely collected for each operation as part of the hospital clinical coding system.

For each treatment visit, the use of local anaesthetic, sedation, general anaesthetic or relative analgesia was recorded. The number of radiographs, extractions, impressions, root canals filled, or restorations was also recorded as for the recall appointments, along with whether scaling or oral hygiene education was carried out, or topical fluoride applied.
Where treatment was carried out under general anaesthetic, the date of initial referral and date of the general anaesthetic assessment appointment were recorded. Data on the method of induction, intubation, and the patient’s physical status according to the American Society of Anaesthesiologists’ classification (ASA score)\(^1\) was noted. It was also noted whether the patient signed the surgery consent form him- or herself, whether there was a legal guardian giving consent, or whether in the absence of a legal guardian, consent was sought under Section 7.4 of the Code of Health and Disability Services Consumers’ Rights 1996. Any complications occurring during the general anaesthetic were also recorded.

### 3.1.3 Data Analysis
Quantitative data were entered onto a database and analysed using SPSS version 17.0 (SPSS Inc, Chicago, USA). After the descriptive statistics were obtained, bivariate associations for categorical variables were tested using the Chi-square test. Differences were considered to be statistically significant where a P-value of less than 0.05 was obtained.

### 3.2 Qualitative - Interviews

#### 3.2.1 Participants
Potential participants were selected from the 2009 master general anaesthetic list for adults with special needs. Fifteen semi-structured interviews were carried out

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\(^1\) The American Society of Anaesthesiologists’ (ASA) physical status classification is used to predict a patient’s anaesthetic/surgical risks. A higher ASA class indicates higher risks. Classification is as follows: Class 1 - a healthy patient with no medical problems; Class 2 – a patient with a mild systemic disease; Class 3 – a patient with a severe systemic disease; Class 4 – a patient with a severe systemic disease that is a constant threat to life; Class 5 – a moribund patient who is not expected to survive without the operation.
with participants for 13 randomly selected individuals with an intellectual
disability who had a GA for dental treatment at Christchurch Hospital between 1

3.2.2 Information and consent
Potential interview participants were contacted initially by letter, and then with a
follow-up phone call. An information sheet was sent to all potential participants
outlining the project (Appendix ii). Participants were given a period of two weeks
to decide whether they would like to participate in the study.

While there were communication difficulties with some of the individuals with
intellectual disabilities, they were given the opportunity to consent and participate
in the study wherever possible. The project was explained to the individual, with
the assistance of the caregiver/support person, and he/she was involved in the
consent process. A consent form (Appendix iii) was completed for each participant,
and, where appropriate, it was confirmed that the project had been explained to
the individual with an intellectual disability, and that he/she had indicated consent
in some way.

3.2.3 Data collection
Individuals with an intellectual disability and their support people/guardian were
interviewed to investigate their experience and perceptions relating to the oral
health care of the individual with an intellectual disability. Where possible, the
individuals with an intellectual disability attended the interviews, alongside their
guardian/support person, and contributed to the interview. Interviews were held
in a location chosen by the participants.
Semi-structured interviews were carried out with consenting participants. Interview participants were interviewed once, and interviews were approximately 20 minutes in duration. Individuals were asked to describe their experiences in obtaining oral health care, and to identify what they thought were the strengths and weaknesses of the service. Caregivers and guardians were also asked what role they played in relation to oral health care for the individual, as well as their self-reported oral health. Audio recordings were transcribed as soon as possible after the interview, and the tapes wiped and destroyed.

3.2.4 Data Analysis
Interview transcripts were analysed by manual coding and labelling of the data in order to identify recurring themes. These were then grouped together to identify patterns and themes that were expressed by the participants. This process was repeated multiple times until no new themes were identified.
4. Results

4.1 Quantitative – Clinical audit

4.1.1 Patient characteristics
A total of 168 adults with an intellectual disability underwent dental treatment under general anaesthetic at Christchurch Hospital between 1 January 2005 and 31 December 2009. Records for 1 patient were unable to be located. The remaining 167 patients underwent a total of 212 sessions over the five-year period, with each patient having between 1 and 3 general anaesthetics for dental treatment during this time. There were 97 males (58.1% of the sample) and 70 females (41.9%). Ethnicity was recorded in the clinical notes for 155 patients, of whom 141 (91.0%) were of NZ European descent, and 10 (6.5%) were Maori; there was 1 patient (0.6%) in each of the Samoan, Niuean, Chinese, and ‘other’ groups. The patients ranged in age from 18 to 69 years, with a mean age of 38.0 years (sd 11.6).

The majority of patients lived in care, with 126 (75.4%) in 24-hour residential care, 36 (21.6%) at home with family or a caregiver, and five (3.0%) lived independently with some support. Data on recorded medical conditions are presented in Table B. The most commonly recorded medical conditions were autism (29.3% of patients), epilepsy (28.1%), physical disability (18.6%), asthma (13.8%), cerebral palsy (12.0%), mental illness (13.2%), and Down syndrome (10.8%). “Other” syndromes were recorded for 13 (7.8%) individuals, and included three individuals with Fragile X syndrome, three with Tourette’s syndrome, two with Angelman syndrome, two with Brachmann-de Lange syndrome, one with Aicardi syndrome,
one with Cri du chat syndrome\textsuperscript{2}, and one with Trisomy 2. Data on medical conditions by sex, ethnicity, and living situation are presented in Table C. Significantly more males had autism and more females had cerebral palsy. More New Zealand Europeans and individuals in 24-hour residential care had a mental illness. In fact, all individuals with a mental illness recorded in the clinical notes lived in 24-hour residential care. Individuals with autism were more likely to live in residential care than at home and none of the individuals with autism lived independently.

\textsuperscript{2} Refer to Appendix (iv) for descriptions of these syndromes
### Table B - Recorded medical conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number with condition</th>
<th>Percent with condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>49</td>
<td>29.3</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>47</td>
<td>28.1</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>20</td>
<td>12.0</td>
</tr>
<tr>
<td>Physical disability</td>
<td>31</td>
<td>18.6</td>
</tr>
<tr>
<td>Heart murmur</td>
<td>11</td>
<td>6.6</td>
</tr>
<tr>
<td>Other heart condition</td>
<td>11</td>
<td>6.6</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>18</td>
<td>10.8</td>
</tr>
<tr>
<td>Asthma</td>
<td>23</td>
<td>13.8</td>
</tr>
<tr>
<td>Mental illness</td>
<td>22</td>
<td>13.2</td>
</tr>
<tr>
<td>Hepatitis B carrier</td>
<td>6</td>
<td>3.6</td>
</tr>
<tr>
<td>Stomach or bowel problem</td>
<td>15</td>
<td>9.0</td>
</tr>
<tr>
<td>Hearing loss</td>
<td>7</td>
<td>4.2</td>
</tr>
<tr>
<td>Vision impairment</td>
<td>4</td>
<td>2.4</td>
</tr>
<tr>
<td>Joint replacement</td>
<td>2</td>
<td>1.2</td>
</tr>
<tr>
<td>Diabetes</td>
<td>4</td>
<td>2.4</td>
</tr>
<tr>
<td>Other syndrome</td>
<td>13</td>
<td>7.8</td>
</tr>
<tr>
<td>Stroke or transient ischaemic attack</td>
<td>3</td>
<td>1.8</td>
</tr>
<tr>
<td>Other medical condition</td>
<td>29</td>
<td>17.4</td>
</tr>
</tbody>
</table>
Table C - Type of medical condition by patient sex, ethnicity, and living arrangement

<table>
<thead>
<tr>
<th></th>
<th>Autism</th>
<th>Epilepsy</th>
<th>Cerebral palsy</th>
<th>Down syndrome</th>
<th>Other syndrome</th>
<th>Physical disability</th>
<th>Mental illness</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>37 (75.5)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>27 (57.4)</td>
<td>7 (35.0)</td>
<td>9 (50.0)</td>
<td>8 (61.5)</td>
<td>17 (54.8)</td>
<td>14 (63.6)</td>
</tr>
<tr>
<td>Female</td>
<td>12 (24.5)</td>
<td>20 (42.6)</td>
<td>13 (65.0)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>9 (50.0)</td>
<td>5 (38.5)</td>
<td>14 (45.2)</td>
<td>8 (36.4)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NZ European</td>
<td>42 (95.5)</td>
<td>41 (93.2)</td>
<td>18 (90.0)</td>
<td>16 (94.1)</td>
<td>12 (92.3)</td>
<td>28 (96.6)</td>
<td>17 (89.5)&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Maori</td>
<td>1 (2.3)</td>
<td>2 (4.5)</td>
<td>2 (10.0)</td>
<td>1 (5.9)</td>
<td>1 (7.7)</td>
<td>1 (3.4)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (2.3)</td>
<td>1 (2.3)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>2 (10.5)</td>
</tr>
<tr>
<td><strong>Living arrangement</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residential care</td>
<td>43 (87.8)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>35 (74.5)</td>
<td>15 (75.0)</td>
<td>12 (66.7)</td>
<td>11 (84.6)</td>
<td>24 (77.4)</td>
<td>22 (100)&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>At home</td>
<td>6 (12.2)</td>
<td>12 (25.5)</td>
<td>5 (25.0)</td>
<td>6 (33.3)</td>
<td>2 (15.4)</td>
<td>7 (22.6)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Independently</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>49 (29.3)</td>
<td>47 (28.1)</td>
<td>20 (12.0)</td>
<td>18 (10.8)</td>
<td>13 (7.8)</td>
<td>31 (18.6)</td>
<td>22 (13.2)</td>
</tr>
</tbody>
</table>

<sup>a</sup>P<0.01  
<sup>b</sup>P<0.05
4.1.2 Recall visits

4.1.2.1 Location and reason for recall

Individuals had attended between one and ten recall visits over the 5-year period, with a mean of 4.2 visits (sd 2.1). These included routine recall visits (check-ups), problem-initiated visits, and ‘other’ recall visits. The ‘other’ recall visit group included oral hygiene reviews, and post-operative reviews. In total, 139 (83.2%) of the patients were ‘current patients’ who had recall appointments set on the hospital dental service computer system at the end of 2009. Of those that were not in the recall system, seven (4.2%) had moved away from Christchurch, three (1.8%) were deceased, and three (1.8%) were attending recall visits with a dentist in private practice.

There were no differences seen in recall attendance by patient age, sex, or living arrangement. Recall visits took place in a number of locations: the Oral Health Centre at Christchurch Hospital; Burwood Hospital; Hillmorton Hospital; Brackenridge Estate; and in patients’ residences as domiciliary visits. The location and reason for recall is presented by year in Table D. Recall visits at Brackenridge Estate ceased in 2006. Only 4 recall visits, in total, were carried out as domiciliary visits, and these took place in 2006 and 2007. The majority of recall visits occurred at the Oral Health Centre, with small numbers taking place at the satellite clinics at Burwood and Hillmorton Hospitals.

Table E presents data on location of recall appointments by patient sex, ethnicity, and living arrangement. Females had significantly more recall visits at the Oral Health Centre, and males had significantly more recall visits at Burwood Hospital, and Brackenridge Estate.
<table>
<thead>
<tr>
<th></th>
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<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Oral Health Centre</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Routine</td>
<td>81</td>
<td>67</td>
<td>94</td>
<td>64</td>
<td>85</td>
<td>391</td>
</tr>
<tr>
<td>Problem-initiated</td>
<td>39</td>
<td>33</td>
<td>29</td>
<td>39</td>
<td>41</td>
<td>181</td>
</tr>
<tr>
<td>Other</td>
<td>20</td>
<td>3</td>
<td>10</td>
<td>6</td>
<td>2</td>
<td>41</td>
</tr>
<tr>
<td>Burwood Hospital</td>
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<td></td>
</tr>
<tr>
<td>Routine</td>
<td>14</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>30</td>
<td>71</td>
</tr>
<tr>
<td>Problem-initiated</td>
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<td>1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
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<td>0</td>
<td>0</td>
<td>1</td>
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<td>1</td>
</tr>
<tr>
<td>Hillmorton Hospital</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Routine</td>
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<td>2</td>
<td>2</td>
<td>4</td>
<td>9</td>
<td>19</td>
</tr>
<tr>
<td>Problem-initiated</td>
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<td>1</td>
<td>1</td>
<td>6</td>
<td>7</td>
<td>17</td>
</tr>
<tr>
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</tr>
<tr>
<td>Brackenridge Estate</td>
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</tr>
<tr>
<td>Routine</td>
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<td>6</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td>Problem-initiated</td>
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</tr>
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</tr>
<tr>
<td>Domiciliary</td>
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<td></td>
</tr>
<tr>
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<td>2</td>
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<tr>
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<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
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</tr>
<tr>
<td>Total</td>
<td>160</td>
<td>115</td>
<td>146</td>
<td>140</td>
<td>181</td>
<td>742</td>
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<td></td>
<td>Oral Health Centre</td>
<td>Burwood Hospital</td>
<td>Hillmorton Hospital</td>
<td>Brackenridge Estate</td>
<td>Domiciliary</td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
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<td>---------------------</td>
<td>---------------------</td>
<td>-------------</td>
<td></td>
</tr>
<tr>
<td><strong>All</strong></td>
<td>3.4 (2.4)</td>
<td>0.4 (1.2)</td>
<td>0.2 (0.7)</td>
<td>0.1 (0.4)</td>
<td>0.0&lt;sup&gt;1&lt;/sup&gt; (0.2)</td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3.0 (2.2)</td>
<td>0.7 (1.5)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.2 (0.7)</td>
<td>0.1 (0.4)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>0.0&lt;sup&gt;1&lt;/sup&gt; (0.2)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>4.1 (2.4)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.1 (0.4)</td>
<td>0.2 (0.6)</td>
<td>0.0 (0.0)</td>
<td>0.0 (0.0)</td>
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<tr>
<td>NZ European</td>
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<td>0.4 (1.1)</td>
<td>0.2 (0.5)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>0.1 (0.3)</td>
<td>0.0&lt;sup&gt;2&lt;/sup&gt; (0.2)</td>
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<td>Maori</td>
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<tr>
<td>At home</td>
<td>4.3 (2.1)</td>
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<td>0.0 (0.0)</td>
<td>0.0 (0.0)</td>
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</tr>
<tr>
<td>Independently</td>
<td>3.6 (2.1)</td>
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<td>0.0 (0.0)</td>
<td>0.0 (0.0)</td>
<td>0.0 (0.0)</td>
<td></td>
</tr>
<tr>
<td>Residential care</td>
<td>3.2 (2.4)</td>
<td>0.5 (1.4)</td>
<td>0.3 (0.7)</td>
<td>0.1 (0.3)</td>
<td>0.0&lt;sup&gt;2&lt;/sup&gt; (0.2)</td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup>P<0.01  
<sup>b</sup>P<0.05  
<sup>1</sup>value was 0.03  
<sup>2</sup>value was 0.02
4.1.2.2 Use of pre-medication for recall visits

Pre-medication with a sedative was given to 32 patients (19.2%) prior to at least one recall. In total, pre-medication was used for 49 recall appointments over the 5-year period, with each pre-medicated patient having between 1 and 4 recalls where pre-medication was used. There were no differences by patient age, sex, ethnicity, or living arrangement in the number of recall appointments where pre-medication was used. Individuals with autism had a significantly higher proportion of recall visits where pre-medication was used (13.7% of recall appointments) than individuals without autism (5.7% of recall appointments) (P=0.017). There were no differences in the proportion of recalls where pre-medication was used for other medical conditions.

4.1.2.3 Use of radiographs at recall visits

Patients had between 0 and 6 recall visits where radiographs were taken, and 22 patients (13.8%) had radiographs taken at 50% or more of their recall appointments. There were no differences in the proportion of recall visits where radiographs were taken, and patient age, sex, living arrangement, or medical condition. The 4 individuals in the ‘other’ ethnic group had, on average, a higher proportion of recall appointments where radiographs were taken (44.1%) than Maori (26.3%) or Pakeha (13.5%; P=0.029).

4.1.2.4 Scaling, topical fluoride, and oral hygiene advice

Thirty patients (18.0%) had some form of scaling or tooth cleaning carried out at 50% or more recall appointments. Hand scaling was carried out for 16 patients (9.6%); polishing with a rubber prophylaxis cup was carried out for 17 patients (10.2%); ultrasonic scaling was carried out for 22 patients (13.2%); and 51 patients
(30.5%) had their teeth cleaned with a toothbrush at one or more recall appointments. On average, females had their teeth cleaned with a toothbrush at 12.6% of recall visits, while it was 7.0% for males (P=0.032). Individuals with an ‘other’ syndrome had hand-scaling carried out at a greater proportion of recall appointments (P=0.023), and teeth cleaned with a toothbrush at a lower proportion of recall appointments (P=0.035) than those classified without an ‘other’ syndrome.

Oral hygiene advice was given to 61 individuals (36.2%) (and their caregivers) during at least one recall over the five-year period. Only 16 patients (9.6%) had oral hygiene advice given during at least half of their recall visits. On average, Maori patients had been given oral hygiene advice at one in three recall appointments, while Pakeha patients had been given oral hygiene advice at one in eight recall appointments (P=0.008).

Topical fluoride was applied to the teeth of 16 individuals (9.6%) during at least one recall over the five-year period. Individuals with a mental illness had topical fluoride applied at a higher proportion of recall appointments (7.4% of recall appointments) than individuals without mental illness (1.7% of recall appointments; P=0.012).

4.1.2.5 Extractions and restorative work during recall visits

In total, 20 patients had some restorative work completed during some of their recall visits. Of the patients who had restorations placed, 11 had one placed, five had two, two had three, one had four, and one had five restorations which were placed over one to five recall visits, during the five-year period. Amalgam was used for restorations for four patients, and glass-ionomer or composite was used for 19 patients during recall visits.
Individuals who lived independently had a significantly greater number of restorations (1.0) placed during recall appointments than those living at home (0.2), and those in residential care (0.2; $P=0.039$). Females had a greater number of restorations placed (0.4) during recall appointments than males (0.1; $P=0.008$).

In total, six patients (3.6%) had one or more teeth extracted during a recall appointment. Only two individuals (1.2%) had extractions at two separate recall visits, and the remaining four (2.4%) had extractions at just one recall visit. Four patients (2.4%) had one tooth extracted; one (0.6%) had two, and one (0.6%) had three teeth extracted during a recall visit.
4.1.3 Treatment visits

4.1.3.1 General anaesthetic treatment visits

4.1.3.1.1 Number of general anaesthetics, location, and operating clinician
All patients had at least one general anaesthetic (GA) for treatment over the 5-year period. The majority of patients (125 patients, 74.9%) had had one general anaesthetic session for dental treatment within the 5-year period, 39 patients (23.4%) required two, and three patients (1.8%) required three general anaesthetics. Patients who lived at home had a mean of 1.4 treatment visits under general anaesthetic; those who lived in residential care had a mean of 1.2 treatment visits under general anaesthetic; and those living independently had a mean of 1.0 treatment visits under general anaesthetic (P=0.028). There were no differences in the number of general anaesthetics by patient ethnicity or sex.

The primary operating clinician for 102 (48.1%) of the GA sessions was a non-specialist senior dentist; 61 (28.8%) of the GA sessions were completed by a specialist special needs dentist, 10 (4.7%) by an oral and maxillofacial registrar or consultant, 37 (17.5%) by an ‘other specialist’ (such as a specialist public health dentist), and one (0.5%) was completed by a house surgeon. A second clinician was present during 13 GA sessions: of those, eight were with an oral and maxillofacial registrar or consultant; one with another specialist; one with a senior dentist; and three with a house surgeon.

The location of general anaesthetics is presented by year in Figure 1. General anaesthetics which took place within the hospital dental department were regarded as out-patient GAs, while those that take place within the day-stay unit, or main operating theatres of Christchurch Hospital were classified as in-patient GAs. There was a dramatic jump in the number of in-patient GAs carried out in
2008 and 2009. Approximately 50% of general anaesthetics were carried out as in-patient cases in 2009. Patients with epilepsy were more likely to have had both an in-patient and out-patient GA for dental treatment over the 5-year period. Some 23.4% of individuals with epilepsy had had both an in-patient and an out-patient GA for dental treatment, while 10.0% of individuals without epilepsy had had both types of GA (P=0.025).

4.1.3.1.2 Waiting time for a general anaesthetic
The average waiting times for a general anaesthetic are presented by year in Figure 2. These are measured by the time waited from referral for a general anaesthetic to a GA assessment appointment, and the time waited from the assessment appointment to the GA date. In some cases, there was no wait for a GA assessment because it was carried out at the same time the patient was referred for a GA, and no further appointment for GA assessment was made. The number of patients waiting longer than six weeks for a GA assessment, and six months for their operation are presented by year in Table F. In 2009, only one patient waited for longer than six weeks for a GA assessment appointment and only five patients waited for longer than six months for their GA. The proportion of patients waiting longer than six weeks for GA assessment, and six months for their GA, was highest in 2006 with 46.7% of patients waiting longer than six weeks for a GA assessment, and 47.8% waiting longer than six months for their GA.
Table F – Number of patients with no wait for GA assessment, who waited longer than 6 weeks for assessment, and longer than 6 months for GA

<table>
<thead>
<tr>
<th></th>
<th>No wait time for GA assessment</th>
<th>Waited for GA assessment for longer than 6 weeks</th>
<th>Total wait for GA longer than 26 weeks (6 months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005</td>
<td>33 (82.5%)</td>
<td>2 (5.0%)</td>
<td>15 (37.5%)</td>
</tr>
<tr>
<td>2006</td>
<td>17 (37.8%)</td>
<td>21 (46.7%)</td>
<td>22 (47.8%)</td>
</tr>
<tr>
<td>2007</td>
<td>8 (32.0%)</td>
<td>7 (28.0%)</td>
<td>8 (32.0%)</td>
</tr>
<tr>
<td>2008</td>
<td>21 (47.7%)</td>
<td>14 (31.8%)</td>
<td>17 (38.6%)</td>
</tr>
<tr>
<td>2009</td>
<td>27 (57.4%)</td>
<td>1 (2.1%)</td>
<td>5 (10.6%)</td>
</tr>
</tbody>
</table>
4.1.3.1.3 Scaling under general anaesthetic
Under GA, one patient (0.6%) had teeth hand-scaled; 126 (75.5%) had their teeth ultrasonic scaled, and seven (4.2%) had teeth polished with a rubber prophylaxis cup. Figure 3 shows the percentage of patients undergoing GA who had ultrasonic scaling by year. It is evident from the graph that the proportion of patients having their teeth scaled while under GA, has increased each year between 2005 and 2009. In 2009, only one patient (2.1%) did not have an ultrasonic scaling carried out under GA; the remaining 46 patients (97.9%) who had a GA in 2009 did have it.

**Figure 3 – Percentage of patients who had ultrasonic scaling under GA, by year**

![Graph showing percentage of patients who had ultrasonic scaling under GA by year. The percentage increases each year from 2005 to 2009. In 2009, 97.9% of patients had a GA with ultrasonic scaling.]
4.1.3.1.4 Restorative treatment and extractions under general anaesthetic

Over the five-year period, a total of 538 restorations were placed under general anaesthetic for the patient group. This was made up of 192 amalgam restorations, and 171 glass-ionomer or composite restorations on posterior teeth, and 175 glass-ionomer or composite restorations placed on anterior teeth. The mean number of each type of restoration is presented by year in Figure 4. The use of amalgam was noticeably lower in 2005 than in later years. When anterior and posterior restorations are combined, glass-ionomer and composite restorations outnumber amalgam restorations.

In total, 117 patients (70.1%) had restorations placed under GA in the five-year period, with between 1 and 18 restorations placed. Table G presents the number of restorations placed by patient sex, ethnicity, and living arrangement. Patients who lived in residential care were less likely to have had restorations placed, and had fewer restorations in the five-year period, than those with other living arrangements. Patients who lived at home had the greatest number of glass-ionomer or composite fillings placed on anterior and posterior teeth. The number of restorations placed is presented by patient medical condition in Table H. A greater proportion of individuals with autism had restorations placed under GA during the five-year period than those without autism. The reverse was true for individuals with cerebral palsy. Patients with a physical disability had, on average, approximately half the number of amalgam restorations placed than those without a physical disability (P=0.04).

Extractions were carried out under GA for 150 patients (89.8%), with patients having between 1 and 22 teeth extracted in a single GA procedure. Twenty-eight patients (16.8%) had extractions carried out in two GAs, and one patient (0.6%) had
extractions during three GAs. The mean number of teeth extracted under GA by patient sex, ethnicity, living situation, is presented in Table G, and by medical condition in Table H. There were no differences in the number of teeth extracted and patient sex, ethnicity, or living situation. However, individuals with autism had fewer teeth extracted than those without autism (P=0.01).

In total, 102 patients (61.1%) had both restorative treatment and tooth extractions under GA during the five-year period. Those who had only extractions accounted for 28.7% (48 patients) and just 17 patients (10.2%) had restorative treatment only. The type of treatment carried out under GA is presented by year in Figure 5. Every year, over half of the patients received a mixture of restorations and extractions. Patients who had only restorative treatment made up the smallest group every year, except for 2008.
Figure 4 – Mean number of each restoration type, by year

Restoration type, by year

![Graph showing the mean number of each restoration type by year.]

Figure 5 – Type of treatment under GA, by year

Treatment mix under GA, by year

![Graph showing the percentage of patients treated with restoration and extraction, extraction only, and restoration only by year.]
| Table G – Extractions and restorations placed under GA by patient sex, ethnicity, and living arrangement |
|--------------------------------------------------|---------|----------------|--------------------------------|----------------|--------------------------------|----------------|
| | Mean number of extractions (sd)* | Number who had restorations placed under GA (%)** | Mean number of all types of restoration placed under GA (sd)** | Mean number of GIC or composite restorations placed under GA (sd)** | Mean number of anterior GIC or composite restorations placed under GA (sd)** | Mean number of posterior gic or composite restorations placed under GA (sd)** | Mean number of amalgam restorations placed under GA (sd)** |
| Sex | | | | | | | |
| Male | 4.1 (4.0) | 72 (74.2) | 3.2 (3.5) | 2.1 (3.1) | 1.1 (2.0) | 1.0 (1.8) | 1.1 (1.5) |
| Female | 5.2 (5.4) | 45 (64.3) | 3.3 (4.0) | 2.1 (3.4) | 1.0 (2.0) | 1.1 (2.0) | 1.2 (1.8) |
| Ethnicity | | | | | | | |
| NZ European | 4.5 (4.5) | 96 (68.1) | 3.2 (3.8) | 2.2 (3.4) | 1.1 (2.0) | 1.1 (2.0) | 1.0 (1.6) |
| Maori | 7.6 (7.4) | 8 (80.0) | 4.5 (4.4) | 2.2 (3.0) | 1.3 (2.8) | 0.9 (1.1) | 2.3 (2.5) |
| Other | 2.0 (1.0) | 1 (25.0) | 3.5 (3.0) | 2.3 (2.6) | 1.5 (1.7) | 0.8 (1.0) | 1.3 (1.0) |
| Living arrangement | | | | | | | |
| Residential care | 4.4 (4.4) | 81 (64.3)* | 2.6 (3.2)* | 1.6 (2.7)* | 0.8 (1.7)* | 0.7 (1.5)* | 1.0 (1.6) |
| At home | 5.4 (5.5) | 32 (88.9) | 5.3 (4.5) | 3.9 (4.2) | 1.8 (2.7) | 2.1 (2.7) | 1.4 (1.5) |
| Independent | 3.8 (1.8) | 4 (80.0) | 4.0 (4.2) | 1.8 (2.0) | 1.4 (2.2) | 0.4 (0.9) | 2.2 (2.5) |

* of patients who had extractions under GA in the five-year period
** of patients who had restorations under GA in the five-year period
*P<0.01
*bP<0.05
<table>
<thead>
<tr>
<th></th>
<th>Mean number of extractions (sd)*</th>
<th>Number who had restorations (%)**</th>
<th>Mean number of all types of restoration (sd)**</th>
<th>Mean number anterior GIC/composite restorations (sd)**</th>
<th>Mean number posterior GIC/composite restorations (sd)**</th>
<th>Mean number of amalgam restorations (sd)**</th>
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<tbody>
<tr>
<td><strong>Autism</strong></td>
<td></td>
<td></td>
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<tr>
<td>Has condition</td>
<td>3.1 (2.1)</td>
<td>40 (81.6)</td>
<td>3.1 (3.4)</td>
<td>2.0 (3.4)</td>
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<td>Does not have condition</td>
<td>5.2 (5.2)b</td>
<td>77 (65.3)</td>
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<td>2.1 (3.1)</td>
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<tr>
<td>Has condition</td>
<td>4.2 (4.6)</td>
<td>33 (70.2)</td>
<td>3.1 (3.4)</td>
<td>2.0 (2.9)</td>
<td>1.0 (1.8)</td>
<td>0.9 (1.8)</td>
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<tr>
<td>Does not have condition</td>
<td>4.7 (4.7)</td>
<td>84 (70.0)</td>
<td>3.3 (3.8)</td>
<td>2.1 (3.3)</td>
<td>1.1 (2.1)</td>
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<td><strong>Cerebral Palsy</strong></td>
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<td>Has condition</td>
<td>5.2 (6.2)</td>
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<td>0.9 (1.9)</td>
</tr>
<tr>
<td>Does not have condition</td>
<td>4.5 (4.4)</td>
<td>107 (72.8)b</td>
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<td>1.0 (1.9)</td>
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<td><strong>Down syndrome</strong></td>
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<tr>
<td>Has condition</td>
<td>4.7 (3.7)</td>
<td>13 (72.2)</td>
<td>4.2 (4.7)</td>
<td>3.4 (4.3)</td>
<td>1.7 (2.7)</td>
<td>1.7 (2.2)</td>
</tr>
<tr>
<td>Does not have condition</td>
<td>4.6 (4.8)</td>
<td>104 (69.8)</td>
<td>3.1 (3.6)</td>
<td>1.9 (3.0)</td>
<td>1.0 (1.9)</td>
<td>0.9 (1.9)</td>
</tr>
<tr>
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</tr>
<tr>
<td>Has condition</td>
<td>5.0 (4.5)</td>
<td>7 (53.8)</td>
<td>2.4 (3.3)</td>
<td>1.3 (2.3)</td>
<td>0.4 (0.8)</td>
<td>0.9 (1.7)</td>
</tr>
<tr>
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<td>110 (71.4)</td>
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<td>2.1 (3.3)</td>
<td>1.1 (2.1)</td>
<td>1.0 (1.9)</td>
</tr>
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<td><strong>Physical disability</strong></td>
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</tr>
<tr>
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<td>3.3 (3.2)</td>
<td>20 (64.5)</td>
<td>2.7 (3.3)</td>
<td>2.1 (3.1)</td>
<td>1.2 (2.2)</td>
<td>0.9 (1.9)</td>
</tr>
<tr>
<td>Does not have condition</td>
<td>4.8 (4.9)</td>
<td>97 (71.3)</td>
<td>3.3 (3.8)</td>
<td>2.1 (3.3)</td>
<td>1.0 (1.9)</td>
<td>1.0 (1.9)</td>
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<td><strong>Mental illness</strong></td>
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</tr>
<tr>
<td>Has condition</td>
<td>3.5 (3.3)</td>
<td>16 (72.7)</td>
<td>2.6 (2.4)</td>
<td>1.5 (2.3)</td>
<td>1.0 (1.7)</td>
<td>0.4 (0.9)</td>
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<tr>
<td>Does not have condition</td>
<td>4.7 (4.8)</td>
<td>101 (69.7)</td>
<td>3.3 (3.9)</td>
<td>2.2 (3.3)</td>
<td>1.0 (2.0)</td>
<td>1.1 (2.0)</td>
</tr>
</tbody>
</table>

* of patients who had extractions under GA in the five-year period
** of patients who had restorations under GA in the five-year period

P<0.01  P<0.05
4.1.3.1.5 Other treatment provided under general anaesthetic
Dental radiographs were taken for 143 patients (86.2%) under general anaesthetic, with each patient having between one and nine radiographic images taken during a session. Among the patients who had radiographs taken, there was a mean of 5.3 (sd=2.7) radiographic images taken under general anaesthetic over the five-year period.

Oral hygiene advice had been given to only four patients when they attended for a GA. Some 38 patients (22.8%) had had topical fluoride varnish applied to their teeth during at least one GA: one patient had received it during two GA sessions, while the remaining 37 had it applied at one GA. There were no differences in the number of patients who had topical fluoride applied by patient ethnicity, sex, living arrangement, or medical condition.

Ten patients had fissure sealants placed under general anaesthetic. Two patients had a biopsy taken, one had sharp teeth smoothed, one had a temporary restoration placed, and one had a swelling incised and drained. Five patients had impressions taken during GA for denture work and nine patients had had a root filling placed under general anaesthetic.

In some cases, there was coordination with clinicians in other specialties to enable the provision of non-dental treatment under general anaesthetic. Four patients had an ear-nose-throat (ENT) procedure, two had a gynaecological procedure, ten patients had blood taken for their general medical practitioner, and one patient had a non-dental radiograph taken during a dental GA.

4.1.3.1.6 Anaesthetic issues
Sedative pre-medication (“premed”) was given to 70 patients (41.9%) prior to at least one general anaesthetic for dental treatment during the five-year period. Of those, 59 had pre-medication for one GA, 8 for two GAs and 2 for three GAs. Data on the use of pre-medication are presented by patient sex, ethnicity, and living situation in Table I. Males were more likely than females to have had pre-medication for at least one GA. Sixty three of the individuals of NZ European ethnicity (44.7%), and one of the ten Maori patients (10.0%) had had pre-medication for a GA, and, of the four individuals in other ethnic groups, three (75%) had had it. Data on the use of pre-medication are presented by medical condition in Table J. Individuals with autism were more likely to have had pre-medication than those without the condition, while individuals with a physical disability were less likely to have had pre-medication than those without a physical disability.

At the most recent GA, only ten (6.1%) patients had capacity to consent for the operation themselves. Consent was sought from a guardian for 130 (79.3%) patients, and for 24 (14.6%) patients, Section 7.4 of the Code of Health and Disability Services Consumers’ Rights 1996, was utilised. With respect to patients’ most recent GA, the ASA (American Society of Anaesthesiologists’ classification) status had been recorded for 132 patients (79.0%). Of those, 75 (56.8%) were classified as ASA 2 (a patient with a mild systemic disease), and 57 (43.2%) were classified as ASA 3 (a patient with a severe systemic disease). The induction method which was used at the most recent GA was recorded for 164 (98.2%) of the patients. Inhalational induction was used for 63 patients (38.2%) and intravenous induction was used for 101 patients (61.2%). Of the 154 patients (92.2%) for whom the method of intubation was recorded, 26 (16.9%) had an oral tube, and nasal intubation was used for the remainder.
Complications affected 24 patients (14.4%) during their general anaesthetic. Three of those patients experienced complications during two general anaesthetic sessions. Complications are listed in Table K.

**Table I – Number of patients who had sedative pre-medication prior to GA, by sex, ethnicity, and living arrangement**

<table>
<thead>
<tr>
<th></th>
<th>Number who had premed prior to a GA (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>48 (49.5)b</td>
</tr>
<tr>
<td>Female</td>
<td>22 (31.4)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>NZ European</td>
<td>63 (44.7)b</td>
</tr>
<tr>
<td>Maori</td>
<td>1 (10.0)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (75.0)</td>
</tr>
<tr>
<td><strong>Living arrangement</strong></td>
<td></td>
</tr>
<tr>
<td>Residential care</td>
<td>56 (44.4)</td>
</tr>
<tr>
<td>At home</td>
<td>14 (38.9)</td>
</tr>
<tr>
<td>Independently</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>

P<0.01
P<0.05

**Table J - Number of patients who had sedative pre-medication prior to GA, by medical condition**

<table>
<thead>
<tr>
<th>Medical condition</th>
<th>Number who had premed prior to a GA (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>with condition</td>
</tr>
<tr>
<td>Autism</td>
<td>28 (57.1)a</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>18 (38.3)</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>5 (25.0)</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>9 (50.0)</td>
</tr>
<tr>
<td>Other syndrome</td>
<td>8 (61.5)</td>
</tr>
<tr>
<td>Physical disability</td>
<td>8 (25.8)b</td>
</tr>
<tr>
<td>Mental illness</td>
<td>9 (40.9)</td>
</tr>
</tbody>
</table>

P<0.01
P<0.05
### Table K – Complications which occurred during GAs

<table>
<thead>
<tr>
<th>Anaesthetic complications</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complication with induction or intubation</td>
<td>15</td>
</tr>
<tr>
<td>Bradycardia and/or hypotension</td>
<td>2</td>
</tr>
<tr>
<td>Seizure</td>
<td>1</td>
</tr>
<tr>
<td>Vomited during procedure</td>
<td>1</td>
</tr>
<tr>
<td>Aspirated during GA</td>
<td>1</td>
</tr>
<tr>
<td>General anaesthetic abandoned</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dental complications</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post-operative bleed</td>
<td>2</td>
</tr>
<tr>
<td>Dentist needle-stick injury</td>
<td>1</td>
</tr>
<tr>
<td>Difficult intra-oral access for treatment or radiographs</td>
<td>2</td>
</tr>
<tr>
<td>Discovery of non-vital tooth requiring a further GA</td>
<td>1</td>
</tr>
<tr>
<td>Tooth fractured during extraction</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Post-operative/recovery complications</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fall in recovery</td>
<td>1</td>
</tr>
<tr>
<td>Low oxygen saturation post-GA</td>
<td>1</td>
</tr>
<tr>
<td>Unplanned admission</td>
<td>2</td>
</tr>
<tr>
<td>Slow recovery</td>
<td>1</td>
</tr>
</tbody>
</table>
4.1.3.2 Treatment provided without general anaesthetic

4.1.3.2.1 Location and number of non-GA treatment visits
The majority of non-general anaesthetic treatment sessions provided for the group of patients over the 5-year period was provided in the Oral Health Centre. A total of 37 (22.2%) patients attended at the Oral Health Centre for between one and seven non-general anaesthetic treatment appointments. Only four patients had treatment at the Hillmorton Hospital dental clinic; two patients had treatment at the Burwood Hospital clinic, and one patient had treatment provided during a visit to the hospital emergency department. No patients had treatment provided during a domiciliary visit.

Treatment was provided for 24 patients (14.4%) without local anaesthetic or sedation and there were no differences by patient sex, ethnicity, or living situation. Local anaesthetic only was used for the treatment of 17 patients (10.2%). One patient managed two treatment visits, two patients managed three treatment visits, and one patient managed five treatment visits with local anaesthetic only. Oral sedation was used during treatment for 11 patients. Ten of those patients had only one episode of treatment with oral sedation, but one patient had six. Intravenous sedation was used for treatment for only one patient, at one treatment visit. Relative analgesia with nitrous oxide gas was used for treatment of only two patients, one of whom had it used over four different treatment visits.

4.1.3.2.2 Restorative treatment and extractions during non-GA treatment visits
In total, 22 patients (13.2%) had restorations placed during non-GA treatment visits. Nine patients (5.4%) had amalgams placed during non-GA treatment visits, with each patient having between one and six amalgam restorations placed over
the 5-year period. Twenty-one patients (12.6%) had glass-ionomer or composite restorations placed during non-GA treatment visits, with each patient having between one and eight restorations placed over the 5-year period. Patients who had restorations placed in treatment appointments without GA had between one and seven appointments where restorations were placed. Twelve patients (7.2%) had restorations placed in one appointment, and 11 patients (6.6%) had restorations placed in two or more appointments.

Eight patients (4.8%) had a tooth extracted during one non-GA treatment appointment. No patients had more than one tooth extracted without GA in the period.

4.1.3.2.3 Other treatment provided at non-GA treatment visits
Radiographs were taken for only three patients during a non-GA treatment appointment. This amounted to a total of four radiographic images for the three patients. Four patients had impressions taken for denture work. One patient had a root filling placed without GA. Four patients (2.4%) had their teeth hand-scaled, 12 (7.2%) had an ultrasonic scale, six (3.6%) had their teeth polished with a rubber prophy cup, and two (1.2%) had their teeth cleaned with a toothbrush during a non-GA treatment visit.
4.2 Qualitative Results – Interviews

4.2.1 Interview participants
Fifteen semi-structured interviews were carried out with participants for 13 randomly selected individuals with an intellectual disability who had a general anaesthetic (GA) for dental treatment at Christchurch Hospital between 1 January 2009 and 31 December 2009. A description of the interview participants is presented in Table L. For two of the individuals, separate interviews took place with both their support person, and their mother. Of the 13 individuals for whom interviews were carried out, 11 lived in residential care, and two lived at home with a parent. None of the interview participants lived independently. Seven of the individuals with an intellectual disability were female, and six were male.

Where possible, the individuals with an intellectual disability attended the interviews, alongside their guardian/support person, and contributed to the interview. However, four individuals with an intellectual disability were not present during the interview as their support person/guardian deemed that they were not able to be present and contribute to an interview. All four of those individuals had severe autism. Nine individuals with an intellectual disability participated in the interviews. Of those, two participated non-verbally only, and four participated to a limited extent (such as yes/no answers).
### Table L – Description of interview participants

<table>
<thead>
<tr>
<th>Individual</th>
<th>Description</th>
<th>Interviewee</th>
</tr>
</thead>
</table>
| A          | 59-year-old female, with an intellectual disability and cerebral palsy, who is non-verbal and has a physical disability. She lives in a community house, and her mother lives nearby and is in regular contact. | a) Support person with Individual A  
            b) Mother with Individual A |
| B          | A 55-year-old male with autism, Angelman syndrome, and a learning disability. He lives in a community house with caregivers, and is independent with his own oral care. | Individual B |
| C          | A 56-year-old woman with Down syndrome. She lives in residential care. She had 2 GA’s for dental treatment in the 5-year period. | House coordinator of community house with Individual C |
| D          | A 24-year-old female with Down syndrome. She lives at home with her mother. She had 2 GA’s for dental treatment in the 5-year period. | Mother with Individual D |
| E          | A 31-year-old female with intellectual disability. She lives at home with her mother. She has a high caries rate and had 3 GA’s for dental treatment during the 5-year period (1 due to a tooth fracture during extraction, which required a repeat GA) | Mother with Individual E |
| F          | A 46-year-old female with an intellectual disability, autism, and scoliosis. He lives in residential care. | House manager of the community house |
| G          | A 42-year-old male with an intellectual disability, autism, and bipolar disorder. He lives in residential care. He had 2 GA’s for dental treatment during the 5-year period. | Support person |
| H          | A 55-year-old male with an intellectual disability and autism. He lives in residential care. He had 2 GA’s for dental treatment during the 5-year period, and has subsequently successfully had some dental work completed under LA only. | Individual H with Team Leader of residential facility |
| I          | A 48 year old female with an intellectual disability and epilepsy. She lives in residential care. She had 2 GA’s for dental treatment during the 5-year period. | Support person with Individual I |
| J          | 43 year-old male with mild intellectual disability, Aspergers syndrome, anxiety, and partially blind. He lives in residential care. | Individual J with his key person |
| K          | 45 year-old male with intellectual disability and autism. He lives in residential care during the week and with his parents at weekends. | a) Key person & support person  
            b) Mother |
| L          | 29 year-old male with intellectual disability and Aspergers syndrome. He lives in residential care. | Individual L with his support person |
| M          | 22 year-old female with intellectual disability and autism. Lives in residential care. | Mother |
4.2.2 Responses of participants with an intellectual disability
Although the responses of the individuals with an intellectual disability contributed only a small portion of the interview data, their views hold much importance as the primary consumers of the dental services. Overall, the most evident theme which came from analysis of the transcripts of individuals with intellectual disabilities was the anxiety expressed by the individuals in regard to dental visits.

4.2.2.1 Anxiety
The anxiety felt by some of the participants regarding dental treatment was evident. Individuals with intellectual disability reported feeling generally nervous about dental visits but also spoke of specific fears such as the drill, needles, people in white coats, and the intimidating operating theatre lights. One participant described the fearful associations he had made with the operating lights in the theatre:

I see this big lamp with those, how many lights is there, I can’t remember, there’s about 6 or 7 lights on a circular lamp, and that frightens me. I have seen that on TV, those big circular lights, and people go under the knife under those lights. Because I have seen horror movies, I mean I haven’t seen horror movies, but I have heard of them. Where bad surgeries go wrong. That’s what terrifies me. I’ve heard of it but I didn’t want to watch it otherwise it would put me off. (Individual L)

Perhaps partially explaining this dental anxiety, some participants described previous bad dental experiences which left them with vivid negative dental memories.
I think it might have been that bad experience I had that first time, when I was younger. I still remember it... Well I got a bit violent. I got a bit angry at the nurse. I found it kind of uncomfortable. It’s mainly the drill. I used to have a really good nurse in another school I went to, yeah. But I think it was always a problem. (Individual J)

Last time I went, when I went with my mother, I saw the, when I was a kid, what they did, they changed the gas mask to the needles. That terrified me. As soon as I saw the needle I started screaming... Poor old mum had to drag me in when they, when I saw the needle. And I didn’t like it at all. I almost had a panic attack. Last time when I went to get that done, I had a nasty panic attack and I couldn’t stop shaking. (Individual L)

4.2.2.2 Treatment under GA

When asked about the dental treatment under GA, a couple of participants recalled the topical anaesthetic patches placed on their hands prior to an intravenous induction. While one individual found this “easy”, another reported that he “panicked” when he saw the needle. Another participant summed up his treatment under GA by pointing to areas in his mouth and reporting “got teeth out, and x-ray, and wiggle and wiggle, and dizzy afterwards”.

When asked how they were after their surgery, the responses of the participants were fairly negative. One individual was concerned that he had temporarily lost the ability to whistle following his dental treatment. This whistling was an ability he seemed to pride himself on, and he reported that his father “used to whistle all the time”. Another individual recalled having to gargle salty water for a couple of days post-operatively, but overall felt “relieved” his treatment was over and glad he had been asleep during treatment. Another participant recalled having a headache, and vomiting post-operatively.
4.2.2.3 Opinion of medical and dental staff

The medical and dental staff were described as “helpful” by one participant, and “scary” by another. When asked what staff did that was scary, the participant reported that he was terrified of needles and suggested that “what they could have done differently was use the gas mask” instead of an injection for the induction.

4.2.2.4 Satisfaction with the Hospital Dental service and participants’ recommendations

When asked whether they were happy with the dental service, one participant answered “at least I can go to sleep”, indicating his relief at having his treatment carried out under general anaesthetic. Another participant who communicated non-verbally smiled and clapped his hands. His support person indicated that this meant he was happy with it. One individual felt that the time spent on the waiting list for his GA appointment was too long, and his tooth had been sore: “Long time, it was sore, yeah. And a bit broken. Not that bad, but with sugar. It was a wee bit loose and the dentist said pull it out, you know” (Individual B).

When asked what recommendations they would make for the hospital dental service, one participant suggested that “everyone gets knocked out when they go to the dentist”. Another felt that the gas mask should be used for induction rather than the needle (IV induction), reflecting his own stated fear of needles. He also expressed a dislike of having to see a different clinician when his own dentist was sick, and for the waiting time when his dentist was running late for his appointment. In addition, he complained that the dental surgery lights were too bright and hurt his eyes.

Recommendations by Individual L:
I think, I recommend they should change needles to what they used to have a long time ago when they put people to sleep. Like the gas mask, the old gas mask, because I enjoyed that. Because it feels like I am going into space when that goes over my face. That’s what I recommend. If that happened I could pretend to go into space.

The other recommendations is if my dentist is sick, maybe move my appointment to the next day when the dentist is better. That way I don’t bump into a stranger. I do worry when people I don’t know come in and check me out. Last time... I met somebody that I didn’t know and I started panicking. I just didn’t like the face. I thought that that stranger was going to get me. I don’t get on with strangers.

I recommend if my appointment’s delayed we can rearrange it to the next date. Rather than me waiting for long. It’s the waiting list that gets me. It frustrates me. It happens to everybody.

And with the lights in the dentist’s office, I think they’re too bright for me when I get my teeth checked. When I walk into the room it hurts my eyes. And it gives me a headache.

When asked how they go with check-up visits, the replies were similarly mixed. One individual replied non-verbally with a smile (this was confirmed as a positive response by the support person). Two other participants indicated that they felt okay about check-up visits until they were told that treatment was required.

Yeah, no, they are alright. If I know what they are doing.... I am always a bit nervous. (Individual J)
I’m quite happy with the check-ups. The check-ups are ok but when I hear that I have to go and get a tooth removed or something, I start to panic.

(Individual L)

The participants with intellectual disabilities identified other concerns. One individual spoke about how his weight had been an issue for his treatment, requiring treatment at the day-stay unit in a hospital bed designed to hold heavier patients rather having an outpatient GA in the Oral Health Centre operating chair. There were also issues raised about continuity of care in terms of the dentist they see from year to year.

4.2.2.5 Daily oral care

Two of the participants with an intellectual disability reported that they were assisted with oral care. A few said they cleaned their teeth a couple of times a day, while another participant admitted that he was “a bit slack on it” and brushed once daily.
4.2.3 Views of support people and parents
When interviewed alongside the individual with an intellectual disability, parents and support people were able to act as additional informants to provide useful information on dental services for individuals with intellectual disabilities. Where it was not possible to obtain the information from the individuals themselves, parents and support people were an important source of information as they are instrumental in facilitating access to care for the individuals they care for, and often accompany them to their dental appointments.

4.2.3.1 Anxiety, sedation, and restraint
Parents and support people were particularly concerned about managing the individual's dental anxiety, and employed a number of strategies to manage this during dental visits. These strategies included discussing the visit with the individual prior to going, coaxing them along, and ensuring they have a settled mood. Having the most appropriate support person attend on the day was instrumental to this, because it was reassuring for the individual with an intellectual disability.

Because of his behaviours, we have to follow a certain process before we actually get him to the Oral Health Centre. It’s a matter of coaxing him along, making sure his behaviour is settled, his mood is settled and he is in a cheerful and approachable, cooperative mood and manner. Otherwise it just turns to custard. He can be too violent. Once we follow that process and stick to that. It’s all ‘be nice’ type process, he will hate the word ‘no’ or anything to do with negative verbal input. So once we got there everything has gone good. (Support person for individual G)

We talk heaps about things like that before we go. So he knows what’s going to happen. And then when we get there, the people virtually say what we
have already gone through, so it’s really good for [him]. (Key person for individual J)

Some of the support people mentioned a bad childhood dental experience which the individual has had that may have contributed to their dental anxiety. They felt that where things hadn’t gone well during a visit to the dentist (or school dental clinic) in the past, this had resulted in ongoing anxiety about dental visits.

We had a bad, at primary school, the dental nurse used to come to primary school, and there was a fair bit of – [she] wasn’t very cooperative there. And her sister and brother used to have to go over and help. And it was sort of pushing her back in the chair. Why I am saying this, is that it caused quite a bit of stress. By the time she got to the hospital system she was pretty stressed about dentists. (Mother of individual D)

As soon as you get a bad experience in the Oral Health Centre, it’s pretty much back to square-one from here-on-in. When they have to go back again. (Support person for Individual G)

As well as anxiety with dental visits, another problem that support people identified with regard to a dental appointment and carrying out treatment was the individual’s tendency to ‘fight’ or be ‘violent’. This was sometimes used to justify the opinion that treatment could only have been possible with the use of GA. A few of the interview participants felt that treatment could not have been possible without the use of general anaesthetic. One of the participants, a mother, wished that a general anaesthetic wasn’t necessary for treatment but felt that it was the only way that dental treatment could be provided.
In order to alleviate some of the anxiety and counteract some of the behavioural issues of the individuals with intellectual disabilities, a number of support people reported that premedication with a sedative (“premed”) had been necessary prior to surgery. In addition, some individuals required premed for check-up appointments as well.

*We medicate her before she goes to the dentist, or any medical thing.* (House coordinator for individual C)

The issue of physical restraint was also raised by some respondents who expressed some discomfort. While they felt that the dental treatment received (for which the use of restraint was intended) was beneficial for the individual, they described some scenarios where restraint may have been used. A support person spoke about restraint that they thought they may have had to apply at one point and was concerned about how this would have been perceived by other people. Another support person was concerned about restraint she saw used by dental staff and was unsure whether physical restraint was more or less ‘*humane*’ than sedation.

*And yeah, the thing is with the check-ups that nobody will voluntarily open their mouth, and they don’t hold for long enough for the dentist to check everything. So they have to be kind of restrained, with holding arms and the head. I don’t know if it’s better just to give them some medication just to be a bit calmer and kind of sleepy before the dental visit maybe. But that’s restraint too. It’s a question if it’s more humane to give them the pills or more humane just to restrain them physically. It can be terrible for us. Because one guy, is really moving his arms all the time, and they are just doing a clean or something. Well, I felt very sorry about him, that, they were holding him really tight. But, what can you do? It’s good for him. But still, the way... yeah.* (Support person for individual A)
It’s just that there may have been a moment where I thought I may have had to restrain him, and you’re always a bit iffy about how people perceive that type of process. You know, to actually hold someone down. But I guess it’s your cruel to be kind type of scenario. (Support person for individual G)

4.2.3.2 Identifying a dental problem

Another large issue which emerged during interviews with support people and parents was the difficulty some of them faced when it came to identifying a dental problem. Support people play an important role in identifying dental problems and arranging dental appointments. However, many of the individuals were not able to tell their support person about a dental problem, and support people had to rely on changes in the individual’s behaviour or demeanour as a clue.

She keeps picking her teeth. We just don’t know. But she visited the dentist, and they can’t find anything wrong. (House coordinator for individual C)

We noticed that when he was eating and drinking he made sounds. We went back to the dentist just in case. He needed 3 fillings at that stage. (Team leader for individual H)

I don’t know that [she] would be able to tell us. We have to look and see if they are loose or anything. (Support person for individual I)

The only way I know, she can’t tell me she’s got sore teeth, is usually she starts hitting her head and pointing to her ears. In the past we have not realised, but then as time has gone on, different times it has been her teeth. (Mother of individual M)
4.2.3.3 Dental staff

Almost all of the support people and parents made positive comments about the dental and medical staff they had encountered at their dental general anaesthetic and recall appointments. Staff were described as friendly, patient, calm, and understanding of the needs of patients with intellectual disabilities. While a few participants praised the dental and medical staff as working quickly and efficiently, others liked it when they took their time and did not appear rushed.

*They are all so patient. That’s the thing I notice. You know, because it takes a wee while for her to get on the chair and sit back, and open her mouth, it all takes time. They are quite relaxed about it.... And I think that is the best thing about going there. Just having time, he just took his time, took his time.... That to me was worth a million dollars. Because it got her over that fear.* (Mother of individual D)

*They seemed to understand what we were going through, trying to keep her calm. And they were brilliant. There was no impatience, and there was no - they just took their time.* (House coordinator for individual C)

*I could tell, just my personal opinion that they had been here before. That they had done a bit of work with disabilities. They seem to work fast and efficiently. It just makes things go smoother you know, the faster you can move, not showing any fuss. Not showing any speed, is the big thing, not panicking, but you could be panicking if you know what I mean. Just getting the job done as quickly and smoothly and as quietly as possible.* (Support person for individual G)

*They just seemed to be very aware that [he] needed extra support and I think they were guided kind of by his reactions. They actually seemed to be really...*
While participants were satisfied with the dental staff that they had encountered, there were some concerns about continuity of care. Some participants reported that the dentist they would see for check-ups would change from year to year.

You just go and I don’t know who we are going to get. (Mother of individual D)

It is good to have the same person. Sometimes, if I go to Burwood it is someone different. And I don’t know them, and they don’t know me and we go through the same questions again. (Support person of individual I)

### 4.2.3.4 GA treatment

Some participants felt that the time waited for the general anaesthetic after finding out that it was needed was too long and felt it would have been better if the surgery had been done earlier. This was compounded where there had been difficulty or delay in identifying that an individual had been experiencing a dental problem.

I’d like to think that by the time I’ve realised that it’s her teeth needing doing or whatever, that we can get her in at the earliest possible time without too much wait, because obviously she’s already, it has been going on for a while. (Mother of individual M)

Participants frequently reported that the time spent waiting at the hospital immediately prior to the general anaesthetic had been problematic. They reported that even short waiting times seemed longer to individuals with intellectual
disabilities and, because of this, was additionally stressful for caregivers. Some of the support people reported that the individuals would be reluctant to sit down in a waiting room, and instead would need to walk around or pace to pass the time. A couple of support people mentioned the difficulty posed by a visible and available coffee cart when the individual needed to be fasting prior to surgery. One support person commented that the rooms in the day stay unit were too small when a hoist was needed to transfer a patient.

When you come there, you need a hoist, and the beds are quite narrow and so you kind of have to fit in there and, those rooms in the day surgery unit are really tight, so you always have to take some chairs out... it could be a bit more comfortable for these people. (Support person for individual A)

He just suddenly stood up, walked out of the room and was going to walk through a door. Probably looking for coffee. He probably thought he knew where the coffee was... ‘it must be through that door, I’ll just go and try that one’ and I was like ‘oh hang on a minute [Individual K], we can’t go through there yet’ and it was actually one of the operating rooms. (Support person for individual K)

But when we arrive I think [she] expects to be seen, and waiting is a big issue. So you have to be really sort of, trying to entertain her or conning her into staying, because she wants to go. And she doesn’t sit. She paces. So that makes it really hard... and I know they have to check the vital signs, you know, the blood pressure and things like that but, and they have got to allow so many hours to do that, but that time is too long. Far too long, you know. I mean, 20 minutes, half an hour, and hell that’s exhausting for a parent or carer or even her to wait. So I would say overall for any procedure it is the
waiting time that is the hardest, and that would be the downfall. (Mother of individual M)

They showed us into a special waiting room and I think there was tea and coffee and drinks there. Although [he] wasn’t allowed to have any of course, so we all sort of declined. No it was all very nice, you know. We just sort of kept [him] busy until, just chatting away and that, just looking at magazines and things until it was time for his appointment. So he was quite ok with it all. And there was a toilet sort of not too far away. (Support person for individual K).

Support people described how, when the time came for the general anaesthetic to be administered, they would accompany the individual into the operating theatre and stay until the individual was asleep. They were happy with this and reported that it provided a ‘familiar face’ for the individual and to provide reassurance. In some cases, both a caregiver and family member attended.

Yeah they asked me to go to theatre too. To give her the gas. Because they wanted to have somebody that was familiar with her, because she can be agitated and stuff like that. (Support person for individual A)

Yes, I go into theatre, for anything she has to be, I go right in there and I hold her right until they have her out. That was good, it was fine. It is harder on me. (Mother of individual M)

A couple of participants had observed some difficulty with the induction or intubation. These difficulties included trouble keeping the topical anaesthetic pads in place on the hand for insertion of the IV line, problems with the mask used for a gas induction, and a difficult intubation.
They put a mask on him but he accepted it really well. We thought there could have been some problems with that... they had to change something to do with the anaesthetic. And the end it required the mask on his face. I don’t think they necessarily have to do that all the time. I don’t quite understand that part of it, I’ve kind of forgotten actually to be quite honest with you. But I do remember they had to change the procedure because some part of it didn’t work properly, so they put the mask on his face, and we thought there could have been some problems. But we just kept generally just talking and, you know, ‘you’ll get something nice to eat when this all over’ or ‘stop by the bakery and get something nice for you to eat’ and all this sort of thing. So, he was really good. (Support person for individual K)

We had to hold things on her wrist. That didn’t stick, but it was to numb the skin. So they could actually... And that took hours. It was ten o’clock. We were there at seven I think. It was ten o’clock before we could actually get it numb enough for them to actually get the injection in. (House coordinator for individual C)

I just, when she had her last teeth done they noticed that getting the tube down into her throat, whatever they had to do, the procedure was actually really quite difficult and they were a bit worried about that. And that was the first time I knew of it, so that makes it really quite, you know, a bit more of a risk. And they said what it was called but I can’t remember. I said to them ‘write it down on a piece of paper so I can go home and look it up’ but it is just that procedure when they are putting them to sleep. (Mother of individual M)
While a couple of participants described how other treatment had been provided while the individual was under GA, it seemed that this hadn’t been offered to everyone. One mother expressed a wish that her daughter could have combined other procedures (such as cleaning of the ears and podiatry) with the dental GA.

And while she was under we had other medical teams there doing blood pressure and all the other vital things that needed to be done. So it was a good opportunity. Because otherwise we don’t get it done. (House coordinator for individual C)

Sometimes I wish I could bring the ear people in to suction out her ears. Do bits and pieces while she is under GA. Podiatry. She has a separate GA to clean her ears out. I just sometimes think, oh I wish I could coordinate it all, and have one lot come in and do the whole lot. That would be good. (Mother of individual D)

Rather than, once [she] goes under anaesthetic they make sure they get everything done while they are there. Sort it all out. (Mother of individual M)

Some of the participants reported some problems during the recovery period following the GA. These problems included vomiting, and occasions when the individual with an intellectual disability would try and climb out of the recovery bed and scream. However, most support people reported that, immediately after the GA, the individual was good and didn’t “wake up sick” or “no vomiting or anything.”

She is never very good because when she comes out she is climbing out of the bed and running drip and everything in her hand. I tried to tell them that as
soon as she is looking like coming around to call me. They were a bit delayed in finding me, and so she was screaming the place down and she had the drip out and everything else pulled out. And I always tell them they have to be really careful because she will rip it out and do more damage, and so they have to be making sure I’m there as she is coming to, or you know, I can help to pacify her until we get her up. (Mother of individual M)

Following dental treatment under GA, some of the support people noticed changes in the individual’s behaviour which indicated that the treatment had been successful.

And health-wise, she has been a lot better. So I think she must have been in quite a bit of pain. She was noticeably a lot calmer afterwards, so we thought she must have been having a lot of pain with her teeth. It worked out really well. (House Manager for individual F)

Yeah, it may just be coincidental you know, because we don’t know if they are really in pain, but I guess it’s an educated guess. The mood is settled, a lot more smiling, you know. A lot more communication, just with mumbling, his type of hello, you know, in his mumbled sort of way. He is just more visual. More waves and handshakes, stuff like that. So the moods do settle with people that do express their feelings a wee bit... But yeah, we do notice when they have had a big session with a few teeth out and fillings that the behaviours settle, the moods change. They just seem a lot more relaxed. (Support person for Individual G)

One support person said that their client had had more teeth out during a general anaesthetic than they had been told. In addition, there was no thickener available to thicken the individual’s fluids post-operatively and they had had to arrange for
this themselves. Another individual reported that a part of a tooth was left in situ and another operation was required. One mother reported problems after returning home following the general anaesthetic, when her daughter wouldn’t sleep for 3 to 4 days. She attributed this to too high a dose of the drug used for waking.

_The surgery went really well. But they took out a bit more teeth than they said. But then she recovered. It was really good. No problems at all. Only they didn’t have a thickener for her, you know, for her drink. Because [she] drinks grade 3 drinks. Very thick. Which they didn’t have. Yeah she eats mouli food, so with her diet, we had to improvise a little bit, to call the house to bring some thickener, so we were able to give her water to drink._ (Support person for individual A)

_They left part of your tooth there, and they had to do that again didn’t they?_ (Mother of individual E)

_Whenever they bring them around, they obviously gave her too high a dose or whatever it was, and we had her awake for, she wouldn’t sleep for 3 or 4 days or more and then it went on for nearly a month of we couldn’t get her back in her sleeping pattern, and we had a really bad time._ (Mother of individual M).

### 4.2.3.5 Dental recall/check-up visits

In general, participants reported that visits for dental check-ups went well, particularly where the individual understood that no treatment would be taking place that day. Strategies that participants used to prepare the individual for the visit included explaining ahead of time what the dentist will do, the promise of a
post-visit treat, and ensuring that the best support person accompanies the individual on the day.

I think as long as it’s explained what’s happening, he’s pretty good with it. He usually has a treat afterwards. (Team leader for individual H)

I find she is quite cooperative. She will open her mouth. But of course, they are never doing any fillings. They are just checking, x-raying, sometimes it’s successful, sometimes not. So when we go to the dentist it is usually just a check-up, and then we wait until she has got quite a few cavities, and then they take her in. (Support person for individual I)

And then, also I have the camera, and I keep telling her, repeating, and taking the camera and getting her to sit in the chair. Telling her ‘good girl, look mum’s got it on the camera’ so, you know, and when someone is looking at her teeth and showing right down into her mouth and things like that so then she can see it back. It is a visual thing for her, you know. I stumbled on that a wee while ago, so she likes that. But if they mucked about it’s like ‘well I’m over it now, we’ve been in, I’ve opened my mouth, now I’m going’ and then she is ready to go. As soon as it’s done we’re out of there. To her it’s – we’re going, we get seen, and we go home – it’s just black and white, no grey. (Mother of individual M)

Normally if I’m on, and I normally take another person with me because (he) can be a bit unpredictable. He is normally pretty good, but in saying that, if there is coffee around or something like that, he is pretty strong. And as you know he is obsessed with coffee. He will go over me to get it, so sometimes I will take one of the male staff. (Support person for individual K)
Opinions on the waiting time after arriving at the dental department for a check-up appointment were mixed. Some participants reported having a long wait; others reported that they never had to wait long. A couple of participants mentioned that sometimes they may have to wait longer when the dentist has been held up with the appointment before theirs. One support person felt that, as there was a risk of being “stuck” at the department waiting, they would make sure that they “don’t plan anything else, so we have the time”. It was felt that a long waiting time could make an individual with an intellectual disability quite anxious.

For [her] in particular, it’s the waiting. She is not a good waiter. The longer she waits, the more anxious she becomes. But it’s a fact of life isn’t it. We all have to wait, but she doesn’t wait patiently. Till the end she’s really got herself in a turmoil. I take her to the toilet, and we’ll have a drink of water, and go for a walk. But normally we don’t have to wait too long. But even half an hour, for [her], is a long time. (Support person for individual 1)

The main waiting room created concern for some of the support people as they were concerned about the potential for disturbance of other patients. For a couple of individuals, the actual check-ups had taken place in a private waiting room rather than a dental surgery as a way of overcoming the individual’s reluctance and anxiety. However, the availability of a smaller separate waiting room was not widely known, and one support person who expressed a wish for a separate room would instead wait in the vehicle in the car park until the appointment time.

I’ve actually felt more comfortable to have the guys wait in the vehicle. Because they’ll cause quite a disruption in the waiting room... I am just wondering if we could have a separate room available if we do need to wait, instead of waiting in the car. Like I have no problem with that, but I just
think it’s maybe just a little bit inappropriate. (Support person for individual G)

[She] is so bad we can’t even get her into the surgery. We can get into the waiting room, but no, we can’t go into the surgery. For the doctor to have a look at her, he has to come out and visualise her there. (House coordinator for individual C)

4.2.3.6 Satisfaction with the Hospital Dental Service
Overall, support people and parents were satisfied with the oral health service they had received at Christchurch Hospital. A number commented on the affordability of the service, and compared the cost of treatment with that of dentists in private practice. Some also felt that the hospital dental department was more suitable for treating individuals with intellectual disability than a private dental practitioner.

No, we are very lucky. Because it would be hopeless really just going to just a, my dentist for instance. It would be just too, it just wouldn’t work. So having the hospital one is good. I suppose with most dentists they allot so much time and then you are in and out. So there ... you don’t feel like you are under pressure. (Mother of individual D)

I think the cost is very good. It is affordable for treatment. I think that’s a big plus for our people. I take some of them to their normal dentist that their parents have taken them to all the time, and I notice a huge difference in cost for dental care. I don’t know if it is government subsidised or not, but it’s very good. And also, if they have a denture or partial plate it is always very natural looking and they make sure it fits. Just normal care. (Support person for individual I)
Interestingly, a number of participants described the service as being ‘part-time’. However, a reported strength of the service was the capacity for patients to get an urgent dental appointment when a dental problem arose.

_They always say that if there is any pain, or anything happens, just to ring them straight away. It wasn’t an issue, no. We’ve never had to ring. Once I think I rang, and we went in because I wasn’t quite sure. We were waiting for an appointment, and I wasn’t quite sure. A bit had broken off. So we just popped in and they checked it. So that was fine. But no we didn’t have to wait very long._ (Mother of individual D)

_Sometimes getting an appointment is pretty hard because a lot of them only work part-time. But apart from that, with [him], we only had to wait a couple of days for an urgent appointment – they squeezed him in. That was really good._ (Team leader for individual H)

_He has regular check-ups and that, and when there is something wrong he goes straight and gets it done._ (Support person for individual K)

There had evidently been some problems with the recall system, with a couple of support people mentioned problems with being recalled for their check-ups late, or left off the system altogether.

_They were running a wee bit behind last year. They seem to have caught up this year. That was the only thing. Running behind was the only problem we had. They seem to have made a concerted effort to get in front this year._ (House manager for individual F)
We were left off the recall. And I was sort of thinking we haven’t heard for a while, so I rang, and she had been missed. (Mother of individual D)

4.2.3.7 Reported oral health status
Many support people felt that the individual with intellectual disability whom they support had a poor long-term dental prognosis. They viewed the eventual loss of all teeth as being inevitable and were concerned about how the individual would cope with dentures. A number of participants expressed what their wish would be if they were in that position, but were not sure whether such a treatment could be successful for the individual. A few participants mentioned the effects of a good diet on oral health. There were a couple of support people who felt that the individual had good teeth and that the long-term prognosis was good, which was based on what the dentist had told them.

But all the brushing is not going to make any difference. Her teeth are pretty rubbish. It will stop some of the plaque. I mean you and me, we would have had them out and false teeth. Mind you they don’t do that today do they, they try and keep every tooth. Which is good because years ago it was just ‘out they come’. (Mother of individual M)

Because it’s so difficult to actually get a good, his teeth brushed properly, I suppose it will just be a matter of time before they are all out. In saying that though, a lot of the causes of bad teeth – the sweets, the sugar, the soft drinks, the lollies, which we do not have a lot of, the diet is actually really quite good here. You know, it’s very rare to have sweets and soft drinks. Mostly because the sugar brings out the behaviours and so we try to eliminate that. Birthdays, Christmas, special occasions, but it is not on a regular basis like so called normal people do, you know. So they actually
have an advantage in that respect. People monitoring their diet. (Support person for individual G)

He is losing a lot of his teeth like a lot of our people. But at this stage he’s really good. He is able to eat hard things, soft things, cold things, hot things, so it’s really good. (Team leader for individual H)

I think her teeth will wear out as they loosen. I think more-or-less just, and they have to come out because there is a possibility she might swallow it. I don’t know that [she] would be able to tell us. We have to look and see if they are loose or anything. I think eventually they won’t be there. Because she has lost quite a few of her teeth, and they just more-or-less had to be taken out because they were falling out. (Support person for individual I)

She has had a lot out and we just, one day we are going to be told that they can’t do anything for them, and there is no way she will hold false teeth in her mouth. And I know they have got a new technique of screwed in teeth, but man, I imagine that would be pretty expensive. I mean, modern technology is moving along fast but in some ways, when you are dealing with special needs it is hard, it’s not just the normal thing. (Mother of individual M)

The concept of them losing their teeth- I can’t see a way around it though.... because we know what it entails – holding our mouth open. If we hold our mouth open long enough, the work will be able to be done, but our people don’t understand that and it means anaesthetic. I just can’t see a way around them getting teeth replacements. And none of ours would want false teeth. So if I could wave a magic wand, it would be that they could have their
teeth replaced. But I can’t see how that could happen. (House manager for individual F)

Well last time he went to the dentist for a check-up they said his teeth were perfect. So they said he’s got good teeth and that, so obviously we are doing something right (Support person for individual K)

When support people and parents were asked about their own oral health, the responses were mixed. Only a few felt that they had good oral health. A number of support people reported that they wore dentures. A couple of respondents reported that their teeth had deteriorated after having children. Some of the support people were able to identify how their own oral health may affect that of the individuals they assist with oral care.

I think in the last ten, fifteen years I have only had one filling. So no, mine is good. (Mother of individual D)

I used to have good teeth before I got pregnant and my teeth have just gone to the pack since I have had children to be honest. (Key person for individual K)

I’ve got false teeth. I lost mine after I had the two children. They just seemed to go to the pack so I just had them out and got false ones. (Mother of individual A).

If you are fussy about your teeth, you will be fussy with other people’s teeth. And oral health, because I do get plaque so I am aware of it with other people. (House manager for individual F)
Like anyone, I don’t like, I’ve got dentures, I don’t go very often now. But it is something you have to do. And something [she] has to, we all have to do it. It is an experience we try and make as pleasant as possible. And, you know, I was the same, I thought ‘oh no I don’t want to go to the dentist’ but if I was treated like [her], I probably wouldn’t have worried so much about it. (Support person for individual I)

4.2.3.8 Assisting with oral care

A number of support people reported that they had encountered resistance from the individual when assisting with oral care, and some felt that they could potentially be hurt in the process. Other difficulties reported were that it was not possible to get the individual to rinse out after brushing, and while an individual may have been able to brush their teeth themselves, the nature of the community house meant that free access to the bathroom was not possible.

If you push anything anywhere, try and be a bit more forceful, you’ll just meet with resistance. And most likely get your head knocked in. You know, he’s 110kg and he knows how to use it. So it’s a matter of just doing the best you can really. (Support person for individual G)

But people find her hard to do her personal hygiene. But she is a kind of rough lady, and she doesn’t like you touching, or physical contact. Anyway, she usually keeps her mouth open when brushing her teeth. Like she’s really vocal, she doesn’t like it, but she keeps her mouth open, so we really can see and brush her teeth properly. Sometimes she really refuses, so we give her time to calm down, and then continue. ... So, yeah, it’s possible to do it properly. (Support person for individual A)
I think that is a barrier for him you know, the fact that he can’t actually go and brush his teeth when he feels like it. He has to wait for staff. So that can cause problems because sometimes, dare I say it, he can be overlooked. (Support person for individual K)

It was clear that support people employed a number of strategies for assisting with oral care, specific to each particular individual. A couple of support people described the need for them to take their time when the individual was reluctant. Some were using an electric toothbrush, and one used a special double-headed brush to make providing oral care easier. The decision to use these specialised brushes was made by the support person themselves, rather than on the recommendation of the dentist. Other strategies that were described were demonstrating what they wanted the individual to do, and singing songs to encourage brushing.

We used to have an electric toothbrush, but I have gone back to the other one. Just the standard one. It’s just easier. It is not such a big head. I just thought I had more control with it. With the standard one. (Mother of individual D)

We got a toothbrush from Nurse Maude. It is a two-sided brush so it basically does both sides of a tooth with one brush. I think that has helped because you don’t have a lot of time in her mouth. We are just doing the best we can really. With her willingness. (House manager for individual F)

He is quite stubborn. With his tongue. He tries to push the brush out. You just have to be really gentle. Like this morning, it was just playing and dancing around a bit. You know it’s not working this side because he’s got his tongue there, so you go to the other side, and then come back. You’ve just
got to sort of dance around the whole thing. And, it's not the best, but it's better than nothing, you know, that's just how it works. (Support person for individual G)

He will brush a little bit, but we finish it off for him. He likes water. (Team leader for individual H)

He is actually starting to brush his teeth by himself now. And he has an electric toothbrush, so no, it's good. (Support person for individual K)

It's a challenge but, when she was living at home I'd say 'come on brush your teeth' and it was either like no way she would even open her mouth and sometimes she would just walk around with a toothbrush in her mouth just sucking on it. I'd just go [sings] 'brush it, brush it, brush it' you know that song. And she'd laugh and go 'teeth, teeth' like this. (Mother of individual M)

A few of the support people working in community homes expressed criticism of the care that other staff provided for residents, and some discussed how the individual's diet had had a good effect on their oral health.

There were some issues because some of the staff took [her] to the dentist and they didn't brush their teeth after breakfast, before the dentist visit. Which, you don't do because, you don't do it yourself when you go to the dentist, so why should they do it? Which I don't really understand. (Support person for individual A).
Yeah but some staff are lazy, they don’t brush his teeth, simple as that. We have got one staff that just don’t brush their teeth. (Key person for individual K).

I was always very careful what I gave them to eat. I didn’t give them anything that I didn’t think they could handle. (Mother of individual A)

4.2.4 Summary

The major concern for individuals with an intellectual disability—and their support people/guardians—was anxiety related to dental visits. Individuals with an intellectual disability reported that visits to have dental treatment completed under GA were generally negative experiences. Support people and guardians were particularly concerned with the management of this anxiety and in particular, the strategies that could be used by themselves, and dental/medical staff to alleviate this. The roles played by support people/guardians, in organising dental appointments, preparing the individuals for the impending visit, and in reassurance and support during appointments, were instrumental to obtaining a successful visit.

It is clear that, in many cases, support people/guardians have difficulty identifying dental problems in those with an intellectual disability. In this case, through knowing the individual well, they are often able to detect changes in the individual’s behaviour or demeanour, and consider dental problems as a possible cause. In many cases, improvement in the aforementioned behaviour following treatment reinforces this.
There was much positive feedback from support people/guardians regarding the dental and medical staff they had encountered during dental treatment and check-up visits. However, issues with continuity of care where the regular dental clinician was changed clearly created some concern among the individuals themselves, and their support people/guardians.

The time spent waiting in waiting rooms for check-ups or treatment was a recurring cause of stress to the respondents. In some instances, there had been significant difficulty with managing the individual with an intellectual disability during those waiting times. In some cases, the clinical environment was not ideal for the individuals with intellectual disabilities. For example, comments made relating to coffee carts visible to fasting patients, large communal waiting rooms, and the size of rooms for manoeuvring hoists, highlight small changes that could be made to ensure a successful dental visit for an individual with an intellectual disability.
5. Discussion

The aim of this study was to explore the use of oral health services by a group of adults with an intellectual disability. The study found that the majority of individuals with intellectual disability who had dental treatment under GA at Christchurch Hospital in the 5-year period lived in care, many had severe medical issues and few had capacity to consent for the most recent GA. Most of the individuals had both restorative treatment and tooth extractions carried out under GA and, in some cases, non-dental treatment was provided at the same time by clinicians in other specialties.

The major concern for individuals with an intellectual disability was anxiety related to dental visits. Support people/guardians shared this concern, played a vital role in helping to manage this anxiety, and were instrumental to achieving a successful visit. Many support people/guardians have difficulty identifying dental problems in those with an intellectual disability, and often rely on detection of changes in the individual’s behaviour or demeanour. While the majority of feedback on encounters with dental and medical staff was positive, problems with continuity of care were a concern. The time spent waiting in waiting rooms for check-ups or treatment was a frequently reported cause of stress to the respondents. In addition, some problems were identified with the way in which waiting areas were set up for this patient group.

Before considering how the study findings contribute to the understanding of the use of dental services by individuals with an intellectual disability, it is important to consider the choice of methodology and the strengths and weaknesses of the study design.
An explanatory mixed-methods design was used to collect statistical quantitative data from a sample of adults with an intellectual disability, and then follow up some of those individuals (and their caregivers/guardians) in order to explore the findings in more depth. The mixed-methods approach involves the collection, analysis, and mixture of both quantitative and qualitative data in order to gain a better understanding of a research problem than can be achieved by the use of either approach in isolation (Creswell et al., 2007). While this methodology has not been widely used in oral health research, it has been more commonly used in the social sciences.

While clinical audit data can provide useful information on the volume and type of treatment received by a patient group, this type of data is insufficient when considering the personal experiences of the patient group. In-depth interviews are useful when investigating an individual’s experiences, beliefs, and motivations (Bower et al., 2007). The semi-structured interview allows the interviewee the freedom to identify issues that are important to them, and the interviewer to further explore topics as they arise.

The use of a mixed-method study design was successful in this study because the combination of quantitative and qualitative data collected allowed an in-depth exploration of the use of dental services by the individuals. The interviews highlighted issues that the patient group (and their support people/guardians) consider important, and that would not have been identified if only quantitative data had been collected.

5.1 Strengths and weaknesses of the study design
The strength of the quantitative data is dependent on obtaining a full sample. In this study, the data collected should include all individuals who met the inclusion criteria; that is, individuals aged 18 or over with an intellectual disability and who
had dental treatment under GA during the 5-year period. Of the 168 patients who fitted the criteria, clinical records could not be located for one patient (0.6%), so this is not likely to have affected the validity of the findings.

There are a couple of instances where, potentially, a full sample may not have been obtained. In-patient GA lists were not routinely recorded within the dental department, so this information was obtained from the decision support team at Christchurch Hospital. If the diagnosis of intellectual disability was not considered relevant to a patient’s treatment, or if the disability was related to a particular neurological disorder, it may not have been coded as such, and would not have appeared on the extracted data list. In order to ensure as full a record as possible, in-patient general anaesthetic lists available in the dental department and data from the data-extraction were compared and cross-referenced. However, it is possible that some individuals may have been missed.

Occasionally, a dentist may have attended a GA for a patient who was admitted under another specialty team (such as gynaecology, ear-nose-throat or orthopaedics) for a non-dental procedure. While a dental check or dental treatment may have been provided, it may not have been coded for, and the information will not have been included when the data were extracted. If any patients had been missed due to these reasons, it is likely that they would only be a few and unlikely to affect the results of the study.

The data collected in the quantitative phase of the study cannot be generalised to the population as a whole, or indeed the population of adults with intellectual disabilities. It is likely that the individuals receiving dental treatment though the hospital dental service have more severe disabilities than those who receive care in the private sector. In addition, it is unknown how many individuals with intellectual disabilities do not receive regular dental care. Because all of the
patients included in the data-set required a GA for dental treatment, it is likely that their characteristics differ from those who did not require a GA.

Similarly, the data collected in the interviews during the qualitative phase of the study cannot be generalised to the population. While the selection of potential interview participants was random, generalisability was not the intent. The qualitative data collected was information-rich and allowed insight into the experiences and opinions of the participants. This was possible because interview participants included individuals with intellectual disability, caregivers/support people, parents, and team leaders in residential homes, thus enriching the data collected. By the time the 15 interviews had taken place, similar responses were being obtained, which was consistent with the concept of data saturation (Strauss et al., 1998) and further interviews would not be required.

Potential interview participants were randomly selected from the most recent year within the 5-year period (2009), in order to improve the accuracy with which participants recalled events with respect to their dental GA. The interviews took place in the familiarity of the interviewee’s home or workplace in order to help put them at ease, and the participants were assured that their identity would remain confidential. There is potential for error because the interviews relied on the memory of interview participants. In addition, it is possible that participants may have been reluctant to give negative feedback, and instead may have given socially desirable answers or an answer that they felt would please the interviewer (Blinkhorn et al., 1988). The role of the researcher as both a participant and observer in the interview process may have assisted participants in feeling at ease. The interview participants seemed to be comfortable sharing their honest thoughts and opinions during the interviews.
Of the 13 individuals for whom interviews were carried out, none lived independently, and nine individuals with an intellectual disability were able to participate in the interview. However, two of those participated non-verbally only and four participants were only able to participate verbally to a limited extent (such as in giving yes/no answers). This presents difficulties with a semi-structured interview and as a result, the support people or guardians acted as informants in many cases and their opinions were instrumental in the collection of qualitative data. In essence, this meant that, in some cases, the experiences of an individual with an intellectual disability could not be collected first-hand, but rather through their support person.

This problem was related to the fact that potential participants were selected from the group who had required a general anaesthetic for dental treatment. Individuals who have required a general anaesthetic are likely to have more severe disability than those who are able to have treatment under local anaesthetic in a dental chair. Accordingly, communication difficulties were not unexpected. Indeed, other studies have reported difficulties in interviewing individuals with an intellectual disability, particularly where asked to give reasons or express opinions (Cumella et al., 2000).

Although the responses of the individuals with an intellectual disability contributed only a small portion of the interview data, their views hold much importance because they were the primary consumers of the dental services. Overall, the most evident theme that came from analysis of the transcripts of individuals with intellectual disabilities was their anxiety about dental visits.
5.2 Characteristics of the patient group

There were more males than females in the sample. This may be related to the predilection for males of some conditions associated with intellectual disability. The reason for this is unclear. Reports in the literature indicate that intellectual disability is more prevalent in males than females, with an approximate ratio of 1.6:1 (Bray, 2003b). It is also possible that males were more likely than females to require a GA, perhaps due to higher anxiety levels, or more challenging behavioural issues. Because data were collected only for individuals who had received dental treatment under GA, it is not possible to ascertain whether there were any gender differences among those who did not require a GA.

The patient group had very little treatment carried out without GA. This was not surprising, given the severity of disability that many of the individuals experienced. Only a few of them lived independently and it is probable that those who require more daily support are more likely to have dental treatment completed under a GA rather than in the dental chair.

The most commonly reported medical condition was autism; this affected more males than females. Individuals with autism differed from those without autism in a number of respects. They were more likely to live in residential care, indicating that they required more daily support, and consequently were more likely to require a GA for dental treatment. In addition, a greater proportion of individuals with autism had restorations placed under GA than those without, and individuals with autism had fewer teeth extracted than those without. There are a number of reasons for this. Individuals with autism may experience a greater severity of disability and be less likely to have even simple restorative work completed without a GA. In addition, the caries incidence may differ for this patient group, perhaps due to greater difficulties with daily oral hygiene. Early recognition of
dental problems may be more likely in residential care settings due to the involvement of support people in daily oral hygiene routines, and thus ensuring that treatment is sought earlier and extractions are less likely.

5.3 Difficulties encountered in oral health care

For a few individuals, there had to be coordination with clinicians in other specialties to provide non-dental treatment under GA. This reflects the difficulty many individuals face in obtaining dental and medical treatment. When a GA is necessary for a particular procedure, it can be beneficial to have other necessary procedures (particularly minor ones) completed under the same GA. While this may not always be practical (because it involves the coordination of multiple clinicians at one time and may increase the length of surgery), it has the benefit of reducing the number of GAs needed by an individual, or can allow procedures (such as the taking of blood samples) that would not have been possible otherwise.

The risks of GA for individuals with disabilities will vary with patient age, presence of systemic disease, physical limitations, and syndrome-related physiological or anatomical abnormalities (Messieha, 2009). A large proportion of individuals had a severe systemic disease (and were classified as ASA3). This indicates that the risks of GA were somewhat higher for this group. It is therefore necessary to consider the likely benefits of dental treatment against the potential risks of surgery when planning to undertake treatment under GA. This is another reason why the combination of other procedures in addition to dental treatment in the same GA may be useful.

The use of sedative pre-medication prior to a GA for about two-fifths of the individuals illustrates the effect of anxiety for the patient group, a factor that was evident from the interviews. It is noteworthy that males were more likely to have had pre-medication for a GA than females. This may be due to higher anxiety
levels in the males, more challenging behaviour in some of the males, or it may be related to medical conditions such as autism which affected more males and was also a factor in the likelihood that premedication was used.

Oral intubation was used for one in six individuals at their most recent dental GA. The use of an oral tube presents difficulty for the operating dentist in accessing the oral cavity for a thorough examination, placement of radiograph films, and the provision of treatment. As such, it is usually not the first choice for a patient undergoing a dental procedure. It is likely that the use of an oral tube indicates difficulties encountered by the anaesthetist during intubation which precluded a nasal tube. This difficulty may be related to medical issues experienced by the individuals undergoing GA for dental treatment.

5.4 Preventive care
The value of preventive care in reducing the burden of oral disease cannot be underestimated when it comes to potentially avoiding the need for a repeat GA (Glassman et al., 2009). Preventive treatment (such as the application of topical fluoride, and oral hygiene advice) tended to be given during check-up appointments rather than treatment appointments. This makes sense due to the anxiety experienced by individuals, and so patients and their support people may not be most receptive to oral hygiene advice when attending a GA appointment. However, the provision of preventive care during check-up appointments was limited. It is somewhat disappointing that, over the 5-year period, only about one-third of individuals (and their caregivers) had been given oral hygiene advice at a check-up appointment one in ten had topical fluoride applied to their teeth, and around two-thirds had had their teeth scaled, polished or brushed during a check-up visit. Even when this preventive treatment was carried out, it was not done so regularly, with a much smaller percentage of individuals having their teeth cleaned (or receiving oral hygiene advice) during at least half of their check-up
appointments. A possible reason for this may be the resistance that some individuals may have to having their teeth cleaned, and this treatment may have been reserved for the GA session. Another possible reason is that, in some cases, teeth cleaning may have been carried out, topical fluoride applied, and oral hygiene advice given, but the dentist had not recorded this in the clinical notes. A small number of individuals had some preventive treatment provided (such as topical fluoride applied, or fissure sealants placed) during their GA.

5.5 Service factors
The number and mixture of in-patient and out-patient general anaesthetics provided each year during the 5-year period for adults with intellectual disabilities reflects changes to the provision of services within the department during that time frame. The introduction of a regular GA session in the Day Stay Unit at the end of 2007, and the allocation of a dedicated half-day list for the dental care adults with special needs each fortnight (alternating between out-patient sessions at the Oral Health Centre and in-patient sessions in the Day Stay Unit) has resulted in a jump in the number of in-patient GAs carried out in 2008 and 2009.

Prior to the establishment of a regular GA list in the Day Stay Unit in November 2007, there had been difficulties with arranging GAs for dental treatment for adults with special needs who could not appropriately be treated at the Oral Health Centre. A number of patients had their GA cancelled on the day of surgery where an anaesthetist felt that the facilities available in the Oral Health Centre theatre were unsuitable for particular patients (this may partly account for the reduced number of GAs carried out for the patient group in 2007). In-patient GA lists for these patients were arranged on an ad hoc basis, with different anaesthetists, theatres and surgical teams. DSU provided the facilities to cope with patients with increasing age, weight and complexity of medical problems, and had more appropriate recovery facilities where an extended supervised recovery period was
required. It is evident that the DSU facilities provide a much safer environment for
the dental treatment of many of these patients.

Since the establishment of the DSU list, patients who are ASA 3, or weigh more
than 100kg, are generally treated in the DSU. There are occasional exceptions to
this where an anaesthetist may approve of treatment of an ASA 3 patient at the
Oral Health Centre where they feel that the “low-key” set-up, better dental x-ray
facilities, and familiar staff is more appropriate. In other cases, an ASA 1 patient
may be seen for treatment in the DSU if urgent treatment is required and it is the
first available space.

The Ministry of Health guidelines (Ministry of Health, 2000) are that a patient
should be treated within six months of being placed on the wait list. The number of
patients waiting longer than six months for their GA in 2009 was dramatically
lower than in the previous four years. It is likely that the establishment of formal
and regular GA lists has resulted in an improvement in progress towards meeting
the Ministry target. It should be noted that the current two half-day GA lists per
month are supplemented with occasional extra lists “picked up” from the
maxillofacial surgery or paediatric dentistry lists. While the department was close
to meeting the target in 2009, it is clear that this was not done comfortably, and it is
unknown what the resulting waiting times would be without these occasional
extra GA lists.

The recall system for check-ups was working well and a large proportion of
patients are still receiving dental check-ups at the hospital dental service. While
clinics were available in a number of locations, few patients had attended check-up
appointments at the satellite clinics located at Hillmorton and Burwood Hospitals.
This may indicate that individuals with intellectual disabilities that are more
severe tended to attend appointments at the Oral Health Centre. However, there
may be scope for these facilities to be utilised more for this patient group, particularly where the clinic is closer to an individual’s home, and travelling to a nearer clinic has the potential to be less disruptive for the individual.

There was much positive feedback from support people/guardians regarding the dental and medical staff they had encountered during dental treatment and check-up visits. However, issues with continuity of care where the regular dental clinician was changed clearly created some concern among the individuals themselves, and their support people/guardians. In addition, the time spent waiting in waiting rooms for check-ups or treatment was a recurring cause of stress to the respondents. In some instances, there had been significant difficulty with managing the individual with an intellectual disability during those waiting times. In some cases, the clinical environment was not ideal for those individuals. For example, comments made relating to coffee carts visible to fasting patients, large communal waiting rooms, and the size of rooms for manoeuvring hoists, highlight small changes that could be made to ensure a successful dental visit for an individual with an intellectual disability.
6. Conclusion

There are a number of implications for the future delivery of oral health care for this patient group. As a group, these individuals present challenges for the provision of oral health care, given the severity of disability and the presence of systemic disease, and many require a high level of support for daily activities. When dental treatment is required, a GA is often necessary in order to carry out the treatment, and this carries an associated higher degree of anaesthetic risk.

Changes that were made during the 5-year period have led to an improvement in the delivery of GA services for the patient group at Christchurch Hospital. However, there is potential to improve the service with a multidisciplinary approach to coordinate other health services during treatment episodes. In addition, there is clear scope to improve the delivery of preventive oral health care and the utilisation of satellite clinics.

Interview participants identified improvements that could help to alleviate some of the anxiety associated with dental visits. An example was ensuring continuity of care, with a familiar clinician where possible was preferred by interviewees. In addition, the organisation of waiting rooms could be improved by utilising smaller separate waiting rooms where possible, and avoiding visible coffee carts for fasting patients.

This study was limited to Christchurch, and only to individuals who required GA for dental treatment. Given that people with intellectual disabilities were identified as one of the priority groups in the ‘Good oral health for all for life’ document, which highlighted that little is known about their oral health, or of their experiences of oral health services (Ministry of Health, 2006), there is a need for further investigation of the oral health status of individuals with intellectual
disabilities in New Zealand. This would include those receiving care in both private and public sectors, and those who have not required GA for treatment.
7. Appendices

Appendix i – Ethics approval letter

27 July 2009

Victoria Mc Kelvey
Oral Health Centre
Christchurch Hospital
Private Bag 4710
Christchurch

Dear Victoria Mc Kelvey,

The use of oral health services by adults with intellectual disability who required a general anesthetic for dental treatment over a five-year period in Christchurch, and the perceptions of their guardians and support-people relating to their oral health care. A mixed methods study.

Investigators: V Mc Kelvey, K Morgaine
Locality: Canterbury District Health Board
Ethics ref: URA/09/06/040

The above study has been given ethical approval by the Upper South A Regional Ethics Committee.

Approved Documents
Information sheet and consent form dated 24 July 2009

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Final Report
The study is approved until 31 July 2010. A final report is required at the end of the study and a form to assist with this is available at http://www.ethicscommittees.health.govt.nz. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date.

Amendments
It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Administered by the Ministry of Health
Approved by the Health Research Council
http://www.ethicscommittees.health.govt.nz
We wish you well with your study.

Yours sincerely,

[Signature]

Alleke Dierckx
Upper South A Ethics Committee Administrator
Email: alleke_dierckx@moh.govt.nz
Appendix ii – Information sheet for interview participants

An audit of oral health treatment provided for adults with intellectual disabilities under general anaesthetic at Christchurch hospital, and barriers to care perceived by them, and their guardians and support people.

INFORMATION SHEET FOR PARTICIPANTS

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you of any kind and we thank you for considering our request.

What is the aim of the project?

This project is being undertaken as part of the requirements for the Masters Degree in Community Dentistry.

The aim of the project is to improve understanding of the processes which determine the oral health of adults with intellectual disabilities, and to identify possible barriers to oral health care.

What type of participants are being sought?

Individuals with intellectual disabilities who received dental treatment under general anaesthetic at Christchurch hospital during the last year, and their family members, guardians, and support people.

The individual with intellectual disabilities will be asked to consent and participate to whatever extent is possible.
What will participants be asked to do?

Should you agree to take part in this project, you will be asked to participate in a short tape-recorded interview lasting about 20 minutes. Individuals with intellectual disabilities will be asked to be present and to participate in the interviews to whatever extent is possible.

We will analyse the information obtained at the dental school, and Christchurch Hospital. No material that could personally identify you will be used in any reports of the study. The information you give us will be treated with the utmost confidentiality.

Please be aware that you may decide not to take part in the project without any disadvantage to yourself of any kind.

Is an interpreter available for the interviews where required?

Yes. If you require an interpreter for the interviews, one can be provided.

Can participants change their mind and withdraw from the project?

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

What data or information will be collected and what use will be made of it?

You will be asked questions related to your experience in obtaining oral health care for a person with an intellectual disability, your views on their need for oral health care, and any barriers that you experienced in seeking oral health care.

This project involves an open-questioning technique where the precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which the interview develops. Consequently, although the Ethics Committee is aware of the general areas to be explored in the interview, the Committee has not been able to review the precise questions to be used.

An audit of oral health treatment provided for adults with intellectual disabilities under general anaesthetic at Christchurch hospital, and the barriers to care perceived by them, and their guardians and support people. 24 July 2009.
In the event that the line of questioning does develop in such a way that you feel hesitant or uncomfortable you are reminded of your right to decline to answer any particular question(s) and also that you may withdraw from the project at any stage without any disadvantage to yourself of any kind.

The interview will be transcribed by Ms McKelvey and data will be entered into a secure computer. Only Ms McKelvey will have access to the audio recordings of the interview, and only the researchers involved in analysis will have access to the transcribed electronic data. No information will be included in the transcribed data that can identify you or the individual with an intellectual disability.

The study findings may be published and will be available in the library but every attempt will be made to preserve your anonymity.

You are most welcome to request a copy of the results of the project should you wish.

The data collected will be securely stored in such a way that only those mentioned above will be able to gain access to it. At the end of the project any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be retained in secure storage for ten years, after which it will be destroyed.

*An audit of oral health treatment provided for adults with intellectual disabilities under general anaesthetic at Christchurch hospital, and the barriers to care perceived by them, and their guardians and support people. 24 July 2009.*
What if participants have any questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:-

Victoria McKelvey  OR  Murray Thomson
Oral Health Centre  Professor Dental Public Health
Christchurch Hospital  University of Otago, School of Dentistry
Telephone number: (03) 384 1844  Telephone Number: (03) 479 7116

This proposal has been reviewed and approved by Upper South A Regional Ethics Committee

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide):  0800 555 050
Free Fax (NZ wide):  0800 2787 7678 (0800 2 SUPPORT)
Email (NZ wide):  advocacy@hdc.org.nz

An audit of oral health treatment provided for adults with intellectual disabilities under general anaesthetic at Christchurch hospital, and the barriers to care perceived by them, and their guardians and support people. 24 July 2009.
Appendix iii – Consent form for interview participants

An audit of oral health treatment provided for adults with intellectual disabilities under general anaesthetic at Christchurch hospital, and barriers to care perceived by them, and their guardians and support people.

CONSENT FORM FOR PARTICIPANTS

Request for interpreter

<table>
<thead>
<tr>
<th>English</th>
<th>I wish to have an interpreter</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Māori</td>
<td>E hiahia ana ahau ki tetahi kaiwhaka Māori/kaiwhaka pakeha korero</td>
<td>Ae</td>
<td>Kao</td>
</tr>
<tr>
<td>Cook Island Māori</td>
<td>Ka inangaro au i tetai tangata uri reo</td>
<td>Ae</td>
<td>Kare</td>
</tr>
<tr>
<td>Fijian</td>
<td>Au gadreva me dua e vakadewa vosa vei au</td>
<td>Io</td>
<td>Sega</td>
</tr>
<tr>
<td>Niuean</td>
<td>Flia manako au ke faka'aoga e taha tagata fakahokohoko kupu</td>
<td>E</td>
<td>Nakai</td>
</tr>
<tr>
<td>Sāmoan</td>
<td>Ou te mana'o ia i ai se fa'amatala upu</td>
<td>Io</td>
<td>Leai</td>
</tr>
<tr>
<td>Tokelaun</td>
<td>Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika</td>
<td>Io</td>
<td>Leai</td>
</tr>
<tr>
<td>Tongan</td>
<td>Oku ou fioma'u ha fakatonuloa</td>
<td>Io</td>
<td>Ikai</td>
</tr>
</tbody>
</table>

1. I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

2. I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.

3. I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect my future health care.

An audit of oral health treatment provided for adults with intellectual disabilities under general anaesthetic at Christchurch hospital, and barriers to care perceived by them, and their guardians and support people. 24 July 2009.
4. I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports of the study.

5. I have had time to consider whether to take part in the study.

6. I know who to contact if I have any questions about this study.

7. The audio-tapes will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for ten years, after which it will be destroyed.

8. This project involved an open-questioning technique where the precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which the interview develops. In the event that the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s) and/or may withdraw from the project without any disadvantage of any kind.

9. The study findings may be published and available in the library but every attempt will be made to preserve my anonymity.

An audit of oral health treatment provided for adults with intellectual disabilities under general anaesthetic at Christchurch hospital, and barriers to care perceived by them, and their guardians and support people. 24 July 2009.
I consent to my interview being audio-taped
I wish to receive a copy of the results.
(There may be a significant delay between data collection and publication of the results.)

I ____________________________ (full name) hereby consent to take part in this study.

Date: ____________________________
Signature of caregiver/guardian

Signature of participant/patient

Full names of researchers: Victoria McKelvey, Oral Health Centre, Christchurch Hospital
Murray Thomson, Professor Dental Public Health, University of Otago, School of Dentistry

Contact phone number for researchers: (03) 384 1844

Project explained by: ____________________________

Project role: ____________________________

Signature: ____________________________
Date: ____________________________

An audit of oral health treatment provided for adults with intellectual disabilities under general anaesthetic at Christchurch hospital, and barriers to care perceived by them, and their guardians and support people. 24 July 2009.
This project has been explained to the individual with intellectual disabilities

Yes  No

Individuals name:

Date:

Steps taken to obtain consent:

Consent has been indicated by:

Name of witness

Signature of witness

Designation of witness

Date:

An audit of oral health treatment provided for adults with intellectual disabilities under general anaesthetic at Christchurch hospital, and barriers to care perceived by them, and their guardians and support people. 24 July 2009.
Appendix iv - Description of ‘other’ syndromes recorded in patient medical history

Fragile X syndrome
Fragile is an X-linked genetic disorder that is associated with intellectual disability, and has a prevalence of 1/4000 males (Turner et al., 1996). Female carriers may also show some degree of cognitive impairment (Brainard et al., 1991; Fryns, 1986). Fragile X has a characteristic triad of physical features: large or prominent ears, long narrow faces, and enlarged testes (Cronister et al., 1989).

Tourette’s syndrome
Tourette’s syndrome is an inherited disorder characterised by the occurrence of motor and vocal tics, and affects up to 1% of individuals. Many affected individuals show concomitant psychiatric features such as obsessive-compulsive disorder, attention –deficit hyperactivity disorder, or other behavioural problems (Kimber, 2010; Singer, 1994).

Angelman syndrome
Angelman syndrome is associated with severe intellectual disability, epilepsy, gait and movement disorders, speech impairment, hyperactivity, and an apparent happy demeanour. Approximately 70% of affected individuals show a deletion involving the maternally inherited chromosome 15, however, no detectable genetic abnormality has been found in 20% of affected individuals (Dan, 2009; Guerrini et al., 2003). The incidence of Angelman syndrome is unknown.

Brachmann-de Lange syndrome
Brachmann-de Lange syndrome (also known as Cornelia de Lange syndrome) is a rare syndrome estimated to occur in 1/10,000 individuals, and characterised by small stature, intellectual disability, characteristic facial features, behavioural abnormalities and malformations of the cardiac, gastrointestinal and musculoskeletal systems (del Pozo et al., 2007; Kline et al., 2007).

Aicardi syndrome
Aicardi syndrome is defined as a triad of abnormalities that include brain abnormalities (agenesis of the corpus callosum), eye abnormalities (chorioretinal ‘lacunae’), and infantile spasms. The syndrome has only been reported in girls, except for two affected boys who both had two X chromosomes. The syndrome is associated with mental retardation of varying degrees, and most affected girls do not develop communication language, but may communicate non-verbally (Aicardi, 2005). The incidence of Aicardi syndrome is unknown.

Cri du chat syndrome
Cri du chat syndrome is a rare genetic disease resulting from a deletion of the short arm of chromosome 5. Clinical features of Cri du chat syndrome include the typical high-pitched cat-like cry after which the syndrome was named, distinctive facial features, microcephaly, and delayed psychomotor development and severe intellectual disability (Mainardi, 2006). The incidence of Cri du chat syndrome has been reported as approximately 1/50,000 (Niebuhr, 1978).
8. References


Bray A (2003b). Demographics and characteristics of people with an intellectual disability. Review of the literature prepared for the National Advisory Committee on Health and Disability to inform its project on services for adults with an intellectual disability. Wellington: National Advisory Committee on Health and Disability


National Advisory Committee on Health and Disability (2003). To have an ordinary life; kia whai oranga noa. Wellington: National Advisory Committee on Health and Disability.


