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THE DEVELOPMENT OF SPECIAL NEEDS DENTISTRY SERVICE IN MALAYSIA – A SITUATIONAL ANALYSIS (BASED ON NEW ZEALAND EXPERIENCE)

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A thesis submitted for the degree of

Doctor of Clinical Dentistry (Special Needs Dentistry)

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ABSTRACT

Aim: The aim of this project is to understand the expectations of the Malaysian population for future development of Special Needs Dentistry (SND) service in Malaysia. Along with the current recognition of the specialty by Ministry of Health, Malaysia, the Ministry has identified New Zealand as an appropriate nation to provide information on service developments and lessons learnt from an established service.

Methodology: Mixed-methods research design was adopted to carry out this study which contained both qualitative and quantitative components. The qualitative part involved interviewing fifty five participants who represented the major stakeholders in the SND service, both in Malaysia and New Zealand which comprised people with special needs, caregivers, policy makers, dentists and disability support group representatives. The qualitative data were analysed using applied grounded theory. The dominant themes identified were used to formulate the survey questionnaire for the quantitative part in which 345 paper questionnaires were posted. A response rate of 17.0% was calculated from the original surveys returned.

Results: The data suggested inadequate home and professional dental care for people with special needs which underline the necessity to develop the SND service in Malaysia. Transportation difficulties, lack of awareness about the importance of dental care, negative attitude, the difficulties in finding an accompanying person for the dental visit as well as an extended time required by the dentist to treat people with special needs (PSN) were identified as barriers to access dental care facilities. In addition, inadequate knowledge and experience of the local dentists could be one of the contributing factors for their unwillingness to provide the service. The results also suggested that patients who required general anaesthesia for dental treatment, those with complex medical problems and uncooperative patients should be treated under the specialist care. This would be more appropriately provided in the hospital environment than in the community setting. Even though it was suggested that a domiciliary service was necessary, this practically depended on the achievement of the adequate number of specialists in this field and the existence of a well established service and network. Nevertheless, it appeared that the Ministry of Health Malaysia is
well prepared to face the challenges in the development of the SND service in Malaysia.

Conclusions: There were definitely some issues regarding dental health care of people with special needs which had to be considered and could be managed by the Ministry of Health in the future development of the service. Oral health promotion covering areas such as building public health policy, creating supportive environments, strengthening community action, developing personal skills or reorientating health service in the pursuit of oral health goals would help to strengthen the service in the near future.


Aknowledgement

In the name of Allah, Alhamdulillah

for answering my prayer to give me the strength and courage to complete the thesis and to make my journey in this DClinDent course progressed smoothly till its end.

It is with a deep sense of gratitude, I thank my family, especially my beloved husband, my children and my mum who along the journey have been very patient by giving me continuous support in many ways. To the Ministry of Health of Malaysia, the opportunity given to me by granting the course is very much appreciated and will benefit the country especially in improving the oral health care of people with disability in Malaysia.

It is my privilege and honour to also thank my guide, Dr Eithne MacFadyen, for her insight and direction in making this project comes to fruition. Her wealthy clinical experience, personalized attention, constant inspiration and encouragement have been instrumental in moulding me as a professional. Special thanks also go to Professor Robert Love, for his valuable guidance and effectively time advice during the study. I am grateful to Dr Noraini @ Nun Nahar Mohd Yunos for willingly involved in this project as Malaysian Co-supervisor and for her most valuable suggestions. Further, I would like to extend my gratitude to Professor Murray Thomson who with vast experience and knowledge has provided me with the tremendous amount of advice and assistance to enable me to compile the study.

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# TABLE OF CONTENTS

Abstract ......................................................................................................................................... i
Acknowledgement ..................................................................................................................... iii
Table of Contents ....................................................................................................................... iv
List of Figures .............................................................................................................................. vi
List of Tables .............................................................................................................................. vii
Abbreviations .................................................................................................................. xii

1 CHAPTER ONE ......................................................................................................................... 1
   1.1 INTRODUCTION ............................................................................................................. 1
   1.2 LITERATURE REVIEW ................................................................................................ 3
      1.2.1 Definition of Special Needs Dentistry/ Special Care Dentistry .................................. 3
      1.2.2 Assessment of Special Needs Dentistry Service in Other Commonwealth Countries: .............................................................. 4
      1.2.3 United Kingdom ........................................................................................................ 13
      1.2.4 Canada ...................................................................................................................... 16
      1.2.5 Assessment of SND service in the United States ......................................................... 17
      1.2.6 Historical Similarities .............................................................................................. 18
      1.2.7 Changes in Care, Health and Expectations .............................................................. 23
      1.2.8 Oral Health Needs and Wants of People With Special Needs .................................. 26
      1.2.9 Legal and Ethical Issues .......................................................................................... 28
      1.2.10 Implications for Future Research ........................................................................ 32
   1.3 RATIONALE ................................................................................................................... 35
      1.3.1 AIMS ......................................................................................................................... 35
      1.3.2 HYPOTHESIS .......................................................................................................... 35

2 CHAPTER TWO ......................................................................................................................... 36
   2.1 METHODOLOGY ........................................................................................................... 36
      2.1.1 Qualitative Part ......................................................................................................... 36
      2.1.2 Quantitative Part ...................................................................................................... 47
   2.2 Ethical Approval, Maori Consultation and Project Funding ............................................. 53
3  CHAPTER THREE ......................................................................................... 54
  3.1  The qualitative study .................................................................................. 54
       3.1.1  People with special needs ................................................................. 54
       3.1.2  Caregivers ......................................................................................... 63
       3.1.3  Oral health professionals ................................................................. 75
       3.1.4  Policy makers .................................................................................... 95
       3.1.5  Disability support group representative ........................................... 113
  3.2  The quantitative study ................................................................................ 135
       3.2.1  Participants ....................................................................................... 135
       3.2.2  Data analysis ..................................................................................... 135
       3.2.3  People with special needs ................................................................. 135
       3.2.4  Caregivers of people with special needs ........................................... 144
       3.2.5  Oral health professionals ................................................................. 153
       3.2.6  Policy makers .................................................................................... 169
       3.2.7  Disability support group representative ........................................... 180

4  CHAPTER FOUR .......................................................................................... 188
  4.1  DISCUSSION ............................................................................................ 188
       4.1.1  Methodological Issues ....................................................................... 188
       4.1.2  Findings ............................................................................................. 190

5  CHAPTER FIVE ............................................................................................ 210
  5.1  CONCLUSION ............................................................................................ 210
       5.1.1  Future recommendations for the development of SND services in Malaysia ......................................................... 210
       5.1.2  Lessons learnt .................................................................................... 212

6  REFERENCES .................................................................................................. 214

Appendix 1. Semi-Structured Questions For Key Informative Interview For the New Zealand Participants .......................................................... 224
Appendix 2. Semi-Structured Questions For Key Informative Interview For the Malaysian Participants .......................................................... 227
Appendix 3. Survey Questionnaire For People with Special Needs .......................................................... 230
Appendix 4. Survey Questionnaire For the Caregivers .......................................................... 237
Appendix 5. Survey Questionnaire For Oral Health Professionals .......................................................... 244
Appendix 6. Survey Questionnaire for Policy Makers .......................................................... 251
Appendix 7. Survey Questionnaire for Disability Support Group Representatives .......................................................... 257
LIST OF FIGURES

Figure 2.1: Matrix of the data analysis process .............................................................. 46
Figure 3.1: Categories and subcategories resulting from 12 interviews with people with special needs in Malaysia and New Zealand ................................................................. 55
Figure 3.2: Categories and subcategories resulting from 12 interviews with caregivers in Malaysia and New Zealand ................................................................................. 64
Figure 3.3: Categories and subcategories resulting from 16 interviews with dentists in Malaysia and New Zealand ..................................................................................... 76
Figure 3.4: Categories and subcategories resulting from six interviews with policy makers in Malaysia and New Zealand ..................................................................... 96
Figure 3.5: Categories and subcategories resulting from nine interviews with the representatives in the disability support groups in Malaysia and New Zealand .. 114
LIST OF TABLES

Table 2.1: Greene, Caracelli and Graham's List of Purposes for Mixed Research 51 ..... 37
Table 2.2: Number of participants in New Zealand according to each target group ..... 38
Table 2.3: Number of participants in Malaysia according to state of the participant residency and target groups ........................................................................................ 38
Table 2.4: Number of dentists in Malaysia who are grouped according to their work base, hospital dental clinic and community dental clinic at health centre ........... 39
Table 2.5: Number of interview participants in Malaysia and New Zealand ................. 39
Table 2.6: The key topics covered in the semi structured interview ............................. 43
Table 2.7: The coding process ........................................................................................ 45
Table 2.8: Core categories derived from the qualitative analysis ................................. 47
Table 2.9: Questionnaire development ......................................................................... 50
Table 3.1: Oral hygiene practice of people with special needs, by gender, ethnic group and level of disability (brackets contain percentages of respondents nominating that option) ........................................................................................................... 137
Table 3.2: Frequency of daily tooth brushing by people with special needs, by gender, ethnic group and level of disability (brackets contain percentages of respondents nominating that option) ........................................................................................ 138
Table 3.3: Introduction to dentist of people with special needs, by gender, ethnic group and level of disability (brackets contain percentages of respondents nominating that option) ...................................................................................... 139
Table 3.4: Frequency of dental visit by people with special needs, by gender, ethnic group and level of disability (brackets contain percentages of respondents nominating that option) .............................................................................. 140
Table 3.5: Reasons for patients not seeing dentist, by gender, ethnic group and level of disability (brackets contain percentages of respondents nominating that option) ...................................................................................... 142
Table 3.6: Level of patients' satisfaction on various aspects of dental service (brackets contain percentages of respondents nominating that option) ......................... 143
Table 3.7. Barriers experienced by patients to access dental care facilities, by level of disability (brackets contain percentages of respondents nominating that option) 
........................................................................................................................................144
Table 3.8. Sociodemographic data of the respondents from the group of caregivers 145
Table 3.9. Oral hygiene practice of people with special needs as carried out by the caregivers, by age, gender, ethnic group, relationship with clients and level of education (brackets contain percentages of respondents nominating that option) 
........................................................................................................................................147
Table 3.10. Introduction to dentist of people with special needs as known by the caregivers (brackets contain percentages of respondents nominating that option) 
........................................................................................................................................147
Table 3.11. Frequency of dental visit by people with special needs as known by the caregivers (brackets contain percentages of respondents nominating that option) 
........................................................................................................................................149
Table 3.12. Reasons for patients not seeing dentist, as known by the caregivers (brackets contain percentages of respondents nominating that option) ................................. 149
Table 3.13. Perspectives of the caregivers on oral hygiene care for people with special needs, by age, gender, ethnic group, relationship with clients and level of education (brackets contain percentages of respondents nominating that option) 
........................................................................................................................................150
Table 3.14. Level of carers’ satisfaction on various aspects of dental service (brackets contain percentages of respondents nominating that option) ........................................ 150
Table 3.15. Frequency of dental visit which was thought by the caregivers to be appropriate, by age, gender, ethnic group, relationship with clients and level of education (brackets contain percentages of respondents nominating that option) 
........................................................................................................................................151
Table 3.16. The importance of certain types of dental treatment for people with special needs in the perspective of the caregivers (brackets contain percentages of respondents nominating that option) ................................................................. 152
Table 3.17. Criteria included by dentists, describing people with special needs, by age, gender and practice characteristics (brackets contain percentages of respondents nominating that option) ........................................................................... 154
Table 3.18. Categorized mean number of patients with special needs seen in a typical week by dentists, by age, gender and practice characteristics (brackets contain percentages of dentists) ................................................................. 157

Table 3.19. Age range of patients seen by dentist, by age, gender and practice characteristics (brackets contain percentages of dentists) .................................................. 158

Table 3.20. Types of treatment normally delivered by dentists for patients with special needs, by practice characteristics (brackets contain percentages of respondents nominating that option) ........................................................................................ 159

Table 3.21. Types of treatment normally required by patients with special needs, by dentists at their practice (brackets contain percentages of respondents nominating that option) ........................................................................................ 160

Table 3.22. Specialists consulted by dentists in managing patients with special needs, by age, gender and practice characteristics (brackets contain percentages of respondents nominating the specific specialist) .................................................................................. 162

Table 3.23. Criteria of patients with special needs considered by dentists, before making referral to specialist by age, gender and practice characteristics (brackets contain percentages of respondents nominating that option) ....................... 163

Table 3.24. Perspective of dentists about oral health status of people with special needs by age, gender and practice characteristics (brackets contain percentages of dentists) ............................................................................................................ 165

Table 3.25. Common dental problems of patients with special needs as observed by dentists by age, gender and practice characteristics (brackets contain percentages of dentists) ............................................................................................................ 166

Table 3.26. Exposure, knowledge and opinion of dentist about Special Needs Dentistry (brackets contain percentages of dentists) ................................................................. 167

Table 3.27. Confidence level of dentists in treating patients with special needs (brackets contain percentages of dentists) ................................................................. 167

Table 3.28. The suitable location for future special care unit in Malaysia recommended by dentists, by age, gender and practice characteristics (brackets contain percentages of dentists nominating that option) .................................................................................. 168
Table 3.29. Types of training in SND in dentists' best interest, by age, gender and practice characteristics (brackets contain percentages of dentists nominating that option) ................................................................. 170

Table 3.30. Criteria included by policy makers, describing people with special needs, by age, gender and practice characteristics (brackets contain percentages of respondents nominating that option) ................................................................. 172

Table 3.31. Perspectives of policy makers in various aspects of SND, by age, gender and practice characteristics (brackets contain percentages of respondents nominating that option) ................................................................. 173

Table 3.32. Reasons for a need to develop SND service in Malaysia, by age, gender and practice characteristics (brackets contain percentages of respondents nominating that option) ................................................................. 175

Table 3.33. Support provided by the Ministry of Health Malaysia for dental officers who are interested in SND, by age, gender and practice characteristics (brackets contain percentages of respondents nominating that option) ................................................................. 177

Table 3.34. Role of disability support associations in liaising with SND service, by age, gender and practice characteristics (brackets contain percentages of respondents nominating that option) ................................................................. 178

Table 3.35. Future of Special Needs Dentistry service in Malaysia as expected by the policy makers (brackets contain percentages of respondents nominating that option) ................................................................. 179

Table 3.36. Policy makers' view regarding various issues on Special Needs Dentistry service (brackets contain percentages of respondents nominating that option) ................................................................. 179

Table 3.37. Barriers to oral health care facilities as seen by the policy makers (brackets contain percentages of respondents nominating that option) ................................................................. 181

Table 3.38. Sociodemographic data of the respondents from the representatives of disability support groups ................................................................. 182

Table 3.39. Types of disability which often referred to Taman Sinar Harapan and the Community Rehabilitative Centre (brackets contain percentage) ................................................................. 182

Table 3.40. Types of supports given and requested at Taman Sinar Harapan and the Community Rehabilitative Centre (brackets contain percentage) ................................................................. 183
Table 3.41. Program related to dental care organized at Taman Sinar Harapan and the Community Rehabilitative Centres for people with special needs (brackets contain percentage)........................................................................................................... 184

Table 3.42. Views of the representatives of the support group disability about the existing dental service for people with special needs, by age and gender (brackets contain percentages of respondents nominating that option)................................. 185

Table 3.43. Issues related to people with special needs which discourage them from accessing dental care (brackets contain percentages of respondents nominating that option)........................................................................................................... 186

Table 3.44. Views on dental care project for people with special needs (brackets contain percentages of respondents nominating that option)................................. 187
<table>
<thead>
<tr>
<th>ABBREVIATIONS</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASSCID</td>
<td>the Australian Society for Special Care in Dentistry</td>
</tr>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>CADs</td>
<td>Court Appointed Deputies</td>
</tr>
<tr>
<td>CDS</td>
<td>Community Dental Service</td>
</tr>
<tr>
<td>CHILD</td>
<td>Caring and Helping Individuals to Learn and Develop</td>
</tr>
<tr>
<td>DHB</td>
<td>District Health Board</td>
</tr>
<tr>
<td>DHSV</td>
<td>Dental Health Service Victoria</td>
</tr>
<tr>
<td>dmft</td>
<td>Decayed Missing Filled of the deciduous Teeth</td>
</tr>
<tr>
<td>GDS</td>
<td>General Dental Service</td>
</tr>
<tr>
<td>HCC</td>
<td>Health Care Card</td>
</tr>
<tr>
<td>HDS</td>
<td>Hospital Dental Service</td>
</tr>
<tr>
<td>HHS</td>
<td>United States Department of Human and Health Services</td>
</tr>
<tr>
<td>IDEA</td>
<td>Intellectual Disabilities Empowerment in Action</td>
</tr>
<tr>
<td>ICT</td>
<td>Information Computerized Technology</td>
</tr>
<tr>
<td>IMCAs</td>
<td>Independent Mental Capacity Advocates</td>
</tr>
<tr>
<td>IHC</td>
<td>Intellectually Handicapped Children</td>
</tr>
<tr>
<td>MCA</td>
<td>Mental Capacity Act</td>
</tr>
<tr>
<td>MDS</td>
<td>Master in Dental Science</td>
</tr>
<tr>
<td>MOH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>MSc</td>
<td>Master in Science</td>
</tr>
<tr>
<td>NACSCOM</td>
<td>National Council of Senior Citizen Organizations Malaysia</td>
</tr>
<tr>
<td>Acronym</td>
<td>Full Form</td>
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<td>---------</td>
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<tr>
<td>NGOs</td>
<td>Non-Governmental Organizations</td>
</tr>
<tr>
<td>NOHIC/NIDCR</td>
<td>the National Oral Health Information Clearing House of the National Institute of Dental and Craniofacial Research</td>
</tr>
<tr>
<td>NMRR</td>
<td>National Malaysian Medical Research Registry</td>
</tr>
<tr>
<td>NSW</td>
<td>New South Wales</td>
</tr>
<tr>
<td>NZSHCD</td>
<td>the New Zealand Society of Hospital and Community Dentistry</td>
</tr>
<tr>
<td>PACT</td>
<td>the Patients and Community Trust</td>
</tr>
<tr>
<td>PC</td>
<td>Pension Card</td>
</tr>
<tr>
<td>PCD</td>
<td>Professions Complementary in Dentistry</td>
</tr>
<tr>
<td>PHOs</td>
<td>Primary Health Organizations</td>
</tr>
<tr>
<td>POCAM</td>
<td>Malaysian Association of Orthopaedically Handicapped People</td>
</tr>
<tr>
<td>PPAR</td>
<td>the Protection of Personal and Property Right</td>
</tr>
<tr>
<td>SCD</td>
<td>Special Care Dentistry</td>
</tr>
<tr>
<td>SCDA</td>
<td>Special Care Dentistry Association</td>
</tr>
<tr>
<td>SND</td>
<td>Special Needs Dentistry</td>
</tr>
<tr>
<td>SPSS</td>
<td>Statistical Package for the Social Science</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>US</td>
<td>United States</td>
</tr>
<tr>
<td>VFST</td>
<td>Victorian Foundation for Survivors of Torture</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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CHAPTER ONE

1.1 INTRODUCTION

Special Needs Dentistry (SND) is a relatively new specialty in Malaysia. Traditionally, dental needs of the individuals categorised into this group had been addressed on an 'ad hoc' basis, especially those above the paediatric age groups. In Malaysia the latter's oral health needs have always been taken care of by the paediatric dentists. Being a pioneer in this relatively new dental specialty in a developing country like Malaysia requires us to establish levels of need, current facilities, then an appropriate future planning of this specialty in term of training, facilities, auxiliary staff, models of good care and, most importantly service delivery. Acquiring and exchanging knowledge and experience with personnel from different countries about how SND is practised will identify the needs and develop the service delivery system for the special needs groups.

The Ministry of Health Malaysia (MOH) recently recognised SND as a dental specialty to provide better oral health needs of the population with disabilities who, due to advances in medicine and improved general healthcare are surviving much longer into old age.¹ Although, oral health care of special needs children is well taken care of by paediatric dentists, there seems to be a lack of continuity of care once they go into adulthood. Inadequate manpower with advanced skills in handling this special needs group, lack of dental awareness and poor coverage are probably the major contributing factors to unmet treatment needs for this group of people.

In Malaysia, it is predicted that, with an increased number of elderly in the community due to an improvement in health care delivery and health awareness, the population with disability/ies may also expand as older people are more likely to develop coincident or consequent disability with ageing.¹ Apart from that, it has been reported that the number of Malaysian population suffering from various types of disability had significantly increased from 132,655 in 2003 to 197,519 in 2006.² Therefore, the

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¹Personal communication with Malaysia Social Welfare Department officer, July 2008

²Personal communication with Malaysia Social Welfare Department officer, July 2008
demand in oral health care for these special needs groups is expected to outstrip the service currently provided. The same situation is also reported in United Kingdom, Australia and New Zealand.²

Many studies have confirmed that people with disabilities are more likely to have a poorer oral health condition than those in the general population, mainly due to barriers such as limited access to dental service, financial problems and the complexity of medical conditions from which they suffer.³ While in the past few decades, countries like Australia, New Zealand, Canada and United Kingdom have developed a dental specialty programme that addresses the dental management of special needs patients who require oral health care, Malaysia is still exploring this option⁴ and, for this reason, Malaysia has to send oral health personnel overseas to obtain specific training in this specialty.

These commonwealth countries are selected to be the references of this study due to the relationship we have, through an international organization and co-operation within the framework of common values and goals. In New Zealand, the Hospital Dentistry service and the training programme such as MDS in Hospital Dentistry at the University of Otago were the precursor of SND and these were established long before SND was recognized as a registered dental specialty in 2003.⁴ However, this programme has now been changed to a three-year programme known as the Doctor of Clinical Dentistry in SND. Following the recognition of SND as a dental specialty, the New Zealand Dental Council has registered a small number of dentists as specialists in Hospital Dentistry/SND. National clinical meetings of dental officers in the New Zealand hospital systems are held regularly by the New Zealand Society of Hospital and Community Dentistry (NZSHCD) and have been well supported.⁴,⁵ Similarly, the Australian Society for Special Care in Dentistry (ASSCID) which has evolved as an affiliate professional organization of the Australian Dental Association. Its role is not only to provide clinical care for people with special needs but more importantly, advocacy for research, education, professional development and policy issues are clearly focused.⁴,⁵ On the other hand, in United Kingdom, the recognition of the specialty only took place in late 2008 after a series of position papers were submitted
to the appropriate training groups and governmental departments. Since New Zealand is among the first countries to recognize SND as a registerable dental specialty and has had the systems already in place, it has become a learning framework for Malaysia to review and adopt the systems wherever feasible and hopefully, will soon approach a similar stage as New Zealand. In addition, to widen the view in SND/SCD, the development of this specialty in the United States (US) will be considered, although the health care delivery system is significantly different.

1.2 LITERATURE REVIEW

1.2.1 Definition of Special Needs Dentistry/ Special Care Dentistry
The term Special Needs Dentistry (SND) and Special Care Dentistry (SCD) are essentially synonymous. However, the definition varies and is inconsistent. SCD was first used in 1981 when the journals of the American Association of Hospital Dentists, the Academy of Dentistry for Persons with Disabilities (formerly Academy of Dentistry for the Handicapped), and the American Society for Geriatric Dentistry were merged to form a single organization: Special Care in Dentistry. In Australia and New Zealand, the definition of Special Needs Dentistry by the Royal Australasian College of Dental Surgeons is "that part of dentistry concerned with the oral health of people adversely affected by intellectual disability, medical, physical, or psychiatric issues." The Royal College of Surgeons of Edinburgh has defined SND as "the specialty of dentistry concerned with the oral health care of patients with special needs for whatever reason including those who are physically or mentally challenged."

In addition, the Joint Advisory Committee for Special Care Dentistry has described SCD as a specialty which has been created to benefit people with disability. It provides and enables the delivery of oral care and improving oral health of individuals and groups of society who have a physical, sensory, intellectual, mental, medical, emotional or social impairment or disability or, more often, a combination of these factors. The National Oral Health Information Clearinghouse (NOHIC) of the National Institute of Dental and Craniofacial Research (NIDCR) defines SND as an approach to oral health management tailored to the individual needs of people with a variety of medical conditions or limitations that require more than routine delivery of oral care which encompasses
preventive, diagnostic, and treatment services.\textsuperscript{9} According to the Australian National Oral Health Plan-Action 5, 2004-2013, special needs refers to people with intellectual or physical disability, or medical to psychiatric conditions, that increase their risk of oral health problems or increase the complexity of oral health care.\textsuperscript{10} However, the Australian Dental Association has described SND as that part of dental practice which deals with patients where intellectual disability, medical, physical or psychiatric conditions require special methods or techniques to prevent or treat oral health problems, or where such conditions necessitate special dental treatment plans.\textsuperscript{11} Further, in 2006, Faulks and Hennequin proposed a classification of the population in need of special care in dentistry in relation to the International Classification of Functioning, Disability and Health (ICF)\textsuperscript{b}: ‘patient requiring special care dentistry are those with a disability or activity restriction that directly or indirectly affects their oral health, within the personal and environmental context of the individual’.\textsuperscript{12}

It seems that, at this stage, there is certainly a need for a standard definition which will consider the overlapping factors and co-morbidities and covers various aspects of descriptions, be it SND or SCD. This will help the specialty to be introduced worldwide and indirectly promoting the service among the oral health professionals. The creation of a standard definition of SND/SCD is a difficult task as every country in the world has its own vision, mission and priority when dealing with people with special needs. Nevertheless, it is essential for the oral health professionals committed to this field to have mutual understanding about the meaning of SND/SCD.

1.2.2 Assessment of Special Needs Dentistry Service in Other Commonwealth Countries:

1.2.2.1 New Zealand

The New Zealand Health and Disability System is a community-based, publicly funded model which is currently practised in New Zealand through 21 District Health Boards (DHBs) which are responsible for providing the health and disability services to the community in their district. The New Zealand Public Health and Disability Act of 2000

merely formalised these entities in January 2001. The establishment of DHBs has
changed the New Zealand health service from ‘provider/purchaser’ market oriented to
a ‘population-based’ health system.

One of the permanent core advisory committees which are established for each DHB is
Disability Support Advisory Committee. This committee is responsible to advise the
Board regarding issues related to people with disabilities and advise how these are
best tackled by the DHB. However, the committee does not have the right to act on
the issues unless delegated by the DHB to do so. In terms of service delivery, the
Boards can carry out the service themselves or appoint other providers. In general,
dentistry falls under primary health care which provides the communities with health
education, counselling, disease prevention, and screening in order to improve health
status, and provide preventive measures. This is the first level of health care that is
managed by Primary Health Organizations (PHOs) and comprises of a team of doctors,
nurses and other health professionals, occasionally including oral health practitioners.
Apart from that, private dentists, Maori and Pacific providers are also involved in
Community Oral Health Service. Hospital-based Oral Health/Dental departments also
provide secondary and tertiary care in larger New Zealand centres.

‘Good Oral Health For All, For Life’ is the strategic vision for oral health in New
Zealand.\textsuperscript{13} This is an approach to ensure oral health services are accessible and
responsive to the community beginning from the youngest and the most vulnerable
groups (special needs group) in the society. However, while data on the dental status
of the younger group of the population is widely available, there is limited information
on the oral health status of people with special needs and the elderly. This may
challenge achieving the mission which stresses that the oral health service should be
accessible to them through publicly funded oral health system.

Even though special needs patients may obtain dental care from private practitioners
or certain dental specialists, the limited disposable income of people with special
needs can make treatment financially impossible. The complexity of medical
conditions that they may have, longer consultation and treatment time required have
also made this field of dentistry less attractive to general dental practitioners and specialists. The development of SND service addresses the needs of these individuals who for physical, intellectual, medical or psychological reasons are unable to access oral health care in the private "normal" sector. In addition, people with special needs can directly access to Hospital Dental Service without prior referral, as required for other groups of the population. Oral Health Units at Christchurch, Greenlane and Middlemore Hospitals have been recognized to have the best integration of treatment for people with special needs in New Zealand.\(^c\)

In 2009, the Hospital Dental Service Specification has been reviewed by the Ministry of Health, New Zealand and currently, the summary of these papers is being considered by the New Zealand Dental Association Executive.\(^14\) In this document, the role of Hospital Dental Service has been clarified to enable the general dental (private) practitioners to have clear guidelines of referral for patients to access the service. By definition, the Hospital Dental Service in New Zealand is responsible in providing oral health care service for people with special needs that are most appropriately provided within the hospital setting.\(^14\) This may include those with a disability who require special care for primary care and are unable to access oral health care in the community.\(^14\) Secondary and tertiary care may also be provided within this setting for those who require dental services as part of other medical or surgical treatment when special management is needed.\(^14\) In addition, the draft of the specification has outlined the criteria of patients which can be referred to hospital for dental care. This may include:

i. Hospital inpatients requiring essential dental treatment

ii. People requiring primary, secondary or tertiary oral health care in conjunction with other hospital treatment

iii. People needing inpatient, day patient and outpatient dental services that are not available from a dentist or other oral health professional in

an oral health service in the community because of their special dental condition, disability or their need for special management facilities.

To date, recent graduates, part time specialists and a small number of people at a late stage of their career are the essential staff of the hospital dental service and in special needs dentistry service in particular. There are only a few full-time staff because the career pathway for dentists within major hospitals is restricted. This may result from the unavailability of clinical post-entry training in special needs dentistry to advance dentists to specialist level and salary scale. It was suggested that, in 2003, postgraduate training in SND be done in Christchurch using a medical model which was going to be the first time, ever that a complete dental postgraduate course would be run outside Dunedin. However, until now, the proposal has not been implemented.

Another worthwhile programme related to SND is the domiciliary service provided by Hospital Dental Service. Currently, this programme is only focusing on frail elderly in rest homes and hospitals and could be categorized as a symptom driven service. Due to significant increase in the ageing population who are at least partially dentate and have a large need of dental care parallel with high caries and periodontal diseases recorded in this group,\textsuperscript{15} it would be more beneficial if the domiciliary service could be extended to the elderly in rest home care, the independent elderly and rural elderly. In the Strategic Vision for Oral Health, Action Area 6: Develop Oral Health Policy, the oral health needs for older adults is examined based on four groups; independent older adults, moderately dependent older adults, highly dependent older adults and older adults from groups experiencing particular inequalities (both independently and as part of the other three groups).\textsuperscript{13} Therefore, an oral health work programme should be planned to focus in promoting oral health care for each of these groups and it would involve the funding issues.\textsuperscript{13}

In summary, the SND service in New Zealand is available through primary health care and hospital dental community services which is part of the community dental service and provides publicly funded care. In hospital, people with special needs can either be treated as self referred or referred by other health care providers. As more individuals with special needs are now living in the community and some will experience difficulty...
in accessing dental care, an extension of the domiciliary service programme to cover a wider range of special needs group seems to be appropriate in the future.

1.2.2.2 Australia

‘Healthy Mouths Healthy Lives’ is a theme of Australia’s National Oral Health Plan 2004-2013 which aims to improve health and wellbeing of Australian population by reducing oral health care burden and improving oral health status. Therefore, more people will retain their dentition throughout their lives without any difficulty in accessing an affordable and quality oral health service.\(^\text{10}\) The plan is a population-based approach, in which all the programmes are to be implemented widening to all ethnic groups in town and rural areas, and emphasize both prevention of disease and prevention of treatment according to the oral health needs.\(^\text{10}\)

The core of the Plan is the seven action areas which were based on epidemiological data which stressed the urgent requirement to promote oral health care to reduce inequalities of oral health status among the population. Again, this document identifies a significantly poorer oral health status in special needs individuals.\(^\text{10}\) Not only in Australia but in other parts of the world as well, people with special needs experience more substantial oral diseases partly due to limited access to oral health care.

In Australia, oral health care for people with special needs is provided by the Dental Health Service, Department of Health in each State, the States can act independently of each other. Nonetheless, they are still bound to one national guideline i.e Australia’s National Oral Health Plan 2004-2013.\(^\text{10}\) The Dental Health Service facilitates general dental care for geographically and financially disadvantaged persons in the community and other special groups of people. The service is available through public dental clinics, private dental clinics, domiciliary services and an aged care dental programme. The public dental clinics are provided by the State Government, and can either be located in the city or rural areas. The special dental care service for each state in Australia is reviewed in this section.
1.2.2.3 South Australia

In South Australia, dental services are provided through Emergency Dental Care, School Dental Service, Community Dental Service, Adelaide Dental Hospital, Education and Teaching Services and Health Promotion. People with Special Needs in South Australia receive dental service from the Special Needs Unit of Adelaide Dental Hospital, which has attracted national and international recognition for its outstanding work. The unit is staffed by the specialists, general dentists and hygienists. They play a significant role in research programmes and regularly attend the national and international conferences.

There are two important areas in the Special Needs Unit. One area provides services to medically compromised patients while the other provides services to patients with physical or intellectual disabilities.

- The Medically Compromised Area provides dental care to a very diverse group of patients including HIV/AIDS, hepatitis C, cancer, haemophilia and other bleeding disorders, auto immune diseases, severe cardiac conditions, allergies and transplant recipients is catered by. The unit is also involved in the pre-surgical assessment and reconstruction of oral and maxillo-facial prosthodontic treatment for oral surgery patients.

- Dental services to patients with physical and intellectual disabilities are provided, on site at the Adelaide Dental Hospital, at the Strathmont Centre, Glenside Campus of the Royal Adelaide Hospital and the Julia Farr Centre.

Patients are referred to the Special Needs Unit from the Royal Adelaide Hospital, and its associated services, other teaching hospitals in South Australia, Adelaide Radiotherapy Centre, private medical and dental practitioners, the Community Dental Service, and other community organizations such as the Hepatitis C Council, and the AIDS Council.

There are six dental surgeries in the unit including a latex free surgery. This surgery also has its own dedicated air conditioning system to prevent transmission of airborne...
bacteria from other areas of the hospital. A wheelchair lift is provided for patients with limited mobility to access dental services.

1.2.2.4 Western Australia

In Western Australia, access to public dental clinics is limited to those who are financially disadvantaged. Many individuals with special needs would be able to eligible for this scheme.

Some housebound patients are able to access dental care through a domiciliary unit in their home area. This unit is also responsible to deliver dental service for special needs groups and people living in institutions. The clinics are located at the Disability Service Commission sites and in various correctional institutions. Besides that, Western Australia has a special dental programme for elderly which is called an Aged Care Dental Programme. The elderly who benefit from this programme are those who live in the Aged Care Facilities. Under this scheme, the elderly patients are eligible for a free dental examination and an oral health care plan annually. The oral health care plan provides detail of daily dental hygiene and preventive needs. The patients can then be referred to government dental programme for eligible patients or to private dental practitioners for others, if further treatment is required. On the other hand, full fee is applicable for patients who are not eligible for subsidised care but live in remote areas where Dental Health Service is the only dental care available.

1.2.2.5 Victoria

Special Care Dental Services for Victorian residents are provided through Royal Dental Hospital of Melbourne which also provides clinical experience for postgraduate students in SND from the University of Melbourne. The Special Care Unit provides the service for people with intellectual and physical disabilities. There are several dental programmes as listed below, which have been introduced to the community focusing on the disadvantaged groups:

- Ozanam Community Centre - for homeless people in the Melbourne metropolitan area
- Homeless Youth - for young homeless people
• Dental Plus (+) - for people living with HIV/AIDS
• Drug and Alcohol - for people with drug and alcohol problems
• Outreach - for residents of selected boarding houses in inner Melbourne
• Victorian Foundation for Survivors of Torture (VFST) - for clients of VFST who are refugees of war-torn countries
• Melbourne Juvenile Justice - for residents of the Melbourne Juvenile Justice Facility in Parkville

In addition, Victoria has a well established domiciliary service which provides oral health care for completely homebound patients due to their medical, mental or physical conditions. There is a range of treatment offered by this particular service, for example, dental examination, oral health advice, prevention and cleaning, dental restorations, extractions, provision of dentures and denture care. However, if the service is to be provided at the resident’s home, the location should be clean and the followings must be available to ensure adequate care delivery:

• reasonable lighting
• easily accessible power points
• a sink with running water
• a table
• privacy
• freedom from interference from pets
• access ramp for dental equipment
• access to non-meter parking or free parking within a reasonable distance.

The domiciliary service is free for Health Care Card (HCC), Pension Card (PC) and Veteran Affairs Gold card holders. However, in order to be eligible for this service, an application form should be completed by the patient or carer and the patient’s general practitioner and then returned to the Domiciliary Health Unit before an appointment can be arranged according to urgency of dental care required and the geographical area. Also, children with intellectual and physical disabilities can access general dental care delivered by two special needs van provided by Dental Health Service Victoria (DHSV). Dental care is also free for children who attend special or special
developmental schools in metropolitan Melbourne or rural Victoria every one to two years.

DHSV also provides dental treatment for elderly who are HCC and PC holders at a Community Dental Clinic. They are also eligible for the Victorian Denture Scheme through the Royal Dental Hospital of Melbourne and Community Dental Clinics. However, there is a fee for this service.

1.2.2.6 New South Wales (NSW)

Generally, in NSW, the oral health services are provided through the NSW public health system including dental services to children and adults according to criteria which target emergency situations, those in most need, screening services targeted at specific schools and education and promotional services. Each of the Area Health Services is responsible to deliver these services.

Special needs dental care is offered through the hospital dental clinics. The care is provided for those with chemical, medical, mental and physical challenges. Usually, patients are treated by a dentist in operating rooms and emergency departments alongside the medical colleagues. Apart from that, dentists who are involved in this field have recognised qualifications as academic educators and researchers. Additionally, hospital dental clinics are equipped with the clinical training facilities for students in many of the dental programmes.

In South East Sydney and Illawarra area, a free dental service is available for those with special needs including homelessness, drug and alcohol or mental health issues. In other areas of NSW, the funding scheme for people with special needs to receive oral health care varies but is still subject to the NSW Oral Health Fee for Service Scheme and NSW Health Policy for Eligibility of Persons for Public Oral Health.

1.2.2.7 Queensland

People with special needs in Queensland may receive oral health care from public sector at no cost as long as they fall in the category of an eligible adult. They are usually Queensland residents who are the holders of current cards of following types, issued by Department of Social Security:
• Pensioner Concession Card
• Health Care Card
• Pensioner Concession Card - issued by the Department of Veteran’s Affairs
• Queensland Seniors Card

Despite all the efforts to improve oral health status among the elderly, the level of oral diseases in people with disability in Australia remains higher than the rest of the population. This will be further threatened by expected national shortage of oral health providers in Australia by 2010. Australia Health Services (Supported Residential Services) Regulations 2001 incorporating amendments as at 16 March 2006, is documented in Part 3 – Standard of Resident Care that to ensure personal hygiene of residents, their teeth must be cleaned at least once a day. The proprietor must also be responsible that the dental check up of each resident by a dentist or other oral health care provider is done at least every two years and care for and assistance with oral care and safe storage the resident’s denture should be provided if required.

In general, community dental clinics are funded by state government and provide dental care only for certain groups of the population; eligible elderly, special needs groups, single parents, and unemployed. Other groups of the populations such as army, indigenous population and inpatients are funded by Commonwealth Dental Funding. To summarize, the majority of dental service in Australia is obtained from private practitioners with or without assistance of private dental insurance.

1.2.3 United Kingdom

In the United Kingdom, oral health services can be divided into five major categories, they are: General Dental Service (Private Practitioners), Hospital Dental Service, Community Dental Service (CDS)/Salaried Primary Care Dental Service, University Faculty and Armed Services. Following registration with the General Dental Council, newly graduated dentists must undertake and complete a ‘vocational training’ for one year during which they practice dentistry with support from a trainer. They must also at the same time attend lectures and seminars to obtain additional training in the fields relevant to general and community dental practice. After the completion of the
vocational training, they are eligible to proceed on, as a principal in general dental practice and considered to pass more beyond the first point on the salary scale in various branches of salaried primary care dental service.²⁵

People with special needs receive oral health care from CDS which comprises salaried dentists of various grades.²⁵ Most of special needs patients have difficulty getting access to National Health Service or private dentists. For those who are unable to visit a dental clinic, a domiciliary service is provided by the community dentists. Parts of the programmes of CDS are visiting schools, day centres, and residential institutions for people with learning disabilities and for frail older people.

Some local criteria of the patients with disability who can be treated by community dentists have been outlined and so, only those who fulfil the following categories would be accepted by CDS:

- A child or adult with learning disabilities
- A person who is medically compromised
- An elderly housebound or immobile person
- A person with severe dental anxiety
- A patient referred by any other health professional

The patients are usually referred by a variety of health and social professionals but can be self referred as well. Those referrals should be accompanied by appropriate documentation of the type of disabilities that prevent them from receiving treatment within the General Dental Service.

The involvement of hospital dental service varies accordingly. In some areas, CDS dentists are working within a hospital setting, whereas in other areas, they are totally independent without any association to a hospital dental service. For those community dentists who are using a hospital setting, they can work part time or full time at the hospital. They frequently deliver dental care for patients with special needs, which is not provided by other specialists or when the patients require dental treatment under general anaesthesia or sedation. Since all treatment under general
anaesthetic should be provided in a hospital setting, some patients may have to be referred to relevant hospital specialists such as Maxillo-facial Surgery, Restorative Dentistry or Paediatric specialists if the patients are below 16 years old. However, a community dental clinic may also be part of group facility providing day stay anaesthesia or sedation.25

CDS provides free treatment for children below 16 years of age. It is also free for adults except those who need dentures and bridges. Nonetheless, in the areas where CDS and other salaried primary dental care are merged together, National Health Service charges are applicable for all kind of dental treatment. Exception of payment can only be given to individuals who have evidence of having a low income.

It seems that in the United Kingdom, special needs dentistry service is mostly provided by general dental practitioners who have not received formal training in special needs dentistry. Training can be rather ad hoc and obtained through hospital attachment and continuing professional education courses or seminars. Currently, special needs dentistry training has been offered in several programmes resulting from the growing needs in this field worldwide. The programmes include one year MSc in SND in Eastman Dental Institute in London and an examination leading to Diploma in Special Care Dentistry offered by Royal College of Surgeons of England. The Royal College of Edinburgh also awards the successful person in similar examination process, a Diploma of Membership in SND. This significant development provides additional opportunity for dentists to gain formalized qualification in SND.25

Guidelines for the Delivery of a Domiciliary Oral Healthcare Service which is being revised by on behalf of the British Society for Disability and Oral Health is aimed to provide for individuals whose circumstances make it impossible, unreasonable, or otherwise impracticable for them to receive their care in a fixed clinic, a hospital site or from a mobile dental clinic.26 Domiciliary services in the UK can be delivered via the general dental service (GDS), community dental service (CDS) and hospital dental service (HDS).26 In this document, client groups, the requirements of the dental team to deliver the service, the equipment required, the procedure for visiting and the
environmental, health and safety issues are discussed in detail to provide guidance for the commissioning of high quality service to meet the demand and needs of the eligible patients.26

Interestingly, after all the hard work and following an extensive series of articles written by several respected and committed oral health professionals in SCD in the UK at the GDC meeting on 3rd and 4th September 2008, SCD has successfully gained recognition as a dental specialty from 1st of October 2008. Prior to that, in December 2005, the GDC agreed to the principle of the establishment of a Specialist List in SCD.27 Janice Fiske, in her presentation for a meeting in December 2008 had focused on the development of the specialty which involved various organizations, each plays specific roles to ensure the specialty is well established and fully recognized worldwide.28

1.2.4 Canada

Ministry of Community, Family and Children Service, Canada is responsible for public funding of dental care in Ontario.29 However, this funding is only for those who qualify. The eligibility for financial assistance is assessed by the Health Department. Adults with special needs aged 64 and under who require dental treatment fall under those who are qualified for financial assistance. Special needs groups are classified as individuals with certain degree of difficulties to carry out activities of daily living (ADL) as well as lack of financial support. Those aged 65 and above who have dental needs and financial needs are also eligible for dental funding.30

In Canada, most of dental services are delivered by private, for profit practitioners either in their own office or community owned. Only minority of dental practitioners work at non profit community health centres or other community-based sites.31 The community dental practices which are under the Health Department offer oral health information and services to people with special needs, their families and health care providers. The services available cover the following topics30:

- Basic dental care for adults with special needs
- Cavities
• Denture care, stomatitis, dry mouth
• Multiple sclerosis, stroke, cancer
• Diabetes, difficulty swallowing (dysphagia)
• Alzheimer’s disease, mucositis, candida infection
• Palliative care

Even though, there is no domiciliary service in Canada, for people with special needs who reside in hospitals and community agencies, the dental health staff provide special services which include oral health education sessions and individual oral hygiene instruction for clients and care givers. This includes the Toronto Academy of Dentistry which is equipped with a mobile dental unit that can be used by area dentists, the oral health care of homeless is provided by the Shout Clinic in Toronto, an on site dental clinic at Island Lodge Home for the Aged in Ottawa, and the provision of complex continuing care and nursing home patients by dental hygienist at Niagara College, Welland Campus partnered with the Welland Country General Hospital. In addition, the patients in this category may be involved in periodic dental health surveys. The dental health staff may also guide the clients to additional oral health resources upon request and provide dental consultation if necessary.

1.2.5 Assessment of SND service in the United States

Special Care Dentistry Association (SCDA) has defined "Special Patient" in the oral health field as ‘an individual with special needs, including physical, medical, developmental and/or cognitive conditions, resulting in limitations in their ability to receive dental services and prevent oral diseases by maintaining daily oral hygiene.’ This vulnerable group in the United States is principally eligible to receive medical care funding from Medicare or Medicaid (government funded programmes). However, not all dentists in America accept Medicaid patients and this will lead to avoidance of dental care by people with special needs until they become severely ill and the condition is far beyond curable. For example in Pennsylvania, almost 75% of dentists do not accept Medicaid and even if they are involved in the programme, the low reimbursement rate has discouraged most dentists to treat people with disabilities.
The dental services for people with special needs in the United States is mainly catered for by general practitioners. Apart from funding issues, many dentists are reluctant to provide the service because of a lack of training. This results in 8% of children with special health care needs not obtaining the required dental care, as reported by the U.S Department of Health and Human Services (HHS) in The National Survey of Children with Special Care Needs, Chart Book 2001. Changes in dental school accreditation standard which require newly graduate dentists and hygienists to receive didactic and clinical opportunities in treating patients with special needs will increase the number of dentists who will provide the services.35

Unfortunately, in the US, the creation of a new specialty such as SCD does not indicate better dental care for people with special needs if adequate financial remuneration is not available. Despite an increase of awareness in the need of dental care by patients with special needs, partly as a result of further aging of the baby boomer generation and the greater number of individuals with a wide range of special needs, US has seen this as a responsibility for every general dental practitioner to provide the dental care for this vulnerable population.

1.2.6 Historical Similarities

1.2.6.1 Health Inequalities

General health and oral health is closely related. Frequently, they both share the common risks factors. Oral disease is often associated with systemic disease. However, in all over the world, inequalities between dental care and general health care seem to be continuously occurring and accepted.36, 37 This phenomenon should not be happening in this millennium. Unfortunately, inequalities also exist in the oral health care delivery system. Regardless of the developmental status of the countries, there is always a significant gap in oral health level between those with high socioeconomic status, and the poor, as well as the disadvantaged groups.37 People with disabilities or special needs often experience an unfavourable oral health status due to additional barriers such as difficulty to access oral health care and inability to pay for the cost of dental treatment.38 How this issue should be tackled must be taken into consideration
while planning for oral health care delivery. Future plans must aim to reduce the gap and improve the quality of oral health among patients with special needs.

Historically, SND derives from the idea that people with special needs do not receive appropriate dental care proven by many studies and literature. In Malaysia, the issue of unmet treatment needs of people with special needs has long been recognized, which results in an imbalance between their general and oral health.\(^{39}\) In early 1993, ‘Oral health care programme for special children’ was launched by the Oral Health Division, Ministry of Health, which aims to improve the health of children of special needs that will contribute to the enhancement of their quality of life.\(^{39}\) Even though a special programme had been planned for these groups of children since 1980s, full implementation had been difficult due to some constraints from the community and the Ministry such as lack of awareness and insufficient information, social stigma faced by families, financial constraints, poor access to oral health care and services which are not friendly to people with special needs and poorly equipped. As a result, their oral health conditions are left untreated and becomes severe, chronic and untreatable when they reach their adulthood.\(^{39}\)

Reducing health inequalities in New Zealand including oral health involving people with special needs has been addressed in the Strategic Vision for Oral Health in New Zealand. Even though little data is available about the oral health and services experiences of people with special needs, predictive modelling has indicated that there is a decline in edentulism and an increase in caries incidence among older adults and people with special needs.\(^{13}\) Following a report by WHO entitled ‘Closing the health inequalities gap: An International Perspective’ which states inequalities in health are more often occurring in the disadvantaged groups of the population due to less opportunity to improve their physical and social environment, people with special needs at all ages in New Zealand have become one the priority groups in this strategic vision.\(^{40}\)
1.2.6.2 Health Education

Health education is an important element to achieve high standard of oral health. Early intervention of oral health education is appropriate for the patients, parents and care givers in association with prevention and treatment of dental diseases. In many countries, health education is done through a variety of dental health promotion programmes in the community based-dental system. An early dental education will prevent major dental procedures required later in life. The inclusion of oral health care in Activity of Daily Living (ADL) as a part of dental education may improve the quality of life. Any approach must be sensible and realistic for people with special needs.

In New Zealand, the primary care system which is managed by District Health Boards emphasizes early intervention and health promotion as well as disease prevention. Based on ‘Good Oral Health For All, For Life’, the oral health promotion is not only focusing on reducing dental disease but to improve the general health of the community and its individuals. The Ministry of Health New Zealand has developed several levels of educating the society through a promotion approach. Firstly is a healthy environment promotion, since good oral health begins with a healthy environment. Fluoridated water, healthy diet and smoke-free surroundings are crucial to ensure a healthy environment, especially for those most disadvantaged who have barriers to access the environmentally healthy conditions. Water fluoridation is the best public promotion for children and adults and has been supported by many international researchers. However, the commitment of the Ministry to implement water fluoridation may require some political changes. General health promotion actions often share the same objectives with oral health and the Ministry must ensure that these activities include oral health messages. Therefore, the integration of oral health and general health is imperative. The involvement of other health professionals such as Plunket nurses or midwives who are directly involved at an early stage of the development of children should be expanded. Hence, they can encourage patients or caregivers to carry out self dental care at home. Other than that, healthy behaviour should be promoted via preventive and educational approach. Since healthy behaviour is very much influenced by individual action, the implementation of the programme cannot be guaranteed especially when dealing with people with special needs.
Oral health education in Britain involving patients with special needs has focused on both clients and carers but each target group has different issues and needs to be addressed. Their common needs are the basic knowledge and understanding of the general health benefits of good oral health, risk factors of oral health, preventive and dietary advice, technical guidance with oral hygiene and appropriate aids for oral hygiene. It is suggested that carers should be approached in more flexible ways and oral health education to be included in their basic care training. However, continuous training is required in to ensure that poor oral hygiene level in patients with special needs is properly addressed and improved. The preventive programmes and oral health plan are carried out by consideration of the type of disabilities or impairments that affect the individuals. In addition, cultural and social assessment must be taken into account when making an oral health plan for the disabled. In other words, in the UK, oral health education for people with special needs is implemented through an individual approach which emphasizes the practical aspects of oral health care for the clients and/or carers.

In 2002, Reznick et al investigated the perceptions of caregivers regarding the importance of dental care for institutionalized seniors in Canada and identified lack of dental health education among primary care givers. Currently, more emphasis is given on oral health care delivery for the patients with special needs rather than approaching the caregivers to make them aware that oral health disease is preventable. Increased understanding by the caregivers of the importance of oral health may have a big influence in improving oral health status of a dependent population with special needs. One of the initiatives that have been recommended by Ontario Dental Association to educate the clients and carers about dental health is visiting individuals within the community who have poor access to dental clinics. Most patients are screened at a central location where the carers are given appropriate advice on oral hygiene and issues regarding oral health disease and the practical aspects of dental care for a particular patient. There are several centres that have been identified to serve the disabled population in Canada. For example, Mount Sinai Hospital serves the population with special needs in Toronto and surrounding areas and the Burlington Academy has partnered with the Joseph Brant
Hospital to cater oral health care for long term care patients and elderly residing in the community.\textsuperscript{32} Patients will be referred to participating dentists if required. This activity is held during Dental Health Month. Apart from that, the dental practitioners are encouraged to continuously raise awareness on preventive issues to reduce extensive treatment needs in the future.

It seems that, in many countries, there is no specific approach in terms of oral health education for the patients with special needs as well as for the caregivers. Even if the oral health promotion programmes for this vulnerable group exist, their limited access to the information due to barriers such as physical, mental or intellectual disability may result in no improvement in their oral health status. Unless they are individually approached with the active involvement of the caregivers and updated knowledge, the inequalities of the oral health level between individuals with special needs and the rest of the community will continue. Early intervention and ongoing support to improve home care need to be emphasized.

1.2.6.3 Dental Public Health

Many publications have documented the close linkage of general and dental health.\textsuperscript{36} The importance of oral health however, seems to be unnoticed outside the dental community or by medical professionals. In most countries like Australia, United Kingdom and Canada, universal health insurance assists the health care access for all parts of the body but not the oral cavity.\textsuperscript{32, 36} Public funded dental health care is available only for ‘basic’ procedures. Although unacceptable, inequalities in oral health care have long existed in the health care system and require special attention. The most affected groups of population in this basic system are low income people who experience more untreated diseases and suffer more pain with greater dysfunction until treatment is received.

People with special needs in all parts of the world have experienced poor oral health. In Canada, lack of access to oral health care of the disadvantaged group has become a major concern in contributing to the inequality of oral health.\textsuperscript{44} A recent epidemiological study in Adelaide, Australia has also demonstrated variation in the
management of oral disease experience due to inequality in access to oral health care.\textsuperscript{36} Similarly, people with disabilities in the UK have been reported to have problems with commuting to get access to dental care as the majority of them are now living in their own home in a community setting, except for those who are extremely vulnerable and are residents in care homes where the domiciliary service is available.\textsuperscript{2} Additionally, the Strategic Vision for Oral Health in New Zealand has given the primary health care system a responsibility to tackle inequalities in oral health care beyond curative care.\textsuperscript{13} It indicates that inequalities in oral health care also exist in New Zealand which not only affect the people with special needs but also identifies significant differences associated with ethnicity, region and water fluoridation. Again, access and funding are the recognizable barriers which causing the inequality.\textsuperscript{13}

It seems that, in these particular countries, access to oral health care of this vulnerable group is a major barrier to obtain good oral hygiene. Lack of access can be improved mainly through a community-based dental care system which is currently found in most countries in the world. The only difference is the service can either be delivered at the community dental clinic or at the hospital setting. Improved access in a community-based dental care system should include consideration of physical factors, financial support and a team care approach. However, Individuals who are identified as falling out with these parameters would still require access to special care or hospital setting. As currently, there are no specific universal regulations which determine how the special needs dentistry should be practised, the approach entirely depends upon the needs and demands of the service across the country and the skills of the providers.

1.2.7 Changes in Care, Health and Expectations
The relocation of people with special needs out of the institutions into the community has created barriers for this vulnerable group to access to health care and dental care in particular. As a consequence, the oral health needs of individuals and groups who require special care are hardly met and result in poorer oral health status. This could be the biggest challenge that needs to be tackled by oral health care providers currently. In addition, with improvement and new discoveries in medicine, the number
of people who can live longer is significantly increased which is frequently accompanied by impaired mobility. It has been reported that, impaired mobility affects approximately 20% of the elderly aged between 60 to 74.\textsuperscript{42} It increases about 46% in the population above 75 in the UK.\textsuperscript{42} Impaired mobility may prevent the patients performing the oral hygiene measures, and lead to the development of multiple oral diseases. In addition, people are more likely to be living with chronic diseases or life shortening illnesses. These changes may also require alterations to oral health care delivery to people with special needs. Apart from that, as the education level improves, people’s perspective and expectations of oral health and dental services are rising.

In Malaysia, demand for oral health care is increasing among the population. The younger population is becoming more aware about how well they look by retaining their natural teeth. They believe that good physical appearance may improve their self esteem and confidence. Good oral health makes anyone feel more able to enjoy food and thus have a better quality of life whether with or without disability. Therefore, people expectations in dental profession is higher, with increased needs and demands for appropriate services to gain better dental care and treatment. Nevertheless, there is still a huge disparity in dental health attitude between urban and rural community. Most of the people who live in rural areas still believe that tooth extraction is the best treatment for toothache as it can remove the pain immediately without considering the effects it has later in life. Oral hygiene maintenance is poor and complex dental treatment to retain the natural dentition is not affordable. Even if the dental cost at public dental clinics is less than that in private clinics, the types of restorative treatment available are limited. The fact that, the number of specialists is greater in the urban areas compared to those working in the rural areas, may also contribute to inequalities of oral health status between these two populations. The same issues apply to people with special needs living in those societies.

Compared to other countries like New Zealand, Australia, United Kingdom and United States, people with special needs in Malaysia have long resided within the community, with the family. The existence of institutions to care for this vulnerable group is rare
and is more concentrated in the metropolitan areas. Most of the elderly patients and people with special needs are taken care of by their family members at home. In Malaysian culture, the family members are despised for not being responsible by sending their parents or their special family members to the rest homes or disabled institutions unless it is a day care centre or training based centre. Traditionally, carers show more concern about the patient’s general health rather than their oral health. Even if the frequency of tooth brushing practice is satisfactory, the carers have never received any advice from a dentist in the community as they rarely visit a dentist in the absence of any symptoms. In addition, high dental cost could be another factor which results in poor oral health status among people with special needs. This situation is also described by the findings of a survey done by Stanfield et al in the UK that looking at the changes in oral health care of clients with learning disability following the relocation from hospital to community.2,45

Another challenge faced by the oral health care practitioners to improve oral hygiene of the individuals with special needs is lack of manpower. Despite the growing number of dental specialists, none is specialised in providing dental care for this group of people. Lack of training and interest among dental practitioners to treat these groups of patients may be another factor that delaying the recognition of this dental specialty in Malaysia. Clinical training in dealing with people with disability for predoctoral dental students is also significantly lacking.46 Any clinical exposure they have only is with individuals with minimal disabilities. The patients with profound or severe disabilities are referred to specialists to deal with. Only recently has the government realized, with an increase in demand for oral health care of this vulnerable group that they have been referred to several specialties which are not willing to treat and monitor their oral hygiene throughout their life. The treatment provided is limited to emergency care and no long term management plan devised.

The number of patients with disability in higher education institutions is now increasing. This happens due to substantial support from the community and increase in awareness among parents of special needs children about the importance of education in improving the quality of life. This may change their perspective and
expectations to oral health care to a higher level. Regardless of the types of disabilities, individuals, families, carers and the community have begun to realize that these individuals deserve the same rights as the rest of the population. If they have difficulty to access dental care, then the service should be arranged in such a way that the patients can receive dental treatment without the need to travel excessive distance and to subsidize the cost of dental treatment under special schemes if financial support is the major barrier to dental access.

In addition, with changes in health care and expectations, oral health care delivery for people with special needs must undergo similar transformation. Therefore, they should receive appropriate oral hygiene as other ‘normal’ people do. The needs for SND may be influenced by several factors such as ageing population, changing in oral health pattern accompanied by reformation of health care and increase in public value and expectations. A step has already been taken by recognizing SND as a dental specialty and so, the development of care delivery system should involve all members of the dental health care team and integrate with other health professionals in order to facilitate the service.

1.2.8 Oral Health Needs and Wants of People With Special Needs

Oral health needs and wants are two separate entities which need to be addressed when dealing with people with special needs. An assessment what the patient wants and what the professionals believe they need must be carefully balanced. Clear and concise clarification is essential to ensure the patients and all members of their support network understand that oral health needs may not match their wants. Some dental treatments are elective and may not be feasible for people with special needs. ‘Need’ can be defined as ‘the population ability to benefit from health care’. Need is a dynamic element which can change over time and varies from one individual to another. It may be influenced by change in lifestyle, socioeconomic status and the availability of oral health care. Recognizing the patients’ needs and wants are important so that dental treatment or consultation can be provided appropriately within affordable cost, patient's ability to cooperate and commitment to dental treatment. Patients' wants are very subjective matter which always depend on what
they feel or in case of individuals with special needs, may rely on what the carers think is the best. What they want may not always be necessary to be provided and dental practitioners should be able to give appropriate advice based on the clinical judgement and their updated knowledge.\textsuperscript{2}

Generally, in term of treatment needs, periodontal care has been reported to be the most common treatment required.\textsuperscript{47} Patients’ inability to carry out satisfactory tooth cleaning due to limited coordination or change in buffering capacity of the saliva as a result of the medications and poor muscle tone which compromise their self cleansing abilities, are all major factors contributing to periodontal problems. For example, it is recommended that prophylaxis and dental cleaning are performed every three months for patients who are tube fed.\textsuperscript{47} Dental caries is the second most common oral disease that is experienced by people with special needs.\textsuperscript{47} Many contributing factors are relevant to the progression of dental caries. Their medical conditions, the medications they are taking and the diet can compromise the dentition and challenge the dentist’s ability to restore the teeth. Advanced restorative options such as crown and bridge, endodontic and orthodontic treatment are offered less frequently unless it is really necessary and can be tolerated by the patients.\textsuperscript{47} If possible, tooth extraction should be avoided and all efforts must lead to maintaining their natural dentition. However, this intention may create some challenges in treatment planning due to patients’ behaviours and intolerance to oral manipulation. Nevertheless, the roles of dental practitioners are not just confined to clinical treatment. The overall management of the special needs patients may require the dentists to establish contact with other health professionals and disability support bodies outside dentistry to ensure their needs are well met.

Patients’ wants are also important to consider because their satisfaction will rely on fulfilling their wants. If what they want is reasonably matched to their oral health needs as established by dental practitioners, they should receive that treatment. However, if the wants are beyond their needs or the other way around, it is the dentist’s responsibility to negotiate a satisfactory outcome.
1.2.9 Legal and Ethical Issues

There is a lack of published literature representing this sensitive issue with regards to patients with special needs. Legal and ethical matters which are usually needed to be dealt with is obtaining informed consent in order to deliver treatment for patients who are deemed to be incompetent. According to Right 7(1) of the Code of Health and Disability Services Consumers' Right (Code of Rights) New Zealand: “Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise”.

It is well known that, consent is the key element to carry out any form of treatment. It is considered unethical to perform treatment without valid consent. In general, consent can be obtained either orally or in written form. In majority of cases, both methods of gaining consent are appropriate. Depending on the types of disabilities, gaining informed consent from patients with special needs can be difficult. In cases where the patients are unable to give consent, who should be legally allowed to act on their behalf? In this section, this issue will be looked at closely. Buddle Findlay, a law firm which often handles health legal and ethical matters in New Zealand has provided valuable information for health practitioners with regards to obtain consent from patients who are deemed to be incompetent.⁴

There are three important elements in obtaining patient’s consent to health treatment as have been outlined by Bundle Findlay by which health professionals including dental practitioners must ensure;

- a. That the patient is competent, or has the necessary capacity, to make the decision to undergo, or to refuse, treatment; and
- b. That the patient is provided with sufficient information to enable the patient to make an informed decision about the proposed treatment; and
- c. That the patient’s consent is given voluntarily.

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⁴ Informed Consent and Treatment of Incompetence Patients. A lecture by Coates J of Buddle Finlay Lawyers, Counsel for New Zealand Dental and Medical Councils, July 2008
At any time if any of these three elements is not met, valid legal consent cannot be given by the individual. The competency of the patients to give consent is a decision to be made by health professionals and is very much based on the patient’s understanding of the nature, reasons and side effects of the proposed treatment as well as the ability of the patient to retain information. In assessing patient’s competency, they should be encouraged to ask questions or questioning them back to test their understanding regarding the procedure. Other issues such as cultural and religious matters need to be discussed.

In a situation where patient is found to be incompetent to give consent, (The Protection of Personal and Property Right) PPPR Act has authorized three groups of people who can give consent on their behalf. They are as follows:

   i) The incompetent child’s parent or guardian (for those below 18 years old)

   ii) Welfare guardian (who has been appointed by court)

   iii) Enduring power of attorney (a person/a lawyer appointed by the patient to make decision on their behalf)

However, if there is no one available to act on the patient’s behalf, health professionals can authorise the treatment, provided certain criteria that are set out in Right7(4) of the Code must be met. The criteria are as follows; ‘the treatment must be in the best interest of the patient AND reasonable steps must have been taken to ascertain the views of the consumer AND either, if the patient’s views have been ascertained and having regard to those views, the health professional believes on reasonable grounds that the treatment is consistent with the informed choice the patient would have made if (s)he was competent or, if the patient’s view have not been ascertained, the health professional takes into account the views of other suitable persons who are interested in the welfare of the patient and available to advise the health professional’. Otherwise, authorisation can be obtained from the courts. However, in an emergency situation, in order to preserve health and well-being or the saving of life in cases of serious injury or illness, the action can be provided without consent.
Additionally, in the UK, when the Mental Capacity Act 2005 (MCA) for England and Wales came fully into force in 2007, adults are presumed competent to consent in common law jurisdiction. 48 People over 16 years of age with mental illness, dementia, learning disabilities, brain damage, confusion, drowsiness, loss of consciousness, delirium, or concussion are covered by MCA. Any individuals who have been identified as having lack of capacity to make decisions for themselves would require someone to act on their behalf such as healthcare professionals. Social workers and care assistants are also included in this Act. Interestingly, MCA has set out a two-stage test of capacity in order to assess the ability of the affected person in making decision. A person is identified as lack of capacity if they cannot:

- Understand information relevant to the decision to be made
- Retain that information in their mind
- Use or weigh up that information, or
- Communicate their decision.

In this case, another person is entitled to make decision for them in her/his best interest. This person is usually authorized by Court of Protection and is called ‘Court Appointed Deputies’ (CADs). In a situation when a person who lacks of capacity does not have anyone to act on their behalf, the role can be accomplished by Independent Mental Capacity Advocates (IMCAs) who must be independent and would not involved in the provision of routine dental care. However, they should be instructed and consulted, in decision making for people who lack of this capacity.

Act 615 (Mental Health Act 2001) Malaysia defines mental disorder as any mental illness, arrested on incomplete development of the mind, psychiatric disorder or any other disorder or disability of the mind. Under Part XII (General), No 77, paragraph 1, a person with mental disorder who requires surgery, electroconvulsive therapy or clinical trial, consent may be given 49:

a) By the patient himself if he is capable of giving consent as assessed by a psychiatrist;

b) By his guardian in the case of a minor or a relative in the case of adult, if the patient is incapable of giving consent;
c) By two psychiatrists, one of whom shall be the attending psychiatrist, if there is no guardian or relative of the patient available or traceable and the patient himself is incapable of giving consent.

This Act identifies guardian in relation to a minor as ‘parent or the parents of a minor, or a person lawfully appointed by will or by an order of a competent Court to be the guardian of the minor, or a person who has lawful custody to the minor’. Relative is interpreted as any of the following person of or above the age of eighteen;

a) Husband or wife;  
d) Brother and sister;  
g) Maternal or paternal uncle or aunt;

b) Son or daughter;  
e) Grandparent;

c) Father or mother;  
f) Grandchild

h) Nephew or niece.

As in any other acts involving informed consent for people of mentally disorder, their capability of giving consent must initially be determined by the examining psychiatrist. They are considered as lacks of capacity if they cannot understand:

a) The condition for which treatment to be proposed;

b) The nature and purpose of treatment;

c) The risks involved in undergoing the treatment;

d) The risks involved in not undergoing the treatment; and

e) Whether or not his ability to consent is affected by his condition.

In dealing with patients with special needs, dental health professionals should be aware that, there are a lot of hidden issues associated with legal and ethical matters. They must be familiar with the local law and regulation related to patient with special needs at the locality where they are practising. Taking consent may not be as simple as it is with other patients. As mentioned earlier, many parties may be involved in the management of the patients. Therefore, there are a lot of matters relevant to the particular organizations that may not be familiar to dental practitioners. Advice can be obtained from senior dentists or other health experts who frequently deal with these issues if unsure about the management. The dentist’s clinical judgement and expert opinion may influence the patient or care giver in making decisions and then giving consent, whether or not the proposed treatment is to be carried out. In summary, issues associated with legal and ethics matters need to be acknowledged and resolved before the need of the service is required.
1.2.10 Implications for Future Research

Little is known about oral health of people with special needs in Malaysia as well as in other countries in the world. This study is looking at the needs to develop special needs dentistry in Malaysia by covering some of relevant topics such as the patient’s and care giver’s perceptions of the currently available dental service in term of dental health promotion and education, financial and political support to the service, accessibility and barriers to oral health care. Some recommendations will be made ultimately concerning the practice of SND in Malaysia.

Similarly, information in oral health status, needs and provision of care in New Zealand is of small quantity and poor quality. The Oral Health for All, for Life repeatedly refers to the need for information, research, study and development of team approaches in this area of health care deficiency. Anecdotal comments from many different health professional groups suggest that individuals with special needs are marginalized and ignored by mainstream care providers, resulting in an ongoing decline in their oral health.

In response to the priorities outlined by Ministry of Health New Zealand (Oral Health for All for Life), there is a need to match the National Adult Oral Health Study in New Zealand in press, by carrying out an equivalent focussed survey on the oral health status for special needs individuals.

The practising of SND may be unique for every country according to the needs. In some countries, SND is delivered by Community or Dental Public Health while in other countries; it is served under private dental practice. In Malaysia, it is more likely that this responsibility will be taken by Community Dental Health rather than private practitioners. The private practices do not often have access to hospital service to manage patient requires general anaesthesia. Even though there are no national data on the use of private practices and Community Dental Service by people with special needs, it is expected that, few private dentists will have interest in the provision of treatment for special needs patient due to lack of training either in clinical predoctoral training or postdoctoral continuous professional education. Apart from this, the
restricted facilities available may limit the service that can be provided by the private practitioners. Frequently, difficult patients are referred to community hospitals to be managed by specialists working in hospital facilities. Whether or not, SND should be included in formalised undergraduate dental course training may depend on the current oral health needs and demands in Malaysia which warrant special attention in the future.

Additionally, in general, oral health promotion for SND is a challenge to oral health care providers. Despite the low level of oral epidemiological and clinical research outcomes available, recent observation by the clinicians and the researchers indicate that ever-increasing numbers of dentate SND patients.38 In other words, more patients with special needs will retain their natural dentition. As a result, more complex dental treatment will be required but planning needs to acknowledge the realities of maintenance of oral hygiene and disease susceptibility. This is a situation when they need to be properly educated in carrying out daily routine of oral care.

Although, an abundant amount of work has been put forward to promote oral health to this group of people through variety of strategies of oral health promotion and education, there is not sufficient evidence on the long term effectiveness of these substantial efforts. In this millennium, oral health promotion for SND should be diverted from the traditional method which focusing more on dental status to the evaluation of their general health and life characteristics to improve the quality of life.38 The Ottawa Charter of health promotion should be closely followed with the involvement of multi-disciplinary agencies.38 A comprehensive oral health promotion and education approach will help improving SND service delivery.

With the recognition and development of SND in Malaysia in the near future, based on New Zealand experience, the pioneer specialist group in this field must be proactive in the invention of SND programmes covering various important aspects of ‘Professions Complementary in Dentistry (PCD)’ such as service delivery, oral health promotion and education, training of auxiliary dental staff and new dental graduates and preparation of an improved career pathway in SND. The domiciliary service or home visit which is
currently unavailable should take place in the community, particularly for patients with special needs living in remote areas. In addition, there must be an active programme of epidemiology to audit and advance the oral health improvement in SND individuals as the specialty develops. Finally, it is now in the MOH Malaysia's hands to make further recommendations to achieve the oral health vision involving individuals with special needs and thus attracting more dental practitioners to be involved as leaders in this challenging, nonetheless rewarding field.
1.3 RATIONALE

1.3.1 AIMS

1.3.1.1 General Objectives
The main objective of this research project is to establish a future planning of the oral health care of people with special needs in Malaysia through the development of a special needs dentistry service by considering the current perspective of the Malaysian population who are closely involved in the dental care for people with special needs. The development of the same specialty in New Zealand, and other commonwealth countries like Australia, Canada and United Kingdom will be taken into consideration as a baseline to achieve this mission.

1.3.1.2 Specific Objectives

• To explore the perspective of people with special needs, caregivers, organizations which involved in the welfare of people with special needs and oral health professionals in various aspects about the development of Special Needs Dentistry service in Malaysia
• To identify barriers experienced by people with special needs and caregivers in accessing oral health care facilities
• To examine the adequacy of knowledge and exposure received by general dental practitioner in managing people with special needs
• To specify those special needs individuals who need referral to a Special Needs Dentist
• To review the necessity of developing a domiciliary service for people with special needs
• To review the preparedness of the Ministry of Health Malaysia in the development of a Special Needs Dentistry service

1.3.2 HYPOTHESIS
This is an explanatory study and a situational analysis and therefore, specific hypotheses are not required.
2 CHAPTER TWO

2.1 METHODOLOGY

A mixed-methods design has been used in this project which involves collecting, analyzing and interpreting quantitative and qualitative data in a single study.\(^5\) It is the latest research paradigm in educational research. The study utilized the sequential and concurrent partially mixed-method approach in which a qualitative method is used at the initial stage and followed by a mixture of qualitative and quantitative methods in the second phase. The qualitative data were obtained in the form of semi-structured interviews and the results were used to develop the second quantitative method at which survey questionnaires were formulated, and the data were collected through cross sectional survey.

In order to achieve the objectives of this study, it is crucial to explore the view of the population about SND as it is a new specialty in dentistry which is not yet well known in the community, including oral health professionals. Therefore, it is reasonable to initiate the project by seeking their opinion in the form of open ended questions in a semi structured interview to discover the dominant issues in SND field which concern the community and dental personnel. The identification of the dominant themes has assisted the researcher to develop valid and appropriate survey questionnaires focusing on each target group within the range of inquiry to answer the research questions. As outlined by Greene et al (1989), there are five most important rationales or purposes for mixed research which are illustrated in the following table (Table 2.1).\(^5\) For this particular study, the mixed-methods was adopted to increase the study’s validity and interpretability which described by Greene et al as ‘complementarity’. ‘Development’ was another reason for using this method in order to strengthen the validity of the study.

2.1.1 Qualitative Part

2.1.1.1 Selection of participants

The selection of participants for this study was dictated by the involvement of variety of organizations and groups of people in the management of oral health care of people
with special needs as reviewed by many previous studies. Non-probability/convenience purposive sampling was used in the selection of the participants. This method of sampling was utilized as a result of factors such as the availability of the participants and the restriction placed on the researcher in which the manager of an organization chose the participants rather than giving the freedom for the researcher to do so. They were divided into five groups and were selected from identified populations in New Zealand and Malaysia. The rationale of having the interview with the New Zealand’s participants is to test the method of interview and to gain some experience in a supervised environment prior to conducting the similar interview in Malaysia. In addition, it is to enable a comparison of perception on SND between Malaysian and New Zealand’s population. The five major groups of participants were people with special needs, caregivers, representatives from disability support groups, general dental practitioners and policy makers.

Table 2.1: Greene, Caracelli and Graham’s List of Purposes for Mixed Research

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Triangulation</td>
<td>Seeks convergence, corroboration, correspondence of results from different methods</td>
</tr>
<tr>
<td>Complementarity</td>
<td>Seeks elaboration, enhancement, illustration, clarification of the results from one method with the results from other methods</td>
</tr>
<tr>
<td>Development</td>
<td>Seeks to use the results from one method to help develop or inform the other method where development is broadly construed to include sampling and implementation, as well as measurement decisions</td>
</tr>
<tr>
<td>Initiation</td>
<td>Seeks the discovery of paradox and contradiction, new perspective of framework, the recasting of questions or results from one method with questions or results from the other method</td>
</tr>
<tr>
<td>Expansion</td>
<td>Seeks to extend the breadth and range of inquiry by using different methods for different inquiry components</td>
</tr>
</tbody>
</table>

* Sampling Methods. A lecture by Sadiq MA from School of Dental Science, Malaysia University of Science. Given in 2009
From 1 March to 10 May 2009, the interviews were conducted with New Zealand participants. There 21 participants who agreed to be interviewed out of 25 who had been approached. Four did not respond to the invitation letter for unknown reasons. Unfortunately, all of them were from the group of policy makers which left only one eligible person. The invitation letter with attached information sheet and consent form were posted or given personally during appointments. Table 2.2 summarizes the number of participants from each group.

Table 2.2: Number of participants in New Zealand according to each target group

<table>
<thead>
<tr>
<th>Group</th>
<th>No. Of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with Disability</td>
<td>5</td>
</tr>
<tr>
<td>Caregiver</td>
<td>5</td>
</tr>
<tr>
<td>Policy Maker</td>
<td>1</td>
</tr>
<tr>
<td>General Dental Practitioner</td>
<td>5</td>
</tr>
<tr>
<td>Support Group representative</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
</tr>
</tbody>
</table>

The interviews with the Malaysian participants were conducted beginning 15 May 2009 to 17 July 2009. There were 34 participants who agreed to be interviewed. Three regions in Malaysia had been chosen due to active involvement of certain group of dental practitioners in these states in managing oral health care of people with special needs under supervision of paediatric dental specialists or oral maxillofacial surgeons. Table 2.3 and Table 2.4 present the number of participants who had been interviewed in Malaysia.

Table 2.3: Number of participants in Malaysia according to state of the participant residency and target groups

<table>
<thead>
<tr>
<th>States Participants</th>
<th>Kuala Lumpur/ Selangor</th>
<th>Kedah</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with Disability</td>
<td>7</td>
<td>-</td>
<td>7</td>
</tr>
<tr>
<td>Caregiver</td>
<td>4</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Policy Maker</td>
<td>5</td>
<td>-</td>
<td>5</td>
</tr>
<tr>
<td>General Dental Practitioner</td>
<td>6</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td>Support Group Representative</td>
<td>4</td>
<td>-</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>26</td>
<td>8</td>
<td>34</td>
</tr>
</tbody>
</table>
Table 2.4: Number of dentists in Malaysia who are grouped according to their work base, hospital dental clinic and community dental clinic at health centre

<table>
<thead>
<tr>
<th>DENTIST</th>
<th>Kuala Lumpur/Selangor</th>
<th>Kedah</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital dental clinic</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Community dental clinic at health centre</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>6</strong></td>
<td><strong>5</strong></td>
<td><strong>11</strong></td>
</tr>
</tbody>
</table>

The final sample in the qualitative part of this study was 55 subjects in which twelve represent people with disabilities, twelve from the group of caregivers, six were policy makers, sixteen were general dental practitioners and nine were from several disability support groups. Table 2.5 represents the total number of participants in New Zealand and in Malaysia according to different target groups. Following this, the criteria of the selected participants were clarified to ensure the validity of the information obtained.

Table 2.5: Number of interview participants in Malaysia and New Zealand.

<table>
<thead>
<tr>
<th>Participants</th>
<th>New Zealand</th>
<th>Malaysia</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with Disability</td>
<td>5</td>
<td>7</td>
<td>12</td>
</tr>
<tr>
<td>Caregiver</td>
<td>5</td>
<td>7</td>
<td>12</td>
</tr>
<tr>
<td>Policy Maker</td>
<td>1</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>General Dental Practitioner</td>
<td>5</td>
<td>11</td>
<td>16</td>
</tr>
<tr>
<td>Support Group Representative</td>
<td>5</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>21</strong></td>
<td><strong>34</strong></td>
<td><strong>55</strong></td>
</tr>
</tbody>
</table>

2.1.1.1.1 People with Special Needs

People with disabilities who participated in this study were those who were over 18 years old and competent to give consent. They must also be able to provide a meaningful communication. In New Zealand, patients who fitted the eligibility criteria were approached during their regular dental check at the Special Care Unit, School of Dentistry, University of Otago, and were contacted again after two weeks to confirm
their participation. After they made the decision, an appointment for the interview was arranged at a place and time which suited them. Patients in Malaysia were approached by the researcher's counterpart who had chosen the eligible patients from their patient list at Oral and Maxillofacial Clinics in Kuala Lumpur General Hospital and Sultanah Bahiyah Hospital, Alor Star, Kedah. In Kedah, three patients were contacted earlier and were given appointment for the interview by a dental assistant who regularly dealt with them; unfortunately, they failed to attend the appointment and were unable to be contacted on that day. Due to time constraint and patients availability, no patients managed to participate in the study in Kedah. Three patients were later added and selected from a rehabilitative institution in Selangor to compensate the number of cancelled patients in Kedah.

Of these twelve, eight could understand and gave more complex information whereas the other four could only answer simple questions. Four participants were medically compromised patients with one or more physical impairments resulting from their medical conditions. The other four had some psychological problems (extreme anxiety or psychiatric problems) but were stable at the time of the interview. Three of them had mild intellectual disability related to certain disorders like Down syndrome and autism. Another participant had physical disability due to trauma without any significant medical conditions. All of them were accompanied by a caregiver or a family member during the interview.

2.1.1.1.2 Caregivers

This particular group of participants was those who were responsible in providing personal care for people with special needs and who had been looking after the clients for more than three months. They could either be a social worker, health care professional, care assistant or relative/family member. In Malaysia, all caregivers were close relatives of the individuals with special needs. Conversely, the caregivers in New Zealand who had been interviewed were social workers or the immediate family members such as mother or spouse. Twelve caregivers had agreed to participate and provided the information required at their level, based on their social background,
education and attitude. Each one was approached at the clinic while accompanying the patients for dental treatment.

2.1.1.1.3 Oral Health Professionals
The oral health professionals in New Zealand who were involved in this study were general dental practitioners working at private dental clinics and those who worked with Hospital Dentistry. They were purposely selected due to their previous involvement in treating people with special needs. Two of them were working at private dental clinics in Dunedin and the other three were based at a hospital dental clinic.

In Malaysia, the participants were dental officers working at government clinics (hospital dental clinics and dental clinics at the health centre) in Kuala Lumpur/Selangor and Kedah as summarized in Table 2.4. All of them had at least one year working experience in treating various types of patients. However, their responsibilities and work load had limited their availability for interview.

2.1.1.1.4 Policy Makers
Five administrative dental professionals who were involved directly in various fields in the development of Special Needs Dentistry service in Malaysia had extensively assisted this study in looking at the future planning of this specialty. This committee was responsible for the training of the dental auxiliary staff, the specialist training, the development of the facilities, policies, guidelines and the management of any ethical issues involving people with special needs as well as the career pathway of the specialist in this field. On the other hand, only one participant who fell in the group of policy makers in New Zealand responded to the researcher’s request out of five who were initially approached via email.

2.1.1.1.5 Disability Support Groups Staff
There were three disability support groups in Dunedin who agreed to participate upon receiving the invitation letter and the information sheet. The manager of each institution was contacted and he/she suggested the staff who volunteered to participate according to the eligibility criteria (have worked for at least one year and dealt directly with people with special needs). Even though there were more than five people who wanted to
participate, they were more comfortable to be interviewed in a group rather than individually. Thus, it was decided to consider the group interview as one interview or participant. Three interviews were conducted with the staff from the Patients and Community Trust (PACT) group, one with Otago Community Support Service and one representative from IHC/IDEA service. Intellectual Disability Empowerment in Action (IDEA) is an arm of Intellectual Handicapped Children (IHC) organization. These support groups provide care in a range of settings including houses with staffing, day programmes and centres, community support in people’s own homes, family/whanau services as well as help into employment.

There were only two disability support groups who were willing to participate in this study in Malaysia. Three other groups had been contacted but there was no response given during follow up. Due to time constraints, there were only four staff who managed to attend the interview session. Three were the trainers from a private rehabilitative institution which provides vocational training and basic academic education for people with special needs. Another participant was a manager at the government Community Rehabilitative Centre in Putrajaya involved in basic training to carry out personal care and activities of daily living for people with variety of disabilities.

2.1.1.2 The interview

The interviews were conducted at a time and locations of convenience for participants. The nature of the research project and the interview were clarified with the participants prior to the interview, apart from the provision of the information sheet describing the brief details of the study. A consent form was signed by each participant before the interview was carried out.

The interviews with the New Zealand participants were completed over two months and the next two and half months were spent in Malaysia to complete the interviews with the Malaysian participants. The key topics covered in the semi-structured interviews are outlined in the following table (Table 2.6) according to the different target groups. An interview guide was prepared containing a list of questions to initiate the communication. The details of the questions are shown in Appendix 1 and
Appendix 2. Since the interviews were flexible, the interviewees had a great deal of freedom to reply. Other areas were pursued as necessary by the interviewers as the dialogues progressed. A completion of one interview was then used to aid the development of the theoretical framework and refinement of the subsequent interviews.

Table 2.6: The key topics covered in the semi structured interview

<table>
<thead>
<tr>
<th>PARTICIPANTS</th>
<th>KEY TOPICS</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with disabilities</td>
<td>Oral hygiene practices</td>
</tr>
<tr>
<td></td>
<td>Perception of needs for SND service, oral hygiene attitude and knowledge</td>
</tr>
<tr>
<td>Caregiver</td>
<td>Oral hygiene practices for the client</td>
</tr>
<tr>
<td></td>
<td>Knowledge and opinion about the existing dental service for people with special needs/ disabilities</td>
</tr>
<tr>
<td>Policy maker</td>
<td>The definition of people with special needs in their own perspective</td>
</tr>
<tr>
<td></td>
<td>Needs and demands for SND service</td>
</tr>
<tr>
<td></td>
<td>Support provided by government in the development of SND</td>
</tr>
<tr>
<td></td>
<td>Future planning for SND in Malaysia and New Zealand</td>
</tr>
<tr>
<td></td>
<td>Barriers to oral health care for people with special needs</td>
</tr>
<tr>
<td>Oral health professionals</td>
<td>Knowledge and education in managing people with special needs</td>
</tr>
<tr>
<td></td>
<td>Demands for SND service</td>
</tr>
<tr>
<td></td>
<td>Opinion about the development of SND service</td>
</tr>
<tr>
<td>Disability support group</td>
<td>Their roles in managing people with special needs and their involvement in oral health care for people with special needs</td>
</tr>
<tr>
<td>representative</td>
<td>Opinion about the existing dental service for people with special needs</td>
</tr>
</tbody>
</table>

A digital audiotape (Olympus VN-3100PC-digital voice recorder) was used to record the interviews which were then emailed to Office Magic Ltd, Napier for transcription.
However, eighteen interviews which were done with Malaysian participants had to be translated into English before it could be transcribed because Bahasa Malaysia was used during the interview. They were more comfortable to answer questions in Bahasa, as English is not their first language. The translation was done in the form of transcripts by an official translator in Malaysia. As a result, there were 37 interviews sent for transcription. Eventually, 55 transcripts were produced for analysis.

2.1.1.3 Analysis of the qualitative data

General inductive approach or specifically, grounded theory was adopted in analyzing the interview transcripts for this study. It represents a systematic procedure in analysing qualitative data where the analysis is guided by the research specific objectives. The grounded theory as described by Strauss operates "almost in a reverse fashion from traditional research which begins with data collection, through a variety of methods. From the data collected, the key points are marked with a series of codes, which are extracted from the text. The codes are grouped into similar concepts in order to make them more workable. From these concepts, categories are formed, which are the basis for the creation of a theory, or a reverse engineered hypotheses. This contradicts the traditional model of research, where the researcher chooses a theoretical framework, and only then applies this model to the studied phenomenon."

In this project, the transcripts were read repeatedly to identify themes and categories as suggested by several studies in which this particular approach had been used. Firstly, the transcripts were compiled based on the different target group of participants before analyzing them separately. The transcripts were labelled with codes to protect the respondent's identity. The similar themes or analytical ideas were then coded/labelled accordingly to enable the researcher to retrieve and collect all the text or data associated with the thematic idea. Following this, the data were examined together and different cases were compared in that respect in the form of written memos. The memos which were built up provided an insight in developing the subsequent memos and also incorporated new ideas into the data. Then, the similar codes were grouped into categories. The general coding process is illustrated in Table 2.7 as shown below and the matrix of the data analysis is presented in Figure 2.1.
Eventually, core categories from each group of transcripts were identified following the analysis as presented in Table 2.8, and under these all of the data were accounted for.

**Table 2.7: The coding process**

<table>
<thead>
<tr>
<th>Initial read through text data</th>
<th>Identify specific segments of information</th>
<th>Label the segments of information to create categories</th>
<th>Reduce overlap and redundancy among the categories</th>
<th>Create a model incorporating most important categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Many pages of text</td>
<td>Many segments of text</td>
<td>30-40 categories</td>
<td>15-20 categories</td>
<td>2-8 categories</td>
</tr>
</tbody>
</table>

Adapted from Creswell (2002)\(^{58}\)
Reading and studying the interview transcripts

Create a database

Coding line by line

Comparing codes

Developing categories

Writing memos (capture ideas about categories)

Comparing memos

Building analytical framework

Conducting further interviews

Drawing diagrams that link theoretical categories

**Figure 2.1**: Matrix of the data analysis process

Adopted from Coyne and Cowley (2006)
Table 2.8: Core categories derived from the qualitative analysis

<table>
<thead>
<tr>
<th>PARTICIPANTS</th>
<th>CORE CATEGORIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with disabilities</td>
<td>Knowledge and attitude about oral health care</td>
</tr>
<tr>
<td></td>
<td>Access to dental information and education</td>
</tr>
<tr>
<td></td>
<td>Access to oral health care</td>
</tr>
<tr>
<td>Caregiver</td>
<td>Knowledge and attitude about oral health care for people with special needs</td>
</tr>
<tr>
<td></td>
<td>Access to dental information and education</td>
</tr>
<tr>
<td></td>
<td>Access to oral health care for people with special needs</td>
</tr>
<tr>
<td>Policy maker</td>
<td>The definition of people with special needs in their own perspective</td>
</tr>
<tr>
<td></td>
<td>Support provided by the government for the development of SND</td>
</tr>
<tr>
<td></td>
<td>Future planning for SND in Malaysia and New Zealand</td>
</tr>
<tr>
<td>Oral health professionals</td>
<td>The definition of people with special needs in their own perspective</td>
</tr>
<tr>
<td></td>
<td>Criteria of patients with special needs which require warrant referral to specialist in SND</td>
</tr>
<tr>
<td></td>
<td>Knowledge and education in managing people with special needs</td>
</tr>
<tr>
<td>Disability support group</td>
<td>Their roles in advocating people with special needs and their involvement in oral health care for people with special needs</td>
</tr>
<tr>
<td>representative</td>
<td>Knowledge and attitude about oral health care for people with special needs</td>
</tr>
<tr>
<td></td>
<td>Perspective about SND service in Malaysia and New Zealand</td>
</tr>
</tbody>
</table>

2.1.2 Quantitative Part

This is the major part of the study which was carried out in the form of cross sectional survey. The survey questions for each group of participants were formulated upon completion of the qualitative analysis. The themes derived from the analysis were
closely followed in the development of the survey questions to determine quantitatively the existence of correlation among the categories within the target population.

2.1.2.1 Selection of Participants

All participants for the quantitative part of this study were from the Malaysian population because the project was looking at the development of SND service in Malaysia. A total of 345 participants were approached. The inclusion criteria of the participants in this quantitative part were identical to that in the qualitative part.

2.1.2.1.1 People with Special Needs and Caregivers

Eighty people with special needs who were registered with the Malaysian Association of Orthopaedically Handicapped People (POCAM) were asked to participate. They were selected by the manager based on the eligibility criteria outlined in the information sheet. Since there was no registry or record available for caregivers of these patients, a survey questionnaire for a caregiver was also posted together with the survey questionnaire for these people of special needs, assuming that they were looked after by their family members or social workers.

2.1.2.1.2 Oral Health Professionals

The registry of government dental officers from grade U41 and U44 was obtained from the Oral Health Division headquarter. To our knowledge, this group of officers performed more clinical work than those above these two grades. In other words, they were the ones who most often involved in the clinical management of patients. All of them were general dental practitioners registered with the Malaysian Dental Council and did not have any postgraduate qualification. From the list, they were divided into two groups. The first group was those who were working at the community-based dental clinic (not at the hospital environment) of which 73 of them were selected. The second group comprised the dentists who were attached to hospital-based dental clinics consisted of 50 selected participants.
2.1.2.1.3 Policy makers

Dental administrators who were based at the Oral Health Division, Ministry of Health Malaysia headquarter had been approached regardless of their specific portfolio. They were selected because of their roles in policy development and implementation for community dental health programme. The survey form, the information sheet and the consent form were emailed to all of the officers in the division which gave the total number of 30 participants.

2.1.2.1.4 Disability Support group representatives

Disability support groups were chosen from the government and private organizations. Two private organizations were selected based on their active involvement in the provision of social support for people with special needs. They were based in almost every state in Malaysia. Therefore, the manager from each state which consisted of eight from one group and three from the other group were given the survey questionnaire to be completed. Twenty one managers from the community rehabilitation centres and residential centres for people with special needs under the management of Social Welfare Department, Malaysia were selected to participate in this study. Therefore, the total number of samples in this group was 32.

2.1.2.2 Questionnaire development

The dominant themes identified from the qualitative data were utilized to develop the survey questionnaire. Five sets of survey questionnaires were formulated for each group of participants, each contained several sections as shown in Table 2.9. Survey questionnaire from previous studies were also collected to match with certain parts in the questionnaire. Both ‘open’ and ‘closed’ questions were included to examine area of interests. All of the survey forms had to be translated to Bahasa Melayu which was the main language for Malaysian people for ethical approval and administration purposes. Each participant was sent the survey form in both languages, but they were free to complete the survey form in any languages they preferred. The copies of the survey questionnaire for each group were appended (Appendix 3, Appendix 4, Appendix 5, Appendix 6, Appendix 7).
### Table 2.9: Questionnaire development

<table>
<thead>
<tr>
<th>Participants</th>
<th>Section</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with Special Needs</td>
<td>Sociodemographic</td>
<td>Qualitative data</td>
</tr>
<tr>
<td></td>
<td>Oral hygiene practice</td>
<td>Qualitative data, Allison et al, 2004(^{63})</td>
</tr>
<tr>
<td></td>
<td>Perception for needs of Special Needs Dentistry Service, oral hygiene attitude and knowledge</td>
<td>Qualitative data, Reznick et al, 2002(^{43})</td>
</tr>
<tr>
<td></td>
<td>• Dental information and education</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Opinion about the existing dental service</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Barriers to access dental care</td>
<td></td>
</tr>
<tr>
<td>Caregivers</td>
<td>Sociodemographic</td>
<td>Qualitative data</td>
</tr>
<tr>
<td></td>
<td>Oral hygiene practice for the client</td>
<td>Qualitative data, Johnson H et al, 2008(^{61})</td>
</tr>
<tr>
<td></td>
<td>Knowledge and opinion about the existing dental service for people with special needs/ access</td>
<td>Qualitative data, Reznick et al, 2002(^{43})</td>
</tr>
<tr>
<td>Oral health professionals</td>
<td>Sociodemographic</td>
<td>Qualitative data</td>
</tr>
<tr>
<td></td>
<td>Perception about Special Needs Dentistry</td>
<td>Qualitative data, Schwenk et al, 2007(^{62}), Reznick et al, 2002(^{43})</td>
</tr>
<tr>
<td></td>
<td>• Definition of patients with special needs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Demand for SND service</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Criteria for referral</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Common dental problems</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Exposure and knowledge about SND</td>
<td></td>
</tr>
</tbody>
</table>
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis
(Based on New Zealand Experience)

Policy Makers

- Opinion about the development of SND service in Malaysia

Sociodemographic

Perceptions about SND

- Definitions of patients with special needs
- Needs and demands for SND service
- Support provided by the government in the development of SND
- Future planning for SND service
- Barriers to oral health care

Qualitative data

Qualitative data, Arnold et al, 2000

Disability Support Group Representative

Sociodemographic

Perceptions about Special Needs Dentistry Service

- Support provided
- Involvement in oral health care for people with special needs
- Opinion about the existing dental service for people with special needs

Qualitative data

Qualitative data

2.1.2.3 Questionnaire administration

Three hundred and forty five survey questionnaires were posted to the identified participants, each accompanied by an information sheet explaining the purpose of the study and a consent form. A prepaid envelope was included to return the completed form and the consent form to an appointed collection centre at the Oral Health
Division, Ministry of Health Malaysia. The collected completed survey forms were posted in bulk to New Zealand. For those whose email addresses were accessible, the survey forms were also emailed to encourage participations. A second wave of forms accompanied by a cover letter was sent to subjects who had not responded after eight weeks of the first wave of the administration process.

2.1.2.4 Data analyses

The responses were entered into an electronic database (MS-Excel) for analysis. Then, the data were analyzed using the Statistical Package for the Social Sciences (PASW/SPSS, version 18). The Chi-square test applied to examine the association, if any, among the variables.
2.2 Ethical Approval, Maori Consultation and Project Funding

This project was identified as Category A by the University of Otago Research Ethics Committee because of the involvement of vulnerable group of the population. Therefore, the application was submitted to Lower Southland Research Ethics Committee and was approved by the committee. The Ngai Tahu Research Consultation Committee endorsed the proposed project acknowledging that some potential participants could be identified as Maori. The Committee recommended that, the findings of this study be disseminated to relevant Maori Health Organizations, for instance the Ngai Tahu Health Research Unit and Te Ao Marama, the New Zealand Maori Dental Association.

Due to the nature of this project, the proposal had to go through several committees in Malaysia. Approval from Economic Planning Unit, Minister's Department Malaysia was obtained prior conducting the study in Malaysia. An approval was also endorsed by the research committee from Institute of Public Health, Malaysia. As required, this project was registered with the National Malaysian Medical Research Registry (NMRR), through which all the relevant Ministry of Health Committees were approached for approval.

The research was supported by a Fuller Scholarship, University of Otago, and the Oral Health Division, Ministry of Health Malaysia allowed the investigator to utilize their facilities and equipment during three months stay in Malaysia for data collection for the qualitative study.
3 CHAPTER THREE

RESULTS

3.1 The qualitative study

The analysis of the qualitative study data resulted in the emergence of categories based on different group of participants. The subcategories for each category were further clarified under the headings of the target groups involved in this project.

3.1.1 People with special needs

Participants who fell in this category were asked simple and straightforward questions though the questions needed to be rephrased at times, to facilitate their understanding. Occasionally, the participants did not want to answer the questions for unknown reasons. The interviews with people with special needs derived two important categories and seven associated subcategories as summarized in Figure 3.1. The theme was recognized as perceptions of people with special needs about oral health care and the development of SND service.

3.1.1.1 Oral hygiene practices of people with special needs

3.1.1.1.1 Difficulty in cleaning teeth

All people with special needs who were interviewed had mentioned that they had some sort of difficulty in cleaning their mouth. Brushing of the posterior teeth and certain sites gave particular problems as did local factors such as too many gaps in between the teeth due to periodontal problems.

Examples of the responses:

‘...whatever I eat, it gets stucked there. So I cannot clean the teeth....’ (PM2)

‘...I just cannot keep it clean. It’s not that I don’t want to keep it clean...I do all my best to keep it clean...’(PM2)
'Too many gaps and my mouth has been knocked about' (PNZ1)

'Because I have difficulty in opening my mouth, Like I said before, I cannot reach certain teeth to clean..' (PM3)

The respondents thought that their medical conditions, age and physical disabilities had limited their ability to perform satisfactory oral hygiene. Consequently, they felt that their mouth was not healthy and required further attention from oral health professionals.

Examples of responses:

'My age is 71. I can’t see my teeth very clean. Because I have extracted almost all upper teeth except for one molar tooth. Quite a number of teeth are rotten. So, I need attention you know.' (PM1)

'My teeth now actually, I feel nowadays, that’s not safe. It's not in a good condition. I don’t know the reason. Maybe, because of my age. I’m already 68+, going to 69...' (PM2)

Figure 3.1: Categories and subcategories resulting from 12 interviews with people with special needs in Malaysia and New Zealand
3.1.1.1.2 Devices used in oral health care

The informants reported mainly using the manual toothbrush except two of them who claimed to be using an electric toothbrush. Only one had used it effectively, while another participant just used it when he wanted to. The use of toothpaste was found to be a normal practice by the participants, with all of them mentioning that toothpaste was an important aid to clean the teeth. There was a variety of toothpaste brands used by the participants without any particular preference for certain brands.

Another oral hygiene aid which had gained popularity among people with special needs was mouthwash. However, the use of mouthwash was only because of a dentist’s recommendation due to some oral tissue problems or it had been suggested by relatives or friends. Only one informant reported using dental floss regularly and another participant reported using an interdental toothbrush when required. It appeared that, aids to oral hygiene care other than toothbrush and toothpaste among people with special needs in this part of study were only utilized as curative measures following strong recommendations from the dentist.

3.1.1.1.3 Assistance in oral health care

Tooth cleaning was mostly performed by the participants without assistance by others unless when they were severely ill or lacked of manual dexterity due to their physical impairments. Assistance was obtained from the caregivers in the form of getting access to the dental care facilities rather than for personal oral care.

Advice and recommendations made by the dentists were considered paramount for them to maintain good oral hygiene. Additionally, for elderly patients, support from children and spouse had motivated them to improve good oral hygiene care.

Examples of responses:

‘......My children have bought it for me (an expensive toothpaste) especially for me to use...’ (PM2)
‘...now after consulting with Dr Salina, I feel more comfortable. She always advises me how to take care of my teeth and then a proper check up. I’m doing it here only...’ (PM2)

3.1.1.4 Dental visit

Regular dental visits were normally initiated by the service provider and not from the participants’ request. All patients were fortunate because they were already on the list of recall patients or patients who had been categorized as eligible to receive regular appointments at the oral health centre where the treatment had been normally delivered for them.

Examples of responses:

‘...they will call me for appointment.’ (PM2)

‘...he only came to dental school when his dentist recommended he go there to get teeth out....’ (PNZ3)

However, when they were asked about their dental visit before they were placed on the recall list, the visit was driven by one-off tooth/gum problems (toothache or bleeding gum). Certain patients were referred to a dentist by their general practitioner or medical specialist due to oral health problems which were associated with their current medical conditions.

Examples of responses:

‘...when I see dentist, it is usually attached to pain in my mouth’ (PNZ1)

‘My dental check up is practically when I have toothache or when I have to extract my tooth....(PM1)

‘.....but I think it was lichen planus....So, I have the same problem. So the doctor referred me.’ (PM2)
Generally, the participants agreed that a dental check-up should be done at least once or twice a year depending on the needs, to ensure the maintenance of good oral hygiene.

Example of response:

'It's once a year for a recall and then it depends if you've got work to be done' (PNZ4)

3.1.1.2 Perception of needs of SND service, oral hygiene attitude and knowledge

Perceptions of people with special needs about the SND service were grouped into three subcategories; (a) Dental information and education, (b) Opinion about the existing dental services, and (c) Barriers to access the dental care facilities.

3.1.1.2.1 Dental information and education

Information and education about dental health were considered to be important by the participants and were mostly obtained directly from their general dental practitioner. Apart from verbal explanation, reading brochures provided by the dental clinic was found to be useful and helpful. Self study, as mentioned by one of the participants who gained knowledge via reading the relevant information from books or magazines and asking questions of oral health professionals, friends or family members. Obtaining information from the internet was another source which was used by the participants. Nevertheless, the use of the internet was limited to younger and more educated patients. Additionally, electronic media such as television had helped in delivering information about dental health to people with special needs.

Examples of responses:

'Not from other sources. Only the doctor. Doctor only advised me' (PM2)

'..internet and advice from my doctor' (PM3)
Dental education (tooth brushing demonstration) given by the dental therapist during school days was the only form of dental education that had been received by certain participants. For those who used to live in disability/rehabilitative institutions, a dental education programme was organized by a few of the institutions. Observation of tooth brushing done by others was another useful means of education.

Examples of responses:

‘...Hume house, when I was at Hume house. It’s a hospital house..’ (PNZ4)

‘No, I just picked it on the way through watching the children and going to their dentist’ (PNZ5)

Attending seminars or courses about dental health was not a practice among the participants unless they were specially invited by any organization which holds such a programme.

3.1.1.2.2 Opinion about the existing dental services

Generally, all interviewees were pleased with the current dental treatment that they were receiving. All participants in Malaysia attended government dental clinics. Those who had experience of private dental clinics managed to compare the services between those two types of dental health centres. Most mentioned that the facilities at private dental clinics were much better than that in the government subsidized dental clinic in addressing patient’s comfort, especially in the waiting area. Nevertheless, there were comments related to money-driven services, whereby good services were delivered because the private dentists received higher monthly payment and they needed to maintain the pool of clients attending the clinics. It was suggested that, the government should focus on and allocate more financial support to develop medical/ dental facilities, especially for elderly and people with special needs.

Examples of responses:

‘Actually, I find, in the government dental clinic, the facilities are not as good as in the private. In private, they have air conditioner, the facilities are better, they are more
courteous and good attendant, they are well paid. So, when people are well paid, they develop a good service. And also, our government spends too much money on other things rather than to improve the medical facilities for patients.’ (PM1)

Those who had never been treated at private dental clinic felt that, the current dental service they were obtaining was good enough and commensurate with the low dental fee they were paying. Participants commented that the courtesy, passion and professionalism in delivering quality dental services among the dental officers at the government dental clinic had greatly improved since a decade earlier. The cost was low and reasonable, which was not a burden to patients, and it was even free of charge for pensioners and government servants.

Examples of responses:

‘.....the service is already good for me....I can always explain to doctor if I have questions. She asks me a lot of things too. I feel I’m more secured’ (PM2)

‘It’s okay, it is RM5 only.......If you go outside (private clinic), it will cost you more.....’ (PM2)

‘The officers are very kind and professional’ (PM3)

The view of the dental services received by the participants from New Zealand was not very much different from that received by Malaysian participants. All were generally happy with the existing dental service provided by the Dental School. The recall appointments organized by Special Care Unit at the Dental School had improved the frequency of their dental visit, which otherwise was initiated by pain. Some had reported unpleasant experiences at private dental clinics where they had been booked to complete the dental treatment with a particular dentist but the dentist had left with no message. For examples:

‘The service is much better than the hospital’s one’ (PNZ3)
'Because I was booked in to have all this done and the dentist just left without telling anybody. He went over to England' (PNZ1)

Almost all participants shared the same view that dental services for people with special needs should be provided by a dental specialist in the SND field because of their wealth of experience and professionalism in dealing with people with special needs. On the other hand, for some patients, there was no particular preference, even if they had to be seen by newly graduated general dental practitioners, as long as they were able to maintain the continuity of the treatment, were skilful, patient and could provide the information required. Interestingly, several interviewees specified the name of a particular dentist they preferred to see regardless of their specialty because of the development of good rapport between the patients and the dentist. Certain participants felt that undergraduate students were not capable of managing people with special needs due to their lack of experience and the longer clinical session that they had to attend in order for the students to gain approval from tutor before proceeding to the next stage of the treatment. Some patients with special needs would not be able to sit continuously for three hours or even one hour in the dental chair to complete the treatment as at times required by dentist in training.

Some recommendations such as giving more exposure to general dentists and developing creativity and innovation in managing people with special medical conditions, providing a special receptionist counter and comfortable waiting area for elderly and people with special needs were considered as outstanding views from the participants in this group, which, would improve the service in the near future.

An example of responses:

‘The dental officers must do what they should do and must be skilful and should have more exposure. Certain things they cannot do, so, they should be more creative. For example if the patient has limited mouth opening, what other measurement they can do. They should know how to treat patient with special conditions........They must be creative and innovative’ (PM3)
3.1.1.2.3 Barriers in accessing dental care facilities

The participants responded variably when they were asked about the difficulties they were having in accessing dental care facilities. For some, transportation was their major problem because the public transport, especially in Malaysia was not user-friendly to people with special needs. It was accompanied by poor attitude and social stigma faced by society. The general population tend to care less about the well-being of other people, including the vulnerable group of the population.

Examples of responses:

'.......The only thing is to come by public transport that is by train, easier. I came by bus quite a number of time. Rapid bus. Some bus drivers are reckless....Quite a number of time, I off balance because of the bus drivers.......they can cause an accident.... They don’t care there are so many children and people in the bus and the bus does not have enough seat....' (PM1)

'That’s the biggest problem. Actually, the civic minded of these Malaysians are not good. You should be taught as soon as you start schooling......Even that day, I saw this one pregnant woman with big stomach in front of this young fellow. He did not even get up and let the lady to sit down. Me, an old lady had to get up and asked her to sit down.......the younger people is lacking of civic minded’ (PM1)

Long waiting times at government dental clinics were found to be the major factor for not attending dental clinics. The longest waiting time reported by the participants was more than two hours, which was not very pleasant for people with special needs. There were other factors such as a long distance from home to the dental clinic providing the SND service; this was a barrier since they could not tolerate travelling for a long time. Anxiety about dental treatment reduced their motivation to attend for dental care. Apart from that, getting someone to accompany them to the clinic was not a simple issue, as it had to suit that person’s time and availability. Being accompanied by a family member or someone else might reduce their anxiety and help to develop the needed confidence especially when attending the first appointment.
An example of responses:

'The major barrier is actually having someone to come with me for the first time. Because it is really new and you don’t know what to expect when you get there, so yeah, quite nervous’ (PNZ5)

Surprisingly, none of the participants mentioned financial problems in getting access to dental treatment. When the issue was introduced to the interviewer, the comment was that the price they were paying for dental treatment was reasonable and somewhat cheaper than the services provided in a private dental clinic. It was also noted that the findings obtained from the participants with special needs from Malaysia and New Zealand did not differ significantly.

3.1.2 Caregivers

The analysis of the qualitative data from the interviews done with this group of participants resulted in the identification of two categories and six associated subcategories. The overall theme was recognized as the perception, knowledge and attitude of caregivers about oral health care of people with special needs. Figure 3.2 presents a summary of the analysis, which will be explained in detail later in this section. As emphasized earlier, the educational background of the caregivers might have contributed in their perception and might have influenced the results obtained from these interviews.

3.1.2.1 Oral hygiene practices for people with special needs under the care of caregivers

The oral hygiene status of people with special needs especially those who are partly or fully dependent may be associated with the ability and effort of the caregivers in supporting and providing an effective oral hygiene care for them. The results from the interviews with twelve caregivers suggested three factors which might determine the oral hygiene level of this vulnerable group of the population. These were: (a) difficulties faced in cleaning the client’s teeth; (b) daily oral hygiene care practice; (c) barriers in accessing dental health care facilities.
3.1.2.1.1 Difficulties faced in cleaning the client’s teeth

The difficulties faced by caregivers in performing tooth brushing for people with special needs was mostly related to the patient/client behaviour associated with their impairments or disabilities such as intellectual disabilities.

**Figure 3.2:** Categories and subcategories resulting from 12 interviews with caregivers in Malaysia and New Zealand

Examples of responses:

'......but it’s hard with her because she bites on the toothbrush' (CNZ2)

'She brushes her teeth herself but I need to always remind her. She also does not allow me to do it for her and ask me to leave her alone...She is sometimes quite stubborn and does not listen to us.' (CM1)

'Well, it was very difficult when we had farm accidents and you have resultant head injuries because that alters how a person behaves...' (CNZ1)
Some extra efforts were usually required to gain cooperation while brushing the teeth. At certain occasions, more than one operator was needed to perform the oral cleaning. Using a bite block to keep the mouth open was a technique used by some caregivers to carry out the mission; this was considered fairly effective for patients with cerebral palsy or motor disorders.

Examples of responses:

'....But with some people like Jenny (intellectual disabled/ epileptic), it's not as straightforward as saying well, open your mouth so I can get your toothbrush and we'll brush your teeth, we have to do more than that' (CNZ3)

'....if he could not cooperate with tooth brushing, we would place something at one side of his mouth for him and brush the opposite side and vice versa...' (CM2)

Placing the patient in the correct position was also a problem for the caregivers, due to their physical impairments. Both the operator’s and client’s position should be taken into account in order to ease the procedure of cleaning the mouth. Unfortunately, all caregivers did not receive special training or advice in performing oral care for people with special needs, and the job was done through personal experience, observation and common sense.

An example of responses:

'....I sit her down between my knees in the evening and clean her teeth from behind and then I can floss them.....' (CNZ4)

3.1.2.1.2 Daily oral hygiene care practice

Basic tooth brushing techniques (up and down/back and forward) and aids (toothbrush and toothpaste) were normally used by the caregivers. Depending on the client’s condition, special toothbrushes were recommended by the oral health professional, such as for those with a lack of manual dexterity or with severe medical conditions which affected the periodontal health, for example; in the case of cancer patients. Electric/mechanical toothbrushes had gained in popularity among patients
with special needs, as it helped the caregivers to brush their teeth more effectively. The caregivers found that, the mechanical toothbrush had improved the oral health of their clients and facilitated the process of cleaning.

An example of responses:

'The same as you do your own, back and forward or flicking it up, getting as much as you can' (CNZ3)

A soft toothbrush was used by majority of the caregivers, for those with compromised periodontal health and for the patient’s comfort. Fluoridated toothpaste was a preference of the caregivers as advised by the client’s dentist, with no particular favour for any specific brand name. The use of mouthwash as a supplementary cleaning aid was mainly initiated by oral health professionals due to the dental problems that the patients were having. However, the informants could not specify the type of mouthwash they were using.

Examples of responses:

'...We don’t use any other devices for her except mouthwash given by the doctor during our last visit' (CM3)

'I just use normal toothbrush but the extra soft one because he doesn’t like hard one.....' (CM6)

Dental floss was claimed to be used by only one participant for her clients while the others were not very keen to put their fingers inside the client’s mouth for flossing. Surprisingly, 50.0% of the participants had not even heard about dental floss prior to this interview. This is quoted from the statements below:

'......then I can floss them and we use the whizzy toothbrush and do that every night now.' (CNZ4)

'No, I don’t floss her teeth. I wouldn’t be that keen to put my fingers in' (CNZ3)
The frequency of daily tooth brushing was also asked to the caregivers. Two or three times per day was the frequency usually reported by the participants, which was done in the morning and at night before bedtime. Less than half of the caregivers did attempt tooth brushing for their clients after every meal.

An example of responses:

'I do ask her to brush her teeth after every meal or at least rinsing her mouth' (CM1)

Apart from that, for the clients who could perform oral cleaning independently, they still needed to be monitored by the caregivers to ensure proper cleaning was carried out. Most of the time, clients had to be reminded about the appropriate time for tooth brushing.

3.1.2.1.3 Barriers in accessing dental health care facilities

When this issue was introduced, the caregivers reported some difficulties related to the socioeconomic characteristics of people with special needs in obtaining regular professional dental care. The barriers outlined by the caregivers were time management, the surroundings at the dental clinic which might be frightening to them, a lack of understanding of the importance of dental hygiene, communication difficulties with the patients, financial constraints, a lack of knowledge and awareness about dental hygiene among parents and caregivers, and a lack of professional expertise in the SND field. In addition, unfriendly facilities and public transport could also limit the access to dental care.

Scheduled dental appointments did not commonly fit well with the caregivers’ schedule. Those individuals who cared for by family often had appointments changed or move forward until the condition worsened beyond treatment as attempts were made to arrange a suitable time. Other factors such as clients’ unpredictable behaviour would result in curtailment of the planned treatment.
Examples of responses:

‘The only problem I have is because I’m working. So I need to find a time which suits me and the dental appointment. Other than that, I have no problem at all.’ (CM3)

‘I have no other problem except for her behaviour. She may agree to come in the beginning but a minute later she decides not to go. She has to be calmed down and offered something in return for her to come to dental clinic....’ (CM1)

Communication was found to be a major barrier for some participants. In this context, communication between clients and caregivers, caregivers and oral health professionals, and, clients and oral health professionals could become a problem for them in receiving the treatment.

An example of responses:

‘ Probably, communication might be number one. People might not comprehend or if they are told or they hear about these things, they decide for one reason or another not to, so, I think communication is a big thing.’ (CNZ1)

Lack of understanding about oral hygiene, as mentioned by some of the participants also reflects a lack of knowledge and awareness about dental health, as identified by other participants. This had the close link with a belief by some people that dental health was not as important as general health. For some parents, having a child with special needs was stressful enough to make them forget about dental health, with priority given to other medical problems. The limited updating of current knowledge about oral health among the caregivers was reported to be related to poor understanding about the dental problems experienced by the clients. One of the participants emphasized that, “if only the awareness about the importance of oral health care of the parents and caregivers could be enhanced, other barriers could be simply overcome”.
An example of responses:

‘......other barriers, parent’s knowledge, you know, parents are not exposed about the importance of having clean teeth......And I tell you, my mother, she never bothers about having grandson without clean teeth. She herself just brushes once a day. So, knowledge is important. Not having knowledge is a barrier to me..........Like what I said, promotion and dental awareness are not enough...... You have to make people aware then only you will be able to get through any other barriers regarding this problem.’ (CM6)

Even though financial constraints were regarded as a barrier to access dental care, most people with special needs were financially supported by a particular benefit system. In Malaysia, for example, people with special needs were fully subsidized to receive health care at any government health centre, provided that they had registered with the local social welfare department and were holding a disabled person’s card. Interestingly, none of the participants in New Zealand considered low socioeconomic status to be a barrier in accessing professional dental care.

Dental facilities and public transport which were not user-friendly to people with special needs appeared to be troublesome for some participants. In New Zealand, the availability of wheelchair taxis was very beneficial for people with special needs, whose mobility was aided by wheelchair use. The dental clinic surroundings, such as a big dental surgery and a crowded waiting area were reported to frighten the clients. However, continuous exposure to the dental facility’s environment could calm the clients.

An example of responses:

‘...no, I guess, may be the surroundings are a bit frightening to them sometimes, the bigness of the place and that sort of thing. But then again you see, routine and of course a lot of them when they are little are absolutely petrified of uniforms and things.’ (CNZ4)
Long distance to travel from home to dental clinic, could also be a cause of not visiting dentist.

An example of responses:

'...the only problem we have had is the distance in travelling and trying to tie in with the outpatient clinics he is attending. So that has been a problem.' (CNZ1)

3.1.2.2 Knowledge and opinion about the existing dental services for people with special needs

This category describes factors that may influence the way the caregivers perform the oral hygiene care for their clients. It includes three subcategories: training and education; knowledge and attitude about dental health; and perceptions of the caregivers about SND services delivery in Malaysia and New Zealand.

3.1.2.2.1 Training

More than three quarter of the participants declared that they had received no formal training in care for oral hygiene of people with special needs. Those who claimed to be educated about the oral care for their clients had only received verbal explanation from the dentists they were visiting.

Examples of responses:

'No, no, we don't get any training in that sort of line at all...it would be good if someone would, but no, we don't get anything at all' (CNZ3)

'Yes, when he was a regular patients at paediatric dental clinic.' (CM2)

The rest relied upon personal experience and common sense to carry out the routine dental care for their clients. Even when, the dental education was organized for the caregivers who were employed by disabilities institutions, it was about denture care and not about dealing and managing oral care for dentate clients.
Examples of responses:

‘...I just assume it’s sort of a bit the same as you’d do for yourself. Try to do, basically, yeah.’ (CNZ3)

‘...we have about dentures but not about teeth....’ (CNZ2)

Even though training was considered crucial, caring for people with special needs in many ways was not a straightforward care. Their behaviours and needs varied and should be tailored to the individual.

An example of responses:

‘.....well, perhaps, you know, as you were saying about training us or showing us how to do it. But with some people, especially like Jenny, it’s not as straightforward as saying well, open your mouth so I can get your toothbrush and we’ll brush your teeth.’ (CNZ3)

3.1.2.2.2 Knowledge and attitude about dental health

Knowledge and attitudes were assessed in terms of how well they knew about the importance of dental care in various aspects on the basis that their knowledge and attitudes have a great impact on the client’s oral health.

Although some felt that brushing more frequently would gain a better result, all of the informants agreed that brushing two or three times daily was adequate to achieve good oral health. Nevertheless, they were not familiar with tooth cleaning devices on the market other than toothbrushes and toothpaste. Mouthwash, floss, interdental toothbrush, etc were used only if recommended by oral health professionals. Once or two visits to the dentist in a year for a check-up were thought to be appropriate while others only saw dentist only when a problem arose.

When they were asked about the oral health of people with special needs, they thought that people with special needs experienced poorer oral hygiene than the rest of the population. This might be due to the inability to perform their oral hygiene care
and being dependent on others to help care for them. Some thought that exposure to dental care at an early age would improve their oral health status.

Examples of responses:

‘.....their teeth just generally seem to be not as good as people who are not disabled. And even if it’s in the make-up of the teeth, you know they are not strong.......’ (CNZ4)

‘To me, if there is no one who can look after their dental health, they will end up with a lot of dental problems as they usually need assistance from others in performing their daily routine activities.’ (CM7)

‘Actually, they need a lot of people to tell them in how to take care of their teeth. Actually, teeth are very important for the disabled. All these should be taught at the early age.’ (CM5)

The participants commented on not being well educated about oral hygiene care for people with special needs because of a lack of promotion and information resources. Even if the information was available, access could be a problem for some participants. For instance:

‘I think I don’t have enough information. She has just started her dental visit here, so most of the information is given by dentist. I have seen no brochure or advertisement either in newspaper or television or radio.’(CM3)

They also related this issue to depression experienced by parents/caregivers which led to frustration and, thus negligence of oral health care of the person they cared for. For example:

‘...Because to me I have no idea, I have no knowledge about children with disabilities. It irritates me. When it irritates me, it gives me pressure. Every time bathing him, I face problems. And now as you see, I am emotionally distressed plus the difficulties to brush his teeth. It makes things worse.’ (CM6)
3.1.2.2.3 Perceptions about SND service

Even though SND services had been delivered to New Zealand population with disabilities or impairments for a number of years, none of the caregivers in the interviews from New Zealand were familiar with the term “SND”. Some of the participants had encountered SND service for the first time just before the interview. The service given by the School of Dentistry, was considered satisfactory and able to fulfil the treatment needs of that vulnerable group of the population. For some participants, the Dental School was the only dental facility where they had received dental treatment. It was suggested that people with special needs should have more dental visits (more than one visit in a year) at the Dental School to prevent progression of dental caries to a stage that was beyond savable.

Examples of responses:

‘Well, this is the first time I’ve encountered it with Bill, and I think it’s great.....’ (CNZ1)

‘I think it’s wonderful. I got my braces on from the dentist here and I think the school is lovely’ (CNZ2)

‘Well, we’re very lucky to have it, aren’t we, in Dunedin. Yeah. The Dental School. They don’t have it at other places. And I think, it’s wonderful service. I know, it’s expensive but it would be nice if we could have more visits....’ (CNZ4)

The existence of a SND service in Malaysia was unknown for all participants in this group. On most occasions, participants had to have explanations in great details about what SND was all about before further comments could be made. They believed that, it was because of inadequate promotion of SND by the government in electronic media such as television and radio.

Examples of responses:

‘I don’t think so. I think Malaysia, that is what you say we lack of. So far, I haven’t heard anything about special needs. Just for normal children and normal adults. May
be I'm not really up to date but I have never heard such things about special needs promotion here and there though.’ (CM6)

‘No, because the advertisement in TV and radio just to promote the products such as toothpaste and toothbrush but nothing to educate us in how to brush teeth properly either for normal people or for those with special needs.’ (CM4)

Their special needs clients were currently attending an oral maxillofacial clinic or paediatric dental clinic for dental treatment. From the participants’ point of view, the services provided by these two dental disciplines for people with special needs so far, was able to meet the clients’ dental treatment needs. However, they were overwhelmed with the prospects of development of the SND service because it could improve the existing service delivery in such a way that the patients with special needs would be separated from other patients attending the oral maxillofacial clinic, and therefore reducing the waiting time.

An example of responses:

‘The service is great but the waiting time is too long. I still can see no improvement. I really hope that something can be done so that the waiting time can be reduced.’ (CM3)

One participant commented that the dental service, whether delivered by general dental practitioners or specialists was acceptable to the clients. As long as proper management could be given, a specialist would be required only as secondary dental service providers.

An example of responses:

‘Depends on her conditions. I don’t mind her to be treated by general dental practitioner if they can provide proper management. If they cannot do that, then specialist would be the best person.’ (CM3)
Nevertheless, the specialist service was preferable over the ordinary dentist because they thought people with special needs should be managed with a gentle approach, patience and in hands of a skilful dentist, as mentioned by one participant in the following dialogue.

‘Of course, I would prefer to see specialist because they need a skilful person to look after them. We cannot rush and being so hard on them. They need to be treated gently and deal with using psychology. The approach should be different from that in normal people.’ (CM1)

Their uncontrolled behaviour might not be acceptable at the dental clinic where other people were also present. A dentist who was not trained to manage people with special needs might not cope with their abnormal behaviour and this could lead to disappointment for both, patients/caregivers and the dentist. This was clearly reported by a caregiver of an autistic patient in the following text.

‘No, it should be a specialist. It was not him, but I saw a dentist last month. I noticed that there was a boy having problem just like my son (autistic). He couldn’t stay still and the doctor was so angry. That came to my mind that the doctor might not be a specialist in managing people with special needs. Like I said, people with normal condition will never accept their condition....’ (CM6)

3.1.3 Oral health professionals

The data resulting from the interviews with general dental practitioners in Malaysia and New Zealand could be divided into three categories, which could be further classified into several subcategories, under which the results are now presented. Figure 3.3 summarizes the categories and subcategories derived from the informants in this group.

3.1.3.1 Knowledge and education about Special Needs Dentistry

The knowledge and education about SND of the oral health professionals were very much dependent on the location of their dental practice and the institutions where
Figure 3.3: Categories and subcategories resulting from 16 interviews with dentists in Malaysia and New Zealand

their undergraduate training was obtained. The clarification of these categories was extended to cover their understanding of (a) the definition of people with special needs, (b) criteria for patients with special needs to be considered before referral to specialists, and (c) training received in managing people with special needs.
3.1.3.1.1 Definition of people with special needs

In most instances, the general dental practitioners described patients with special needs based on their personal experience, dealing with people who they thought required special dental care. Interestingly, there was a substantial difference between the definition made by the general practitioners from Malaysia and New Zealand.

Generally, the definitions given by the general practitioners from Malaysia ranged from people who were physically and mentally disabled, medically compromised to those who had experienced social and financial crises. They could range from infants to elderly people. Additionally, the inclusion of people who were dependent on others to perform their daily oral hygiene care was essential. The examples of the responses are as follows:

‘From what I understand, patient with special needs who are mentally retarded, physically disabled which need help and assistance from others.’ (DM1)

‘Special need means that they need special attention, I think those with medical problems and those who fall under, I mean the children and also elderly.’ (DM10)

The causes of becoming partially or fully dependent were described as a result of congenital abnormality or abnormality acquired later in life due to trauma or other diseases. Consequently, they were unable to maintain oral hygiene on their own leading to a requirement for special dental care from oral health professionals.

The general dental practitioners (private and hospital dental clinic) from New Zealand defined people with special needs mostly from a slightly different angle. They emphasized on those people who required special dental care and were unmanageable in the private dental setting. Then they described the conditions which caused the situation mentioned earlier, which could be either needing sedation or general anaesthesia to complete the dental work. In this case, the patients might have some medical issues, or mental, psychological and physical disabilities requiring extra care over that required by other patients. People who were facing some barriers to accessing dental care were also categorized as people with special needs in their view.
Examples of responses:

'Probably patients that you’ll struggle to treat in the general dental setting, so patient that, you know, you have difficulty examining or, you know, just incorporation in terms of that. Yeah, I mean, it’s basically patients that can’t generally manage well in a general dental setting that may need some form of extra care in terms of sometimes needing a bit of sedation or work under general anaesthetic. But not all the time, you know, not all the time. May be special needs as well, patients that may be have, you know medically compromised, yeah, quite a lot of big dental issues or, you know, medical issues that go together and make it difficult to treat them in a general dental practice.’ (DNZ2)

'I would define special needs as people who have some sort of intellectual disabilities or some kind of barriers to receive dental care, and that can be mental or physical....’ (DNZ1)

General practitioners from Malaysia who were working in hospital-based dental clinics could describe people with special needs in slightly greater details, while those who were currently attached to community-based dental clinic mainly defined people with special needs as those who were medically compromised, physically and mentally disabled only.

Examples of responses:

'The definition of patients with special needs is patient who is medically compromised, mentally and physically disabled.’ (DM6 – community dentist)

‘For me, special needs patients are those who are medically compromised and they are not able to maintain their oral hygiene by their own and they need special care and help by dentist or hygienist.’ (DM2- hospital dentist)

3.1.3.1.2 Criteria for patients with special needs who require referral to specialist

Most of the participants were happy to treat patients with special needs if it was within their capability and if the facilities available were appropriate to handle the
patients. In a lot of cases, the initial examination and history taking would determine their decision on whether referral to a specialist was necessary.

Examples of responses:

‘...if I couldn’t actually manage at my level of treatment.......if I would like to offer them more than I could offer in my service...’ (DM8)

‘For me, I would like to try to manage the patients first. And of course if the patients need more special treatment, I have to refer them.’ (DM4)

Uncooperativeness was claimed to be the major reason for referral by the informants. It was followed by complicated medical issues that the patients were having which might influence the management of care required. The oral hygiene status of the patients was cited as one of the criteria for referral.

Examples of responses:

‘...if the patient has medical problems that privately cannot handle, or if the patient is uncooperative, those are two reasons why I would refer....’ (DNZ5)

‘....The things that I consider before I refer a patient to specialists are their cooperation and of course their oral health status....’ (DM1)

Other reasons for referral were communication and high expectation from parents or caregivers. Both Malaysian and New Zealand participants felt that they were not knowledgeable enough to provide information to patients, parents or caregivers about the oral health related to certain special needs conditions, leading to misunderstanding between the dentist and the patients/caregivers. When this issue arose, a second opinion from a specialist in this field was crucial to create confidence among patients/ caregivers towards the offered treatment.
Examples of responses:

‘...Sometimes, there is miscommunication between us. As dental officers, we don’t have much knowledge about special needs children. Probably, there is miscommunication, so, it is better for the specialist to talk to parents.’ (DM5)

‘I would certainly see if I can have a good communication with them and if I can get hold of the caregiver and say if they have got ways of telling the patients what we want to tell them, but otherwise, if we can’t get mutual understanding of what we are going to do or they don’t quite understand and they can’t cooperate, then I’d refer.’ (DNZ1)

Since almost half of the participants were running a busy practice, time spent on each patient was taken into consideration. Some could not afford to spend extra time in managing patients who required special dental care, as it would drag out the waiting time of other patients and would reduce the number of patients they could see on that particular day, and this would lessen the daily income of the practice. Referral to a specialist would be considered if the patient was unmanageable within the expected time frame set by the dentist.

Examples of responses:

‘...The other main reason I send them if they I get them into having a treatment done and I normally allow a quarter of an hour just for positioning and stuffing around and you end up spending more time attending their needs, and suction and all that.....’ (DNZ4)

‘Those patients that we can’t provide any treatment, which are not cooperative at all, who become restless at the unit and require so much of attention, we need to treat many patients here and require a lot of time and then we have to refer them.’ (DM11)

Occasionally, for patients who could not be treated in the dental chair, they might be best treated under general anaesthesia to ensure proper dental management and safety. In this case, specialist review and management was necessary as most private
dental clinics and community-based dental clinics were not equipped with operating theatres or anaesthetic services.

An example of responses:

‘... definitely I will refer them to specialist, especially those who require treatment under GA (general anaesthetic) because I think the best person to treat them is dental specialist.’ (DM1)

In New Zealand, according to one of the participants who was working in hospital dentistry, each hospital had its own guidelines for accepting referred patients. Generally, the criteria accepted by this particular hospital included patients with medical problems affecting their oral health management and medically, physically or socially compromised patients. Another criterion used in New Zealand applied to financially compromised patients, who often experienced a lot of social crises in their life at the same time. However, ‘medically compromised’ and ‘financially compromised’ covered a broad range which would always depend on the personal judgement of the dentists at the receiving end to decide whether or not the referral was appropriate. Lastly, all patients for treatment within the hospital dentistry service must be referred by other health professionals for eligibility. This is indicated in the dialogue below:

‘Well, I was going to say within New Zealand at the moment, most hospitals have their own guidelines for what they will accept. To be accepted within our service you have to be referred. Generally, you either have to be medically compromised, but that’s a very broad term. Medically, physically or socially kind of compromised. There’s also another criteria there at the moment which is accepted in New Zealand and it’s if you’re financially compromised and cannot afford treatment within private practice, they’ll often refer you to hospital. But the kind of patients who are financially compromised often have a lot of social factors going on, so they are, you know, possibly have anxiety issues with the dentist of, yeah, generally the criteria is quite broad.’ (DNZ3)
The referral criteria which emerged from the interviews with the general dental practitioners are summarized below:

- Uncooperative
- Complex medical problems
- Poor oral hygiene in relation to special needs conditions
- Poor communication
- High expectation from patients or caregivers which was impossible to achieve due to their conditions
- Extra time required to care for the patients
- Patients with physical and social impairments who could not tolerate dental treatment in private setting
- Financially compromised patients with some other issues related to special needs conditions

3.1.3.1.3 Undergraduate and in service training in managing patients with special needs

Inadequate exposure to the SND field during undergraduate study had led to a lack of confidence in fresh graduates for managing patients with special needs. All participants claimed that one or two lectures given about patients with special needs within the five-year programme of their undergraduate degree did not prepare them enough to work with this vulnerable group of population. Clinical training in SND for undergraduate students was not in the curriculum in training centres where the informants had obtained their degree, whether in Malaysia or New Zealand. Three participants had graduated in Australia and one who was trained in Adelaide University had had an opportunity to see patients with special needs under supervision by an oral surgeon once a week in her final year.
Examples of responses:

‘During undergraduate time, we were like given an exposure but not by treating the patient. I remember we were given a lecture on special needs, just a lecture, it is just a theory.’ (DM10)

‘I never got any in my undergrad...’ (DNZ4)

The unavailability of experienced lecturers and experts in this field was the contributing factor to the inadequate information and clinical exposure received by the undergraduate students. It was suggested that SND should be included in the undergraduate curriculum because the demand for the services was expected to increase in the near future. An example of the response is as below:

‘I think no. I think from my experience, we have to improvise or update the syllabus at the dental school especially in special needs dentistry because there are a lot of problems like, we lack of specialist in this field in government.’ (DM1)

Experience was a main source of learning when they had to deal with patients with special needs. The participants were exposed to treat various types of patients throughout their working experience. Depending on where they were working, some might have more opportunity to see patients with variety of conditions. The first-year dental officer programme conducted in Malaysia for fresh graduates in their first year of working was useful in developing their professional skills under the supervision of specialist from different dental disciplines. Attachments to hospital-based dental clinics such as the Oral Maxillofacial department and the Dental Paediatric department increased the chances for them to manage patients with special conditions. In the absence of specialists in SND in Malaysia, both departments were responsible for managing those who required special dental care. This programme had enhanced their confidence in treating patients with special needs and might develop an interest among the younger dentists to pursue further training in SND.
Examples of responses:

‘....but I did have, in the first year dental officer programme, I was attached to dental paediatric unit at Kuala Lumpur Hospital. So, I was quite exposed to treat this kind of patients, cases like Down syndrome and physical disabilities.’ (DM7)

‘Yes, throughout the years, you do get cases like that, you know, you do get confidence…..’ (DM7)

Apart from that, visiting vocational training centres for people with intellectual disabilities to do general dental examinations was part of the community service which had to be undertaken by the general dental practitioners working at the community-based dental clinic. This is indicated in the following dialogue:

‘......The other one when I started working with this dental clinic, because we have this community service that we do, not medically compromised, it’s like disability sort of community who was trained as a working staff. And then, we do actually go to do just check up. I don’t have exposure of giving them treatment......actually, have a general idea what sort of difficulties and what sort of state of oral hygiene that they have. But to tell you like direct exposure, I don’t have it.’ (DM8)

The house surgeon programme for fresh graduates in New Zealand, based in a hospital setting, was able to provide valuable training for the graduates to develop their professional skills in the management of patients with special needs before they went out working on their own in private practice. However, considering the amount of exposure in one year of training, it was still not adequate enough to develop their confidence. Some participants had decided to attend seminars or courses related to SND but it was all depended on the special interest of the practitioners.

Examples of responses:

‘....I didn’t find it too difficult to adjust to the situation when I started my job. But that was at a hospital setting and I had people to help me out if I needed to.’ (DNZ5)
'The special needs dentistry that I have experienced was only after I graduated when I had some special needs patient in hospital settings, and also there was a continuing educational course that I attended in Australia that they talked about special needs patients as well, but they mainly talked about the ones bounded in rest homes or care centres that we have to actually go through. But I don’t really think that’s adequate.’ (DNZ1)

3.1.3.2 Demands for Special Needs Dentistry service

Demands for SND services in this study were measured by the average number of patients of special needs who attended the practices in one week. Other areas included, were common dental problems presented by patients and the treatment required for them. The places where the patients came from were also included in this category.

3.1.3.2.1 Estimated number of patients with special needs seen at the dental practice

In Malaysia, there was a significant difference in the numbers of patients seen at hospital-based dental clinics and community-based dental clinics. However, the numbers cited from participants at different hospital-based clinics also showed some variation. A participant who was based in a hospital setting claimed that they could manage almost maximum of 40 patients with special needs in a week while another who was based at another hospital could only see about in average five to six patients with special needs within the same period of time. This number was much less at the community-based dental clinics and at the private clinics (New Zealand), at which not more than five attended in one month. Hospital-based dental clinics tended to treat patients referred by community or private dental clinics, whereas community and private clinics saw patients who required primary dental care. Adults with special needs were seen by one participant at the hospital paediatric dental clinics where he worked.
3.1.3.2.2 Common dental problems in patients with special needs seen at the clinic and types of treatment required

Oral hygiene status of this group of population was very much related to the commitment of the caregivers in performing the oral hygiene care especially with those who were fully dependent on others to carry out their daily routine activities. Some patients presented with very good oral hygiene, despite their difficulties in maintaining their oral hygiene care. Assistance from parents/caregivers could improve the oral hygiene status to a satisfactory stage, as recorded by the participants.

An example of responses:

'**Most of them have periodontal diseases and also a lot of caries. Possibly due to their oral hygiene regimen and their own health which determine their ability to clean well.**' (DM9)

Dental caries and periodontal problems were cited to be the most common dental disease found in patients with special needs. The caries burden in this population was estimated to be on average, five teeth with caries per person.

Examples of responses:

'**Usually they have bad oral hygiene which because of their behaviour, they themselves won’t brush their teeth and their family members, those who are not aware of the needs of taking care of their oral hygiene which leave the mouth like that, so we see gingivitis, we see a lot of rampant caries with the....caries, gingivitis, accumulation of plaque and calculus.**' (DM11)

'**...As an average, dentition with caries like for example 5 caries in dentition.**' (DM8)

Some might experience rampant caries while others might present only with some plaque accumulation. Periodontal diseases were also found very common in this group of patients. Other associated dental problems mentioned by the participants were dental abscesses secondary to caries, temporomandibular joint dysfunction (TMD) and soft tissue injury. A discontinuous arch was another problem which was frequently...
identified by the participants. In other words, they had a lot of missing teeth, even at a young age.

Examples of responses:

‘Caries, definitely, periodontal disease, abscess secondary to caries and TMJ dysfunction.’ (DM7)

‘Caries. Caries and.., that’s it. Discontinuous arches. That’s it.’ (DNZ4)

‘In elderly patients, since we have inexperienced carer who are looking after them, some patients got ulcerations because they keep biting on their soft tissues. This is the thing which I usually face when treating them.’ (DM1)

Patient’s social background could also influence the types of dental problems that they were having. People who were cared for in institutions often had periodontal problems with low incidence of dental caries. In comparison, high caries rate and dry mouth were reported to be very common in those with psychological problems and drug abuse background due to the drugs that they were taking and smoking habits.

‘High decay rates. They are dental phobics. Those that I was saying before that have been cared for from day dot, the institutionalized ones, generally the only problems you have with them are calculus and gum problems,......Those who come from kind of a psychological or a drug abuse background tend to have very high decay rates, very dry mouth. They’re either on methadone, they smoke, yeah, and they just don’t have oral hygiene as a high priority,...’ (DNZ3)

3.1.3.2.3 Patients’ resources

People with special needs who attended a dental clinic came from a variety of resources. In Malaysia, the informants who worked at the hospital dental clinics usually received patients by referral from other peripheral clinics either from dental clinics at the health centres, private dental clinics/hospitals, or in-patients. No patients would be accepted without referral from other health professionals. However, a referral received from institutions which accommodated such patients was very rare.
unless home visit service/domiciliary service was organized by the dental clinic within that community. However, the domiciliary service in Malaysia was not fully established. Walk in patients could obtain a primary dental care from the peripheral dental clinics. Dentists who were working at these centres would also treat patients referred by other health professionals for maintenance phase.

There was no difference in the referral system between New Zealand and Malaysia, except that the private dentists were the main provider of primary dental care in New Zealand. On the other hand, the primary dental care in Malaysia was provided by both community and private dentists. Apart from accepting referral from private dentists, patients referred by institutions, community trusts and rehabilitative centres were also treated by the hospital dentists in New Zealand. In other words, patients with special needs in New Zealand could access dental care facilities with assistance from wide range of organizations.

3.1.3.3 Opinion about the development of Special Needs Dentistry service in Malaysia

With the development of the special needs dentistry service in Malaysia, it was expected that, the general dental practitioners would have some knowledge about the services, as they were the ones who were responsible in providing advice and direction for further management to the patients.

3.1.3.3.1 Service delivery

Participants in this group strongly agreed that, they were not updated well enough by the government about the current development in dentistry in Malaysia. Being a new specialty in dentistry worldwide, they believed that, those involved in the policy and future plan of special needs dentistry should ensure that the information could be easily accessible to the general practitioners. This would aid in providing proper and quality care for patients with special needs, while at the same time could increase the interest of the general practitioners in this challenging but rewarding field of dentistry.
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis
(Based on New Zealand Experience)

Example of response:

‘Okay, since I’m working at Paediatric Dental Clinic. I strongly suggest that or recommend that we have to set up a special clinic in every state because in Malaysia we have a lot of people with special needs. Besides that, we have to increase the number of specialist in SND because we definitely need them. We cannot handle them alone and we need to work as a team.’ (DM1)

The participants gave their full support for the development of the SND in Malaysia for various reasons. Firstly, the number of people with special needs in Malaysian population had increased steadily in the past ten years. Hence, they predicted that there would be an increase in demand for the dental care in line with the improvement of medical care, which enhanced their life expectancy considerably. This group of patients were currently managed by the paediatric dental clinics and the oral maxillofacial department. The huge demand for the special dental care service could not be entertained by these two departments alone, hence, SND was regarded to be a dental discipline which would provide better care for them and therefore, would improve their quality of life.

An example of responses:

‘I think it’s good. This is the high time they have this unit because there are so many of these patients are being neglected, you know. If they go to the peripheral clinic, they won’t be treated because of the bulk of patients there and dentist won’t have time for them. They are not cooperative and how much time can they spend just to persuade this kind of patients. And then if they go to hospital, even for me, I’m not very happy to treat them because, it takes so much time.’ (DM11)

Secondly, the development of the SND service was believed to be able to improve the oral health status of people with special needs. There would be more patients who could be attended by the specialist in SND and more specific treatment could be delivered according to patients’ needs and demands.
Thirdly, it could solve the dilemma faced by the general practitioners when an adult patient with special needs required a referral for specialist’s attention. Theoretically, patients above 17 years old would not be under the care of the paediatric dental specialist. However, they were also at times, not eligible to be seen by the oral maxillofacial surgeon, and inexperienced general practitioners were not confident to provide the special care required. This situation might compromise the attainment of proper care necessary for the patients that could lead to further confusion and chronic conditions. The development of the SND, seems to answer this ongoing dilemma and expected to fulfil the current needs for the services.

An example of responses:

‘In my opinon, I think we need it. I did find a problem,.....a situation where we’ve got a patient that more than 18 which have, sort of special need patient. At that point of time, the specialist between OS and paediatric, they actually like who want to do this patient. Should we refer them to OS, should we refer them to paediatric. Apparently, paediatric usually treat patient at 16 and below. And we’ve got patients who are disabled, I think we need to treat them more gentle and I think OS is like,..more, not really suitable for them. Because they need more attention you know and need more of your time which is good for paediatric specialist but the thing is paediatric specialist have their own patients. So, when we develop SND, it’s much easier...so, this group of people can be referred to one particular specialist.’ (DM8)

In New Zealand, although the SND service was considered as a well established dental specialty, not all participants from New Zealand were aware about the existence of the service. Those who knew about the service claimed that there were still a lot to be done to improve access to the dental facilities. Adults with special needs were traditionally picked up by paediatric specialists and general dentists who had a kind of interest in public health. The number of specialists in this field in New Zealand was still small. Currently, they could still be managed by oral surgeons or general dentists working at the hospital settings. This is clearly stated in the following text:
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis

(Based on New Zealand Experience)

‘In New Zealand? It’s quite variable and it’s always being picked up by the hospital, so traditionally these adults have kind of been treated by paediatric specialist or just general dentists who have an interest in working in public health. In New Zealand, I think that we’re under-represented in kind of specialists and just general practitioner working within that setting to actually help. Because at the moment, a lot of the care is directed towards general restorative care and there’s not a lot of focus on trying to prevent or improve kind of oral hygiene, so it’s a bit of a vicious circle, really.’ (DNZ3)

Rarely, they would be accepted at the private clinics due to the financial constraints of the patients or the myth that it was going to be a terrible situation.

An example of responses:

‘…..but I have a feeling that sometimes people kneejerk and don’t treat them because they are going to be terrible, whereas a lot of them it’s actually not too bad. But, there’s only a few of them are truly terrible but most of them are okay. So,…’ (DNZ4)

Treatment wise, the system was directed to general restorative care, and less attention given to prevent the dental diseases among the patients, which resulted in unresolved ongoing problems or could be interpreted as vicious circle. Nonetheless, providing information about dental prevention programme would not be financially rewarding for the dentist in addition to the attitude of the population, which felt getting information should be free of charge. This had made the preventive dental care much less popular service than the restorative care. Even though the treatment was free for children under the age of 18, the service was not hugely utilized by patients with special needs. As a result, their oral hygiene status remained at poor stage for years or at worst, until the end of their life time.

An example of responses:

‘...It’s not where the money is and it’s not the same I guess financially in the public health service. But that’s what the patients expect. They don’t come to see you to get a lecture on oral hygiene. It’s just a very kiwi mindset that they don’t want to pay for that information. They want their tooth fixed or they want their tooth out.’ (DNZ3)
3.1.3.3.2 Facilities

The informants reported that dental facilities for people with special needs in Malaysia should be located both in the hospital and community health centres. Hospitals were thought to be the best place to set up the special care unit for a start, as these centres had been acting as a pool of patients with variety of special needs conditions. Therefore, referral could be obtained from other departments and clinics at the hospitals.

An example of responses:

'...but the actual practice I believe should be hospital based. Because hospital usually get more of this type of cases and they will get referral you see from other departments and probably from other clinics.' (DM7)

Since these patients were more vulnerable to medical emergencies, having medical colleagues available at the hospital would certainly ensure patients' safety.

Example of responses:

'.....you know, for those like having various medical problems, hypertension, diabetes or heart problems and everything, they need to be in hospital because whatever treatment that is done they are prone to have medical emergencies, so, they should be treated in hospital.....' (DM10)

'In my opinion, it should be at both sites but it is needed more at hospital because usually patient with special needs are brought to hospital. At hospital, they will get more attention as we have the link with other medical specialty. With the existence of SND, the care for patients with special needs is much better.' (DM1)

It would be appropriate to set up a special care unit at a community health centre as it would be easily accessible by the community. Most of the community health centres were located at rural areas which delivered services only for the population within that particular community. Therefore, it was expected that the general practitioners working in the community clinics would encounter 'first hand' dental patients who
sought for primary dental care. By having the special care unit within a reachable distance, more patients could be contracted, hence, advice and information about oral health care for people with special needs could be delivered more effectively. In other words, this special care unit would have different function from that in the hospital. Oral health screening and providing oral health information and education for preventive care for people with special needs and the caregivers, were foreseen to be the main roles of the special care unit based in the community health centre.

An example of responses:

‘I would love it to be community based. It is more reachable and you can see more people. Because I think, being a community based, make it closer to the community itself whereas in hospital, cases treated are referral cases. And I think, specialist in SND should be attached to community centre which is closer to the community that the hospital.’ (DM)

Additionally, according to the informants, the “non user-friendly” aspects of the existing dental facilities to people with special needs must be taken into consideration while planning for new special care units in the future, be it at the hospitals or in the community health centres. They also believed that, the current dental facilities had limited the access of people with special needs to dental care and consequently, affected the oral health status of this vulnerable group of the population.

3.1.3.3.3 Education and promotion about oral hygiene care for people with special needs

The informants reported that, the availability of the information only limited to certain groups of population. A lack of information occurred not only to the affected patients and the caregivers but was also experienced by the general practitioners. Not knowing about current developments in dentistry would prevent them from providing quality care for the patients. It was hoped by the informants, that in the near future, with the availability of specialists in SND in Malaysia, general practitioners could become educated about the SND services and then, could further extend the knowledge to
patients and caregivers to create awareness and motivate the community about the importance of oral health care for people with special needs.

An example of responses:

‘I think, we need more. There is not enough promotion and result in lack of knowledge about this kind of patients who need special attention. Not that they don’t want to treat but they don’t know what is going on in SND. So, we have to enhance the promotion.’ (DM3)

Special attention should also be given to the caregivers to improve awareness and education about oral hygiene care for people that they cared for. In spite of having kind and motivated caregivers, as observed by the informants, patients with special needs often presented with poor oral hygiene. The main concern was whether these caregivers fulfilled their responsibilities in providing the dental care for these patients in a satisfactory way, or just to complete their daily checklist. However, patients in this group could have unpredictable behaviour, thus the caregivers must be taught individually about cleaning the mouth of their clients, as everyone would respond differently with mouth cleaning.

An example of responses:

‘I reckon – I think plaque control in rest homes just continually shocking and I have had one patient I can think of in particular who got onto an electric toothbrush, her carer is extremely caring and motivated, but she always turns up with a mouthful of plaque, like right to the incisal edges, and she’s together in her head but I think she gets a bit grumpy and stuff and I don’t know but whatever happens we’ve always got heaps of plaque. So, I think a lot of cares don’t really give a rat.’ (DNZ4)

The involvement of other health professionals was crucial when dealing with people with special needs. Having medical colleagues with basic knowledge about preventive dental care could help delivering the information to a large number of patients, as they were the ones who frequently dealt with the general health of the patients which might also be associated with the dental health.
An example of responses:

‘....And I think that, would actually need a bit of a help from our medical partners on that as well, because I don’t think they are very good at promoting oral health.....’
(DNZ3)

3.1.4 Policy makers

The involvement of policy makers in this part of the study was essential in order to review their plan and recommendation for future development of SND service. There were six dental administrators who agreed to be interviewed including one from New Zealand. The data from the interviews resulted in the emergence of three categories with each corresponded to several subcategories, as shown in Figure 3.4.

3.1.4.1 Knowledge and education about Special Needs Dentistry

3.1.4.1.1 Definition of people with special needs in their own perspective

The participants had different interpretation about people with special needs which generally covered a group of people from infant to elderly. Interestingly, the definition was modified according to their portfolio and their role in the Ministry of Health.

A participant whose role was to look into the development of the dental specialty in Malaysia defined people of special needs in the perspective of the service delivery. The definition focused on the special care required to establish the service for this group of patients, so that the patients could obtain adequate dental treatment as necessary. The main reasons for the special dental care were outlined as anxiety and extended time of care.

An example of responses:

‘A patient with special needs is the one who requires special attention when undergoing dental treatment. In our case, this is the patient who shows fear or inability to stay on the dental chair for long treatment either out of fear or due to certain disabilities which will impair them from undergoing normal treatment as other normal
children. They will require certain aids or certain types of manoeuvres so that they can be treated or undergo treatment suitably.' (PMM1)

Figure 3.4: Categories and subcategories resulting from six interviews with policy makers in Malaysia and New Zealand

Another instance in which the definition was influenced by their responsibility in the oral health division was by an informant who was managing the development of dental facilities and equipments in Malaysia. She interpreted people with special needs as those whose needs should be attended with special equipments and facilities suitable for their disabilities or impairment, as indicated in her dialogue:
'To me, those who require specific equipment, specific needs in term of treatment room. They need special treatment.' (PMM2)

Other definitions provided by the policy makers fitted well with those definitions in literature even though currently, there was no single definition that fully encompassed the diversity of the group when considering a specific context. They managed to link the definition to the conditions that the patients might have, which affected the care required to manage their oral hygiene within the professional and home care facilities.

Example of responses:

'......a person with special needs is generally one adversely affected by intellectual disability, medical, physical or mental health issues that affect their access to oral health care.' (PMNZ1)

'......people who need others to allow them to continue with routine daily activities or whatever....' (PMM4)

Some confusion was noticed among the policy makers whose roles were not directly related to the development of the SND in classifying people with special needs who would be eligible to receive treatment under the care of specialist in SND. The inclusion of children with special needs and the school dental service which were not within the scope of this specialty was mentioned by the informants.

3.1.4.1.2 Oral health care and status of people with special needs

The informants shared a common understanding that oral health status of people with special needs who were fully dependent, relied on the attitude and knowledge of the caregivers about oral care. Considering that more people with special needs were residing in the community nowadays, they could possibly have better oral hygiene. In a home environment, care was given in one to one basis, therefore, a patient could gain individual attention in their routine daily activities. The situation was reversed for those residing in the institution leading to poor individual care as attention needed to be given to a group of people rather than an individual. However, the informants
believed that, some institutions could perform better care than the others depending on the organization and the management of the institution for people with disabilities. Provision of dental care might not be as important as other types of health care in certain institutions. Well trained caregivers were lacking in Malaysia as reported by the participants. Most of the time, they were focusing on the patients’ diet and needs, other than health care.

An example of responses:

‘It depends, if let say the institutions have special programme which cater for this people, then it shouldn’t be a problem. We have to look at certain institutions. Certain institutions are very good. They have all these specialized people such as speech therapy. The whole lot of people are there in more stable kind of institution. And then the caretakers are well trained. Some are not trained to take care of them, the just look at their food and whatever they needs other than the health needs. So, I feel that it depends on situation because certain people, even though they are home based but if the parents do really take care of their health needs, they will be doing great. (PMM2)

Apart from that, the quality of the service provided by the Ministry of Health possibly had some influences on the oral health status of people with special needs as cited by the informants. It would take into account the manpower available to provide the service, the time allocated to see this kind of patient and also follow up schedule arrangement by the dental care provider.

Example of response:

‘....So, like that. If the carers are very committed, they will take care. And it is also our service, how good do we provide. How often we can go. We are shorthanded also at the moment. Officers and nurses.......Now, this is like a new specialty and new group of children to be looked after. So, we have to keep time for this group too. So, how much time can we provide....’ (PMM5)
3.1.4.2 Current situation and policy in the oral health care delivery of people with special needs

3.1.4.2.1 Service delivery

According to the informants, the delivery of the SND service in Malaysia could not be fully established until the dentists who were currently trained in this specialty completed training. A specific system of patient management involving those with special needs did not exist. Current patients’ management was on an ad hoc basis. Patients could be referred to oral surgeon at the nearby hospital by the general practitioner if there was any area of concern regarding the patient’s special conditions. There were times that the patients might not be accepted by the oral maxillofacial department due to inappropriate referral. In-ward patients with special needs who were having dental problems could access dental care through referral by medical colleagues to the oral maxillofacial department which was normally located in the hospitals. Walk in patients commonly gained dental treatment at the dental clinics in the community health centres within their residential area.

An example of responses:

‘At the moment, the system in our country is very compartmentalized because we have categorized the types of care according to age groups. So, initially, all the referral cases from the primary care level is being referred to either paediatric specialist or those above 17 will be referred to the oral surgeons. Of course, there were a lot of hassles at that time, the oral surgeon were not that happy when they actually referred above 17 to them...’ (PMM4)

Those who had been undergoing dental treatment during childhood at paediatric dental clinic might continue getting dental care from that department into adulthood, even for maintenance phase. This happened due to the absence of specific specialty which could manage these patients’ special dental needs and care.
An example of responses:

‘...So, at the moment, dental specialists who are treating them are paediatric dental specialist and also we do not actually have enough to concentrate on children with special needs in addition to other children who are referred for other cases. Also, these patients who beyond the age of 17, there is no specific specialty or dentist who can actually handle them. So, paediatric specialist are actually treating children beyond the age of 17 and certainly there is a need that the adults to be treated by a particular group of specialist.’ (PMM1)

The most recent programme identified by the participants was to recognize several cooperative institutions which provided nursing care for elderly in Malaysia. This outreach programme would enable an identification of carers who were closely involved in the management of care of the residents. They would then be invited to attend seminars and training sessions about dental care for the elderly, organized by Ministry of Health. The programme was called ambassadorship training (training the trainers) programme which was expected to be fully implemented in the near future. This is clearly stated in the text below:

‘...in fact, recently, we have seminar for elderly (the geriatric), we also go along that line, identification of this cooperative institutions and then identifying the carers who are cooperative and we train them into oral health care. They will be the ones who would be full time with the patients, and so they will carry on day to day care for the patients, even if with or without the presence of our oral health care professionals. So, we are going along that line. We call it training the trainers. It will include even parents or the carers at home but we are going to the institutions first because these are the captive groups.’ (PMM4)

Another ongoing programme which had been implemented for a number of years was approaching children with special needs at school, via the school dental service to guide them and the parents/caregivers to get access to paediatric dental clinic to obtain further treatment as necessary. These children would be tagged with the paediatric dental department for a certain amount of time until they reached 17 years
of age after which the management would be continued by the oral maxillofacial department.

An example of responses:

‘...and then actually we have this ongoing programme where we see these children very early so we can also tag on these children with special needs or patients with special needs when they come to the health centres early enough....’ (PMM4)

The participants believed that financial status was not an issue for patients with special needs, as the dental treatment for this particular group was fully subsidized by the government, provided that the service was delivered by the government dental clinics. However, the cost for prosthetic appliances, such as dentures, crown and bridge work, and implant were not included in this policy. Nevertheless, under certain circumstances, they would be still eligible to ask for some discounts with a supporting letter from the local Social Welfare Department. Conversely, dental treatment gained from private practitioner would not be subsidized at all.

3.1.4.2.2 Barriers in accessing dental health care

There were a number of factors identified by the participants as being barriers for people with special needs in gaining access to dental care facilities. A lack of awareness and knowledge about the importance of oral health was first on the list to be the main causes for not seeking dental treatment at an early age. This applied to both, people with special needs and the caregivers, which meant high quality of home dental care could not be offered. Depending on the educational background of the caregivers or parents, the social stigma of having children with special needs would further compromise the children’s oral health care throughout their life. They tended to isolate the children at home until the problems became severe and difficult to treat, before they came forward seeking dental treatment. More educated parents were more tolerant of social perceptions about having children with special needs, compared to less educated parents. As mentioned by the informants, a lack of awareness and knowledge might also be caused by an inadequate promotion or
broadcasting by the responsible organizations, which in fact resulted from the lack of manpower to provide the care for this group of the population.

An example of responses:

‘It’s always been awareness. They are not aware. Knowledge. Probably, we have not been broadcasting or promoting....... We don’t have. We are not confident that we can provide that care. We want to but are we able to. That sort of things.’ (PMM4)

A low socioeconomic status might play a major role in discouraging people with special needs from seeking dental treatment. Having children with special needs might also be a burden to the parents either financially or emotionally. The informants noted that, that would be costly for the parents/caregivers to bring the patients to dental clinics especially for those who lived in rural areas where the closest dental clinics were located miles away from their house. In this case, transport could also be a problem. They would rather spend the money for something more important such as food and daily living requirements. They might be emotionally sensitive and avoid the child being exposed to the community.

Since people with special needs were mostly dependent on others to help take them to the clinics, the unavailability of carers to accompany them seems to be causing some difficulties in accessing oral health care facilities. Dental facilities were also not easily accessible for people with special needs which would not allow them to act independently in order to obtain dental care. Some of the dental premises were located above ground floors without a lift for wheelchair access. So, they need to rely on others to help them out in this situation.

An example of responses:

‘Barriers..one is that they have to depend on somebody else to take them for treatment and so they only come when they are in pain..... That is the barrier firstly they depend on people to take them. Secondly, our system is not yet in placed that we have a special counter nationwide to cater for these people. Of course at certain MOH facilities, they have created this place for special needs. Because of their conditions, they would be treated special. These are the barriers of care which is the accessibility
and facility wise does not allow them to go on their own. Most of our clinic, they have staircase and they don’t have a lift for wheelchair so they need people to carry them up. So basically, these are the barriers.’ (PMM2)

Other crucial issues stated by the informants which made the management of patients with special needs more complex than that in normal population was the medical problems they might have which complicated the oral conditions. Many agencies might need to get involved which made the case management more complex. Inadequate skills and knowledge of oral health professionals in managing people with special needs could affect the provision of necessary care for the patients.

An example of responses:

‘Some of the major barriers are the complex health and disability issues that complicate oral conditions and often require many agencies to get involved and make case management complex,........dental practitioners who don’t have the skills and knowledge to offer the necessary care......’ (PMNZ1)

3.1.4.2.3 Involvement of other stakeholders in the development of SND

The participants’ narratives suggested the importance of working as a team, between non-governmental organizations (NGOs) and particular Ministries in the government which related to the management of people with special needs in various aspects. An absence of a registry for people with special needs in Malaysia led to the difficulty to trace these people in order to encourage participations in a dental health outreach programme. However, some had become members to several special needs associations which were run privately. Therefore, the management of these private associations should encourage the members to come forward seeking dental care or getting involved in any dental programme organized by the Oral Health Division, Ministry of Health.

An example of responses:

‘I think NGO’s role is very important. In Malaysia, they are fast catching up. They have to work together. Because at the moment, I don’t think there is a registry for people
with special needs unless they come forward. So, it is part of their role to motivate among their members so that more of these special people come forward. So we need them to play part of whatever and the input is very important.' (PMM2)

Some participants believed that the involvement of the organizations other than Ministry of Health was unsatisfactory, even though the cooperation was there. Creation of networking should be led by the Oral Health Division, but due to lack of capacity in the Ministry, it had been held back and resulted in a one man show programme. Another problem stated by the participants was that, some organizations or departments of health at the state level did not see the dental care for people with special needs as a priority.

Examples of responses:

‘....The very fact if we approach them and we discuss this matter, I think the cooperation is there. It’s just that we have not really ventured this deeply because of our capacity. Once we have done it, now we are only going through the rehabilitative community centres and the institutions because that is what we can handle at the moment. If you want really to create our network, I would feel that they are very cooperative....’ (PMM4)

‘...some states don’t see it as priority. Those which we gave more places only sent one participant. Because they don’t see it as priority...’ (PMM4)

Schools which provided a special class for children with special needs could play a role in delivering the information about dental care either to the caregivers or the patients themselves. Some schools were found by the participants to be proactive in seeking regular dental check-ups for these children. For some, they were just waiting for the government to make a move. The regular dental checks for these children who were at schools was already in the system, if the schools were national schools funded by the government. On the other hand, those in private schools could not get access into the system automatically unless the management of the school made an approach to the department of health within the area of concern.
An example of responses:

‘...I noticed that, there are some schools or organizations who will write regularly to ask for care. Some are active, some, they wait for us to make a move, to go and look for them....’ (PMM5)

Apart from the Ministry of Health, financial assistance by other stakeholders, in the delivery of the dental care for patients with special needs was welcome. If it was not possible, their involvement in promotion of care for this group or the provision of additional equipment and materials would improve the service as much as the service was needed.

An example of responses:

‘Okay, other stakeholders, if they can involve in the funding, it will be very good, otherwise, it would be in the promotion of care for these people and equipping or providing additional equipments, materials and so on if they are able to assist.’ (PMM1)

3.1.4.3 Future planning for SND in Malaysia and New Zealand

The future planning for SND either in Malaysia or New Zealand was initiated with advice and input from senior dental advisors of the respective Ministries. The guidelines and policies were developed for us to follow and the policy makers would have to ensure that it would be fully implemented to achieve the target. The planning would cover the mechanism of service delivery, the facilities required to accommodate people with special needs, support provided by the government to encourage the development of this specialty and the domiciliary service.

3.1.4.3.1 Service delivery

In term of service delivery, the policy makers continued to debate where the best place a special care unit should be located. Most agreed that, a special care unit should be based in a hospital on the basis that these patients might have other medical problems which would complicate the management of care, thus they might
require some support from the medical site as well. By having the special care unit at
the hospital, it would be easy for them to access the dental facilities while having
other treatment at the same centre. On the contrary, it might be inconvenient to the
patients to travel from one place to another as far as their conditions and cost, were
concerned. Besides that, the nature of their disabilities and impairment required the
specialty to be close to an operation theatres and physicians.

An example of responses:

‘I personally would prefer it to be hospital based because somehow this special needs
people may present with other medical problems as well. They would need the support
from the medical services. Whatever that we plan should be patient centred so that
whatever treatment that they receive, they can have it at one place. One stop centre
for them rather than referring them from one place to another which may be
inconvenient for them. Some of them especially those who come from socially deprived
group, they don’t have the fund to go from one place to the other. They have to
depend on a lot of people....’ (PMM2)

Considering the fact that, the patients were scattered everywhere in a community, if
the unit was to be set up at a hospital, a referral system must be developed which
would link the community and hospital based dental clinics. A referral system
suggested by the policy makers should take into account the reference from the
community clinic to the hospital and vice versa. The role of the specialist in SND might
be to stabilize the active oral diseases and after it had been managed, the system
would allow the patients to be referred back to the dentist at the community dental
clinic for the maintenance phase. For some patients, they might need to be followed
up continuously by the special care unit. In doing so, the specialist in SND and general
dental practitioners must have clear guidelines about the type of patients with special
needs who are eligible to be referred to the specialist and those who could receive
treatment at the community dental clinics. Therefore, referral guidelines were the first
thing that future graduates in SND should look into before the service could be
delivered and marketed to the community.
An example of responses:

‘There must be some kind of a system of referral. That would be the link there. It works both ways. The referral can come from the community goes to you at the hospital and then after that when you have stabilized, I was hoping, in the situation is that, the patient you may refer back to the officers who referred to you. And you can get on to the next case. Maybe some cases you would not refer back and keep it with you at the hospital because of the medically compromised situations. So you have to play that back or you have those guidelines. Whatever happens you must have those guidelines.’ (PMM3)

On the other hand, according to a number of participants, by having the special care unit set up at the community health centre, it would be easily accessible by the community. This was due to the nature of the service delivered at the community health centre which allowed the system to be approachable by the patients. Dentists at the community dental clinics would be the first person that patients sought for treatment. Additionally, the service could capture a wider range of the population by being at the community-based centre because most of the people with special needs were residing in the community.

Another suggestion by the informants was to set up the unit at a hospital and provide secondary dental care but there would also be a unit at the community dental clinics which would act as a screening centre and provide dental education specifically for people with special needs. The special care unit at the community health centre might not necessarily be managed by the specialists in SND. It could be handled by a general practitioner who had a keen interest in people with special needs and by the auxiliary dental staff who were trained in managing this group of people. On a regular schedule, the specialist, who was based in the hospital, could do a visit at the special care unit in the community to monitor the overall service and provide assistance as required. Only patients with specific and complex special needs problems would be seen at the hospital level by the specialist. Other patients with special needs managed at the community setting would continue having treatment there as necessary.
An example of responses:

‘…..Because, the whole system here is just not you and hospital and wait for things to come. You must be related back to what’s happening there in the community. We must remember also that the way that we have our community may be different from that in the Caucasian society. We have to go and make those adjustments you know.’ (PMM3)

For a start, it was recommended that a link with the medical colleagues should be developed to seek out the patients. The medical colleagues must be informed about the extension of the dental service to people with special needs. A clear definition about the type of patients which could be managed by SND must be acknowledged to other health professionals so that the necessary referral could be made and a pool of patients could be created to run the service.

The setting up of domiciliary service was also introduced to the participants in this section. The narratives appeared to agree that visiting people with special needs at home could be difficult, as the formal registry of the patients did not exist and they were scattered around the country. Added to this was a lack of manpower and mobile equipment to run the service. If it was going to be implemented, the target groups might be those who were in an institution, because they could be easier to approach as the institutions were usually registered with Social Welfare Department. The current situation in Malaysia might not allow the domiciliary service to be fully implemented until the proper system of registration of people with special needs in the Ministry was in place.

An example of responses:

‘…..Don’t wait for them to come to us, we will go to them but it is not a home visit but institution based….. That’s why I said we must have the registry. In Australia, they already have the system where they do home visit for special needs but these people must have the list but in Malaysia we can do that as yet.’ (PMM2)
3.1.4.3.2 Facilities

The existing dental facilities could be classified as not being user friendly to people with special needs especially for those who use a wheelchair as mentioned by all the Malaysian participants in this group. Most dental clinics were located on the first floor or the second floor which usually could be accessed by staircase. Lifts were not provided, because according to the Economic Planning Unit, the premises of a health clinic could only be fitted with lifts if it had more than certain number of floors.

In order to facilitate the people with special needs and to reduce the barriers in accessing dental care, future plan of the upcoming dental premises would always focus on the people with special needs. The floor plan design of the surgery and the waiting area for the special care unit must be large enough to accommodate a wheelchair or a stretcher. The position of the dental unit should also be taken into consideration in such a way that the patients can be seated easily and comfortably. Rest rooms would be built specially for people with special needs with easy access. The most important feature was that the location of the special care unit must be on the ground floor or if it had to be above the ground floor, provision of a lift was deemed essential. Ramps and railings were the other two important elements that should be provided for the building. The informant who was managing the dental facilities developmental unit in the Oral Health Division cited that for all briefs of requirements of future dental facilities with particular attention to a special care unit, these essential aspects had been included for approval by the Economic Planning Unit, as indicated in her statement below:

"Because I'm attached with Facility Development Unit, my unit looks into a brief of requirement of facilities. All facilities that are planned, we would stress on special needs. The design should also cater for people with special needs. For example, the surgery whereby we need the door to be wide enough to accommodate wheelchair and the way we place our dental chairs so that the special need people can have easy access. From equipments to facilities. And also if we have rest room area, we would also like to cater for special needs people. And of course our clinic, first thing is we want it to be located in the ground floor but we always insist that if it is located on the
first floor, there should be a lift that will cater for these people. That is our plan but whatever materialized from that is beyond our control. That is our brief that we always put in.’ (PMM2)

3.1.4.3.3 Support provided by the government in the development of SND

The recognition of SND as one of the dental specialties in Malaysia had indicated that the support from the government in the delivery of health care for people with special needs was overwhelming. The informants described that, the support was provided in various aspects in the development of the specialty, including the specialist training in SND, encouragement of collaboration of other organizations to promote the care to the community, creation of a systematic referral and standard management of care for people with special needs and organizing programme related to SND for care seeker and care provider.

Training specialists in this field was the first step taken by the government to ensure that the oral health care of people with special needs would be in the hands of an expert. The general dental practitioners who showed a keen interest in SND were sponsored by the government to undergo clinical training in SND overseas (New Zealand and Australia). It is expected that, the presence of the specialists in this field would motivate and increase the interest of other general dental practitioners in SND. With the expectation that the demand for SND service would increase in the near future, the Public Service Department had allocated at least two scholarships for general practitioners to pursue a Master’s degree in SND every year since 2008. Additionally, the training unit in Oral Health Division was also looking into a programme to train the auxiliary dental staff such as dental nurses and dental assistants in the management of care for this group of patients. Various training programmes for auxiliary staff, from overseas were thoroughly reviewed in order to develop a training programme which best suited the Malaysian community and health environment.
An example of responses:

‘........I asked him to look up what is available overseas because I'm looking at the DSA's training. Maybe what is available in overseas, maybe we could do something. They have got this kind of certificate like special care dental nursing, health education and so many others. Because we are thinking to upgrade the DSA qualification to Diploma. So they have got even sedation, like special course training, paediatric nursing and radiography. Special needs and paediatric, sedative we really need....’(PMM4)

The health care providers were considered to be the most important stakeholders by the informants. The importance of collaboration and cooperation with the health department should be understood by the oral health coordinator. Currently, they are now focusing on elderly oral health programme, as the elderly group can be classified as people with special needs too, especially the ill ones. Guidelines on oral health care for elderly had been established for reference by the general dental practitioners several years ago. The elderly programme covered both the well and ill elderly, although the target groups were the ill geriatric population. Since the aim of this programme was to promote wellness, the inclusion of the whole group of the elderly population was appropriate. The manager from Family Development Unit, Public Health Division was invited to participate in the auditing session of the implementation of the guidelines in the government community clinics in the states. This was done to increase their awareness about our intention and passion in improving oral health of elderly so that, later whatever programme held by the health department would incorporate dental health as one of their agenda. The success of such programmes was proven with the inclusion of cross reference to oral health division at clinic level in the latest guideline on general health management of elderly developed by the Public Health Division.

An example of responses:

‘In fact, one of the major stakeholders should be the health care provider. In fact they have come up with a guideline last year on the implementation of care for the elderly at community and clinic level. So, they brought up the whole process flow and where
they need to have the opportunistic screening and then at certain areas/points where they also included the cross reference to oral health division at the clinic level. They are monitoring this quite closely. I was very happy when I saw that guideline, the plan of action on the implementation........’ (PMM4)

It is important for SND unit to work together with the Social Welfare Department as it is responsible to look into the welfare of people with special needs in term of financial support, social welfare and vocational training. There were a number of institutions managed by this department which provided day care services for people with special needs. Collaboration with the local branch of the Social Welfare Department could help in educating the caregivers and people with special needs about oral health care. Some oral health divisions at state level had incorporated regular dental visits to the nearby Community Training Centre for people with special needs in their yearly programme. The mobile dental unit was responsible for doing a yearly dental examination for the residents at that centre and making referrals to other community dentists or specialists as necessary. It was expected that, this ongoing programme would provide continuity of care for patients and would improve significantly with the presence of the specialists in SND. Collection of basic oral health status data was planned for the establishment of the service to provide for research, auditing and quality control issues.

There were other organizations which play a role in the care of people with special needs such as NACSCOM (National Council of Senior Citizen of Malaysia), KIWANIS and Down Syndrome Association. It was stressed by the informants that, creating networks with these organizations could make SND well known by the community. Now that they had a venue to attend for dental care, the demands for SND service would increase, more data could be collected, therefore some justification could be made to improve the service so that high quality dental management and prevention programme for this population could be included to the level of international standards.

In comparison, even though SND service in New Zealand had been developed for years through hospital dentistry service, the current situation showed not much difference
from what had been happening in Malaysia. New Zealand was claimed to have an insufficient group of practitioners who advocated for people with special needs. There were only few graduates in this field. The Ministry of Health New Zealand had recognized SND as an area needing further work on the service coverage and specification. The draft document of the service specification was published in the NZDA news recently.\textsuperscript{14} Research involving oral health care of people with special needs in New Zealand was lacking and required further attention. Moreover, even though the current SND service was based in the hospital, the informant believed that, the practice should be both at the community or hospital settings. The development might be improved by better support service needs of the patients. They also thought that, with the skills of the specialist practitioners, providing the service within the community setting might not cause any problem at all. Nonetheless, a primary care for those with disability who unable to access care in the community, the provision of secondary and tertiary care would be better achieved within a hospital setting, when special management was required or when dental services were required as part of other medical or surgical treatment.

3.1.5 Disability support group representative

The information provided by representatives in the disability support group reflected the degree of cooperation and support which could be obtained in collaborating with the development of SND either in Malaysia or New Zealand. Their perceptions about oral health care of people with special needs would influence their preparedness in working together with the dental team in the provision of dental care for people with special needs. In this section; (a) their roles and involvement in oral health care for people with special needs would be clarified; (b) their opinion about existing dental service for people with special needs would be reviewed and; (c) their knowledge and education in oral health care would also be explained. Figure 3.5 summarizes the areas of concern involving this group of participants.
3.1.5.1 Roles and involvement in oral health care for people with special needs

It was identified that the roles of the disability groups were generally similar from one organization to another. Their roles were very much involved in the management of activities of daily routine of the clients including the oral health care. Most of the disability support service associations or organizations in Malaysia acted as day care centres while at the same time providing vocational training to develop their skills in certain areas that could be used as a financial resource when they were out working in the community. Some centres provided personal training for people with special needs.
to develop their social skills in order to live independently. Attending the support centres which were under the management of Social Welfare Department was free of charge, in fact, they were eligible to receive a monthly personal allowance if they were registered as people with disabilities with the local branch of the Social Welfare Department. However, the eligibility applied only if they would be able to attend the day care centres at a minimum four days a week and comply with the Social Welfare Department eligibility criteria.

An example of responses:

‘...So, the parents tend to send them here so that they can meet others with the same condition and continue learning the social skills from our staff. We are open from 8 to 12 pm in weekdays. In addition, those who come here are automatically eligible to receive RM150 monthly as personnel allowance. However, they have to come here at least 4 days in a week. Otherwise, they will not receive the allowance. Some parents do not understand the rules and regulation endorsed by The Welfare Department. They thought, everyone with special needs can get the same amount of allowance. There are a lot of categories for them to be eligible.’ (SGM1)

There were several centres managed by non-governmental organizations which provided full time residential support for people with special needs. They were not fully publicly funded bodies, therefore, parents or caregivers would have to pay some amount of money for the services.

‘No it is under NGO’s management. This is the place where people with special needs are sent by parents who are not willing to look after them anymore. It is operated full time. The parents would only come in the weekend to take them home and return them on Sunday. And of course the parents have to pay for the service.’ (SGM1)

The functions of the disability support organizations in New Zealand were slightly different from that in Malaysia. Some might involve in community supports while others were providing support at residential service centres. Those with mental and intellectual impairment were the groups of people who were often under the care of these organizations. These categories covered a wide range of special needs.
conditions. It was suggested that the community service could be provided as two hours support a week or two to four hours a day, which would involve looking at personal finances, and health or risk assessment of the person. Residential support might be provided from eight to 24 hours a day. It included washing, personal clothes, cooking, cleaning and community activities.

'So for some people PACT as a whole maybe can provide two hours support a week which would involve maybe looking at bill payments, ill health, or like just little catch-ups, risk assessments on the person etc. Or people may have somebody going daily into the person’s own home for maybe two to four hours. Then that would be more community support services. We have a residential support where people can receive maybe for eight hours to 24 hour support a day. That's for people with mental health or intellectual disability or a dual diagnosis. And that support can be as detailed as washing, personal cares, cooking, cleaning, supporting the person to go to the doctor, community access, like lots of community activities on exercise, diet, all those kind of things. So maybe just a little bit sometimes for some people or full time care for others, depending on the needs assessment that comes through. Like when we first start supporting the person.' (SGNZ2)

3.1.5.1.1 Their roles in provision of dental care for people with special needs
It was clear from the narratives that some organizations were aware about their role in providing home dental care for their clients, while others were genuinely involved in the vocational training. The community service which was provided, required the carer to clean the client’s teeth as a routine basis especially for those who were totally dependent on others to carry out their activities of daily living.

Some carers who were attached with such organizations had made a great effort in getting some funding through governmental scheme available, for the client to receive needed dental treatment such as dentures or crowns. The dentures had greatly improved the client’s self esteem and her quality of life.
An example of responses:

‘But through a new initiative, I think it must have been a Labour government, a scheme became available called PARDS, and so I referred one of the people I support and very luckily they were approved. These are people that it’s recognised that they may be able to take up some form of employment in the future, so I was able to get one person, she had very few teeth left and she’s a young woman in her late 30s, and through that funding I was able to obtain, she has now new dentures, which has improved her self-esteem and her physical health.’ (SGNZ1)

A representative from PACT group, a well known disability support organization in Dunedin discovered that there were support workers who had poor skills in maintaining client’s oral hygiene. It was reported that, they tended to forget and miss this important routine for various reasons. Even though basic tooth cleaning was carried out for the clients, there was still a lack of support in other mouth cleaning measures such as flossing, or identification of problematic periodontal tissues or presence of any obvious pathological lesions associated with teeth. Based on lengthy experience in nursing and support provision in community service and residential care, a document called Personal Carer Document which consisted of checklist of daily routine care provided by the carer was produced. Tooth/mouth cleaning and identification of any signs of discomfort in the mouth generating from teeth or by other related factors were occupied in a particular section of the document.

An example of responses:

‘Yes. Yes, we do have some. We’ve recently produced a document called Personal Cares document, which I can give you a copy of after this interview. I’ve got a few things I want to give you actually to support what you’re doing. But that is a document we produced which gives information around how to clean somebody’s teeth and what kind of support that person may need as part of that. From my experience I think quite often dental care may be overlooked. I’ve been a nurse for 15 years in community support centres and in residential kind of settings and I think quite often support workers either miss or forget. There can be many different reasons for that. It’s not always, I know some people always have their teeth cleaned as well, but I think still
there would be a lack of support around flossing, or following up dental problems or identifying sore gums or ulcers or other kind of complications with the teeth, just because of the poor skills. We've got some support workers have to identify that.’ (SGNZ2)

This group also already used a World Health Organization (WHO) screening programme to review the client’s oral health. They were also responsible in supporting the clients accessing dental care facilities every six month or at least once a year. The ability of the support worker to recognize a change in behaviour related to tooth ache was also reinforced by the management of the support group, so that any problem could be attended immediately.

An example of responses:

‘...The other project we’re doing at the moment is a health check which is a screening check for the World Health Organisation, like mental health, sexuality, heart and respiration, exercise, mental health. But under general health oral care comes under that, and we’ve noticed that people may not attend their dentist very regularly, even though you should go every six months. I believe every six months would be normal for excellent care. Probably, more in reality. But we’ve been looking at how we make sure that the 800 clients that I run the PACT throughout Otago all attend those appointments on a regular basis. At least once every six months or once every year. That includes having that payment, if we can afford to go to the dentist, we’re looking at that at the moment. But also to help support staff recognise when somebody’s behaviour may be related to tooth pain. I’m trying to think what else....’ (SGNZ2)

In addition, educating staff about basic dental care for the clients was part of the responsibilities of the support group. Even though, they were not formally trained to speak on the oral hygiene care, some information could be delivered based on experience and basic knowledge obtained while visiting a dentist.

An example of responses:

‘..There's no specific plan but when I do education for staff, it's something that I haven't specifically done but it's something that I can speak to, just the importance of
cleaning teeth. And also doctors will often prescribe Savacol, so I'll get questions about the best way for support staff to use this for the people that they're supporting.’ (SGNZ5)

3.1.5.1.2 Participation in oral health care programme for people with special needs

For most organizations, there was no specific programme related to oral health care which was held on regular basis. The programme was often initiated by the Ministry of Health rather than being part of the annual agenda of the organization.

In Malaysia, an initiative was made by the Oral Health Division to conduct the oral health programme on yearly basis at the Community Training Centres at each locality. This would encourage an active participation of the organizations in oral health care for people with special needs. In this particular event, a seminar for parents and caregivers was held by inviting public health dentists to speak on oral health issues and care, essential for the improvement of quality of life of people with special needs. Free oral health screening for the residents was also incorporated within the event, accompanied by puppet show and poster presentation by the local community dental clinic. Through the screening, those who were identified of having dental problems which needed further attention were referred to the dental clinics or specialists as appropriate.

An example of responses:

‘Yes, last year, we worked together with the Dental Unit at Putrajaya Health Clinic with Dr Leslie and his team in organizing a session which included dental check up, a talk for parents, puppet show and other stuff. We plan to do it every year. Those who were not able to attend the session were given appointment at the dental clinic.’ (SGM1)

However, under certain circumstances, the patients rarely attended the dental appointment arranged by the dentist to be seen at the nearby community clinic or hospital dental clinic, as caregivers or parents did not see dental care as an important element that should be looked after appropriately. The narratives showed that, the participation of the parents and caregivers in any programme including oral health
programme organized by the support groups in Malaysia was very poor and frustrating. A lack of parents’ involvement might reflect the poor management of the organizations and it could lead to the closing down of the centres. Getting the monthly allowance could be the main reason for the parents or caregivers sending their children to the centres. Therefore, their participation in any programme was not considered vital and tended to be ignored. Other than that, the community dentist was responsible to arrange an annual dental visit to the nearby Community Training Centre in order to do the dental examination for the trainees.

An example of responses:

'......What are we lacking of is the involvement from parents. They want to do everything after office hour which may be easier for them to come but we cannot manage to organize every programme after office hour as we also have our family commitments. When there is less involvement of parents in the conducted programme, it seems that, that particular centre is not well organized and less support will result in the closing of the centre. Some parents just send their children with special need at this centre for them to get the allowance.' (SGM1)

The informants did agree that such programmes were useful in delivering information to people with special needs and the caregivers, about the importance of oral health care. The awareness had brought along the involvement of other organizations such as the Ministry of Education to participate especially at school level in any projects associated with dental care for people with special needs.

3.1.5.2 Opinion about the existing dental service for people with special needs

The view of the support group regarding the existing dental services for people with special needs was crucial in making improvements and future planning to develop better services in the future. Through the interviews, the informants were concerned about service delivery, the barriers for people with special needs to access dental facilities, and the necessity of the establishment of a domiciliary service.
3.1.5.2.1 Service delivery

From the transcripts, for some people with special needs, visiting dental clinic might induce the anxiety feeling and led to aggressive behaviour which might give negative feedback to other patients at the waiting area. There was a situation when several private practitioners had refused treating certain patients due to their high level of aggression, violence, and anxiety or other factors that may place the service and the dentist at risk, therefore, the patient had been referred to the dental school for further management. Managing patients with aggression could be challenging for certain general dental practitioners. It was clearly mentioned in the narratives that, in any situation, staff at the Dental School (School of Dentistry, University of Otago) would do their best to accommodate this group of patients to meet their treatment needs.

When dealing with people with special needs, the informants noticed that the communication between the dentist and the general practitioner was lacking in certain areas. Quite often, health professionals could not recognize behavioural changes in patients that were associated with their dental problems. Medications were usually an answer for unacceptable behaviour and the dental problems could be untreated for several years. Hence, it was important that, the medical professionals were informed about this issue. It was suggested that, an establishment of a system which could facilitate the relationship between the dentists and the general practitioners or other health professionals would improve the management of patients to a higher standard.

A team approach practised at the dental school in managing patients who undergoing comprehensive dental treatment under general anaesthesia, was greatly appreciated by the participants in this group. Despite the dental treatment, having other treatment required such as blood investigations, chest X ray, or as simple as ear, nose and throat examination under the same session could be very helpful to make full use of the general anaesthesia and resources. Frequently, physical health examination for those with intellectual disabilities offered some challenges when they were awake.
It was also observed that, the younger dentists experienced some difficulties in dealing with people with special needs, by virtue of their lack of experience. It was recommended that training around people with special needs in terms of communication and skills should be incorporated within medical and dental programmes at the university.

An example of responses:

'......Some of the other doctors, like the anaesthetists and stuff like that, and the registrar, just probably by virtue of their lack of experience I think find it a little bit more difficult dealing with people with special needs. Because they are a totally different group of people and the communication needs are much different and there's not a huge amount within med training or dentistry training around people with special needs.' (SGNZ5)

In Malaysia, the main service provider for people with special needs was the government dentists. A limited number of narratives from this group suggested that, the dentists should have more frequent visits to the rehabilitative or training centres where these people were lodged so that the patients and the caregivers would be more familiar with them and have better awareness and attitude about regular and proper dental care.

The informants agreed that there was no continuity of care in the current services. Building a rapport and trust between the patients with intellectual disability and the dentist could possibly take a large amount of time. In the dental schools or at the community clinics, a particular dentist did not stay for long and the turnover was somehow very fast. Meeting a different dentist in each appointment could develop excessive anxiety, as patients took longer to adjust their thinking.

An example of responses:

'It's also about that relationship stuff, too, because most of us build up a relationship over time with our dentist or whatever, whereas for a lot of our clients they haven't had those opportunities to have done that......' (SGNZ3)
3.1.5.2.2 Barriers to access to dental care facilities

There were various reasons for people with special needs not having dental checks as regularly as any other groups in the population. It was identified from the narratives that the attitude of the parents and the caregivers had so much influence in the oral health status of the people with special needs. Social stigma about having children with special needs in Malaysian community still existed and parents were embarrassed to take their children with special needs out to join the community activities. They often could not cope with the children disruptive behaviour and kept them at home until they became severely ill. Furthermore, the parents or caregivers did not appreciate the importance of having good oral health and dental prevention was not considered as priority. Frequently, in this time, parents seemed to focus more on the children academic capability rather than maintaining good health.

An example of responses:

‘I think parents also are not into it yet. We tend to overlook on the dental care. Most parents are more concern about education. For example, they have been asking us to emphasize on education because they would like to see them know how to read. However, when they come here, it’s already late, so we try but may not be possible. So we emphasize on the self skill including dental care.’ (SGM3)

An old belief remained in the general society and also within the group of people with special needs was that, living without teeth would mean they could avoid going to dentist. Therefore, very often, tooth extraction was an answer to any dental problem and the social workers would have less trouble in looking after their mouth and made their job much easier. Changing this attitude was a challenge to dental professionals as other factors such as patients’ behaviour and special needs conditions could also reinforce the belief to stay as an easy way out.

An example of responses:

‘Sometimes I think there’s a belief within intellectual disability or in general society maybe that if you have no teeth that you don’t need to go to the dentist. I’ve done a lot of screening for health dental care in this organisation and other organisations in
Dunedin as well, and many support workers would tell me “he has no teeth, therefore he doesn’t need to go to the dentist”. So a very, very common belief. I don’t know how you go about changing that. Just by teaching it to everybody and making sure that they know that.’ (SGNZ2)

Inability to understand the children’s or the client’s body language and behavioural changes which could be related to dental problems resulted in poor dental care and the conditions left untreated for such a long time. This could be associated with staff and client ignorance.

An example of responses:

‘I think one of those things is a communication. They cannot tell their parents when they have toothache. Sometimes, the parents are not concerned about it. I think this is an important area to look into. More often, it is not.’ (SGM4)

Poor communication between the service provider and the support group might cause failure to attend dental appointments without prior notification. The support workers might at times forget about the appointments for a reason as simple as not checking the diary a day earlier or the clients decided not to go for the appointment at a very last minute.

Anxiety was found to be one of the major barriers for not going to dentist. Most people with special needs could not tolerate being surrounded by people in public and they may act aggressively to compensate their feeling. Being at a place full of strangers could be stressful for the person and for the public too because they could behave in a socially unacceptable behaviour. It could worsen with long periods at the waiting area. To avoid this stressful situation, the caregivers were not very keen to take the clients to the dental clinic unless they were sure about a presence of serious dental problem which affected the client’s daily life.

An example of responses:

‘…..Probably fear. I think fear’s a huge thing, and because they have to come into like a public place, often some of our people we support find public places really difficult,
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis
(Based on New Zealand Experience)

and there's quite long waiting lists, well, not waiting lists, but there's quite long wait times within a public area, and that can be very stressful for the person, but also it can be stressful for the public because the people we support with intellectual disability don't necessarily behave in a socially acceptable way, and that can promote fear with members of the public. And so it just builds up barriers.' (SGNZS)

Financial problems and poverty always came together with people with special needs. Attending regular dental appointments meant more costs for the clients. Even though, they lived under certain benefits, the amount could only support and meet their basic needs. The allowance obtained would just entitle them to receive emergency treatment and this would not allow them to receive preventive treatment.

An example of responses:

‘....like, we do know what people are entitled to from Work and Income and in Balclutha the case managers that I work alongside as I go with the people I support are brilliant, but they can’t change the system, and presently there’s $300.00 per year allowed for emergency treatment and it frustrates me that that $300.00 is not an entitlement that can be used every year for some preventative work like getting the hygienist to clean the people’s teeth......’ (SGNZ1)

Fortunately, in Malaysia, the cost for dental treatment was not a major issue as it was fully subsidized by the government. Attending the government dental clinic was cost free for people with special needs in Malaysia according to Dental Fee documents provided by Oral Health Division. However, a minimal amount must be paid for prosthodontic appliances such as dentures, crown and bridge work or implant.

From the support workers' point of view, lack of knowledge could be a barrier for them to clean the client's teeth. There was always a high risk with some of the clients when come to personal cleaning. A tendency to bite might create a boundary between the carer and the clients. Additionally, the carer was not trained and well informed about the appropriate management in handling specific cases when clients' habits and behaviour came into the scene, leaving the teeth and mouth in such a poor condition.

† Dental Fee for patients attending Public Dental Clinic in Malaysia, provided by the Oral Health Division, MOH Malaysia
An example of responses:

‘It’s that lack of knowledge....... Prior to that, I mean, there is a high risk with some of the clients. If you put your finger near their mouth you are going to lose it or, you know, it’s going to create something else, other behaviours or whatever. So that’s a barrier for a lot of people.’ (SGNZ3)

Apart from that, the current dental facilities may not good enough in accommodating people with special needs. For example, a lift was unable to accommodate a stretcher or a wheelchair especially at peak time when other people were also trying to attend the appointment in time. A waiting area could also be crowded at times with insufficient chairs placed to accommodate all visitors. This scenario might induce a stressful condition which the clients could not cope and lead to leave before treatment is begun. Even if the client managed to enter dental room, they might refuse to be examined or became uncooperative.

An example of responses:

‘It’s just, I mean, if you’ve got, I mean, I’ve been in the lift with a guy who will hit other people and things if they’re too close, and how do you get into a lift to come to a Dental School and go and stand in a waiting room, you know.’ (SGNZ3)

3.1.5.2.3 Domiciliary service
The transcripts had indicated that, home dental visit or domiciliary service could be beneficial in certain situations. Even if the service was yet to be fully implemented, an attempt to make it become a reality would be helpful for many parties like the clients, caregivers or the dental care providers. Even if the service might not apply to every single patient with special needs, for some clients who were unable to tolerate the outside environment, the domiciliary service would be appropriate. Although, it would just be an introduction session to develop trust between patients and dentist, it would prepare the patients of what they were going to expect at the dental clinic. This might assist in gaining patient’s cooperation and reduce the anxiety feeling of the patient in order to get more work done. The informants believed that, for patients who routinely underwent dental treatment under general anaesthesia and could never cope with
dental examination on the dental chair, the consultation could be done at home or the residential centres which might save time, energy and cost.

Examples of responses:

‘I guess in saying, I mean, some of these things aren’t the norm, they’re sort of. Like the people who can’t cope with the waiting rooms and things aren’t the sort of norm, and we have been I think well served by the medical school and things like that. I mean, the majority of the guys I support, it’s okay. But I guess the thing is it’s not the best. But, you know. But I don’t want to get into a situation where they sort of say hey, you know, I think they do a good job and for most of our guys it works and it’s affordable. But, yeah, for some people it doesn’t work. I like that idea of that domiciliary service. That sort of thing sounds nice for a few of our guys that can’t cope in a waiting room and can’t cope with that big building.’ (SGNZ4)

‘For the guys who have typically had a general anaesthetic to get dental work done, that would have – I mean, that would take so much stress out of us trying to get them into that building. I mean, if they could have just visited and read the notes and visited, that would have been – I mean, we would have driven them around.’ (SGNZ4)

It was recommended that, if possible, to implement domiciliary service as an outreach programme to include people who had never been treated at the dental clinic in the system. Mental health centres or day care centres for people with special needs could be good places to start the service, as almost five percent of the residents were not be suitable to go out in public. Such services would prevent people from getting serious dental diseases and help in achieving the primary health target.

An example of responses:

‘I think for some people that would be very helpful, because I think some people you will never get into a dentist for one reason or another. Either very bad encounters in the past or anxiety. I think it’s a brilliant idea. I think also you could, like for that kind of services, trying to reach people there maybe 5% of Dunedin where it’s very, very hard for one reason or other to get them into the surgery. So you could target places like Asgoes, Schizophrenia Fellowship and Four Twenty, which are all mental health day
centres. Or options, where you could probably have somebody go in there in one day and deal with up to 50 people who have serious dental decay without them having to get lost in the system and remember to come to you. I could probably help you with that if you were looking. Because as a nurse, I have a similar problem where if I have oral health seminars and I want to get people to the doctors just generally, it’s the same people who you get to go all the time. It’s not the people who should really be out there. Like 5% of people maybe who we can never get to do anything. Like for me my target would be how we get services for those, and the domiciliary service is brilliant, if you could get it to visit. Also some of those health care day centres, I think you would also reach your primary health targets a lot better and stop people getting to the stage where they’ve got very bad dental decay. If that’s helpful.’ (SGNZ2)

On the other hand, the major concern was that it had to be affordable by the clients. Usually, visiting the clients at home required them to pay more than that if they went to the clinic.

An example of responses

‘But it needs to be affordable. Often when people go, when health providers go to someone’s home or into a facility where someone’s living, often the cost is more and that can actually put people off and make people less inclined to access that sort of service.’ (SGNZ5)

3.1.5.3 Knowledge and education about Special Needs Dentistry

Different views and perspective about oral health care for people with special needs among this group of participants were observed. It might be associated with the level of knowledge and education received by the informants related to oral health. However, these views were valuable and should be considered in the development of the SND service.

3.1.5.3.1 Oral health care for people with special needs

The narratives cited that taking care of oral health was as important as looking after the general health. Several narratives had placed oral health at the highest priority especially for elderly and people with special needs. They were often under a lot of
medications to maintain their general health, which could have some detrimental effects on the teeth and causing periodontal problems. Any problem related to teeth or periodontal tissues must be attended immediately to prevent progression of the diseases to a stage which was beyond savable.

An example of responses:

‘I would put it at one of the highest priorities because we’ve got older people in our services too that I would imagine some of their medications have had a pretty detrimental effect on their dental health, and just because their teeth are missing, I only just know this from a lay person’s perspective, but I would wonder how much gum disease is there, even when the teeth are not there, you know, because they seem to get a lot of other physical problems that are not really looked at correctly.’ (SGNZ1)

A belief of extracting teeth as a solution for any dental problem still remained in the community. This belief would lead to edentulism which could contribute to difficulties in swallowing and chewing later in life. A set of dentures which was always an answer to replace the natural teeth, normally, could not be tolerated by people with special needs and might cause some discomfort and frustration. This would initiate some other problems related to their behavioural changes, aggressiveness and inappropriate dietary habits, that would affect their general health as a whole. The active and continuous involvement of parents and caregivers in assisting the children in brushing teeth from an early age could prevent further deterioration of their dental health in adult stage.

An example of responses:

‘To me, dental health is very important. If we cannot maintain their oral hygiene and the tooth need to be extracted one by one, they will end up with a denture which is sometimes quite uncomfortable and causing discomfort especially for those with special needs. We use teeth to eat, without teeth, the process of chewing and swallowing will take much longer. They can be taught to brush their teeth from early childhood but requires a lot of patience from the caregivers.’ (SGM1)
Good oral health was thought to be able to improve the community social stigma about people with special needs. Their good appearance represented by clean, straight teeth would make them more approachable and acceptable within the community despite their special needs condition.

Example of response:

‘I think it is very important, you see. When you are born special and then you don’t take care of your teeth, when people look at you, they are so scared to come near. At least, when you have a nice set of teeth, you can smile, people are more willingly to come near. I mean, for me if you have a special child, you have to keep them clean. If you keep them clean and you have a nice set of teeth, people will approach you otherwise if you are too smelly, how do you expect people to come near you?’ (SGM2)

Even though, the informants were aware about the importance of having good oral health, they also noticed that the oral health of people with special needs had been ignored a lot. A participant in this group made a statement according to a study involving the Olympics Olympiad who participated in Special Olympics in China in 2009, 40% of them had some sort of dental conditions which had been left untreated. This figure reflected high level of ignorance in oral health care in the community even among the public figures.

An example of responses:

‘I think it’s ignored a lot. I have an article showing that thinking of figures now here, but I think 40% of the Special Olympics Olympiads who went to China this year, to Beijing, they all had health checks done and I think 40% of them had oral conditions, dental conditions which had gone untreated. Which is very high. And if we see that, that’s our Olympics team not being supplanted you can imagine it would be even higher in general society. I’ll give you the article to take away with you.’ (SGNZ2)

In terms of the service received by the clients, the informants had described that their dental needs should be attended by dentists with special skills to deal with people with disabilities. Even though their needs and demands had no difference from other normal people, the delivery of treatment required special intervention and passion
from the health care provider. The ability of the patients to understand the conversation should be identified by the dentist to ensure the information could be delivered effectively. Communication strategies such as slowing down, simple language, allocating some time for the patient to understand and visual media must be emphasized within the general training of dentists, who were responsible in managing people with special needs. Although, they were not necessarily to be a specialist, they should be familiar with verbal and non verbal communication involving people with special needs.

An example of responses:

‘Depends on the individual. Yeah. I would prefer – I guess it would be nice if they could see the same specialist every time so they develop that relationship. But I think it does need to be someone who doesn’t – I mean, it’s one of the things you strike if someone works out somebody has an intellectual disability, if you’re in a shop or something, typically they’ll talk to the staff and it will be individual, or they’ll raise their voice because they think that they don’t understand and, you know, speaking loudly helps them understand somehow. Or they’ll just completely talk over the top of them and say you need to get this done and the person won’t understand what’s happening. So I think there does need to be some training.......... Yeah. Or include in the training some very specific principles about slowing down, simple language, take your time, give the person time to understand, use some visual strategies. Stuff like that.’ (SGNZ4)

According to the participants, theoretically, everyone should have the same amenities and opportunities to access general dental practitioners, but the reality was somehow a little different. Therefore, it was appropriate for people with special needs to be seen by someone who could handle and manage them in an appropriate way or otherwise it might result in negative perspective about the service and more problems occurring.

3.1.5.3.2 Training
None of the social workers either from Malaysia or New Zealand had received formal training in looking after the oral hygiene of people with special needs. They mostly worked on the basis of their own initiative. The staff whose responsibility was to train
the people with special needs to live independently were utilizing the skills that they learnt from experience and they thought was appropriate for the person to clean their teeth.

An example of responses:

‘There was no special course or anything like that. It is our own initiative but we feel that brushing teeth is a skill, so we teach them whatever our idea or skill to these children. We apply our own formula.’ (SGM3)’

Despite the lack of training, some support workers were confident in sharing the skills they had with the patients and caregivers in the delivery of oral health care, whereas other participants believed that, they were not capable in giving such advice to the caregivers or patients. Nevertheless, they still did the routine cleaning for the patients as they saw fit and necessary. The preventive management was often supported by encouraging healthy diet and reduction of sugary food consumption.

An example of responses:

‘......it needs to be someone with the proper expertise plus people from where I work support people, we can see people haven’t cleaned their teeth and we’re honest with them about a lot of things, ......................................................I don’t think it’s an area where support people – well, they haven’t got the, and you could give the wrong advice because some of them you can see that their gums probably bleed quite a bit. We can encourage with healthy foods and all those things but as for the actual planning, no, it needs to be somebody that understands, yes.’ (SGNZ1)

Based on their past experience, this was the area that someone or organizations should look into in some depth. Training of the staff in basic oral health care management for the person who they cared for should be reinforced to avoid the sustaining of a myth that ‘no teeth, no toothbrush’. The training should not just focus on the tooth cleaning but the overall cleaning of the mouth consisting both, soft and hard tissues. This would help the support workers to start their job with confidence and knowledge about what they were expected to do.
An example of responses:

'To me that reinforces that staff need some training on it, because otherwise people start their job and they think no teeth, no toothbrush. And that’s not the case at all of course.......... But I think it would be good for staff who are on the ground level supporting people knowing about dental hygiene and especially around gums for the people that don’t actually have any teeth.' (SGNZ3)

3.1.5.3.3 Dental health promotion

Dental health promotion was an important element in the development of the SND services. The level of knowledge about dental care of the support workers exhibited the effectiveness of dental health promotion regarding people with special needs. Several transcripts from this group mentioned that, manufacturers of dental products could be actively involved in dental health promotion while at the same time marketing their products in the community. Even a short segment in the advertisement of their products about basic education and assistance in dental cleaning for people with special needs might be helpful for parents, caregivers and patients. The oral health care providers should work collaboratively with the manufacturers as they tend to be more creative in promotion and marketing in the electronic media which usually had more coverage of a wide range of population.

An example of responses:

'Yeah. I think, you know, if organisations like Johnson & Johnson who sell toothpaste, if they were a little bit more actively involved in providing some sort of education and maybe even assistance. Maybe the dental budget, the health necessities would go down because people were better educated.' (SGNZ5)

The fact that the welfare of people with special needs was commonly overlooked in various aspects including oral health was also emphasized by a few informants of this group. At this stage, none of the dental health education or promotion organized by Ministry of Health focused on dental care pertaining to people with special needs. It would be necessary to include some guidance, as simple as how to use the toothbrush
and cleaning their mouth especially for people who were unable to understand complex information. Some general guidance for the carer in taking care of their dental health in the form of a simple brochure and pamphlet might improve the home dental care and could result in significant difference in the oral health status of the patients.

An example of responses:

'...should be essential. At the moment I have never heard the promotion from Ministry of Health pertaining to dental care for people with special needs....' (SGM3)

In general, from the perspective of the informants, preventive care was an important aspect of dental health management to improve the level of the clients' oral hygiene, as the impact of having dental problems in people with special needs could be much greater than that in other groups of population.

To summarize, the results from the qualitative data analysis had successfully identified six major themes which were useful in generating the survey questionnaire in the collection of the quantitative date. The themes are listed as follows:

1. Oral hygiene practice for people with special needs;
2. Knowledge and view on oral hygiene care for people with special needs;
3. Barrier experienced by people with special needs in accessing the dental care facilities;
4. Criteria included to define people with special needs;
5. Demands for the SND service and the support provided for the development of the service;
6. Exposure and knowledge about the SND among the stakeholders involved in this study.
3.2 The quantitative study

3.2.1 Participants

Only 59 participants returned the survey questionnaire out of 345 which were posted, representing 17.0% of response rate. This number comprised of five respondents out of 80 from the group of people with special needs, five out of 80 from the caregivers group, 36 dentists out of 123, eight policy makers out of 30 and five representatives from disability support groups out of 32 who received the survey forms.

3.2.2 Data analysis

Achieving statistically significant differences (p<0.1) was difficult due to a small sample size resulting from a very low response rate in this study. Where the significant differences were observed, they were highlighted in the text which follows. The majority of respondents did complete the survey questionnaire even though there were small numbers of missing responses for some particular variables. Thus these were not included in the report.

3.2.3 People with special needs

3.2.3.1 Sociodemographic variables

The sociodemographic variables for this group of participants included the length of time they had been cared for by the caregivers, the level of disability, the relationship with the caregivers, age, gender and ethnicity. The length of time that the patients had been cared for by the caregivers in this study, ranging from one year to 30 years. The mean of this variable was 13.5 years. Three were reported to have mild physical disability (experienced mild medical, physical or behavioural problems) and two were reported to have moderate physical disability (experienced two or more medical, physical or behavioural problems). Twenty percent of the respondents were cared for by family members, the same number of participants were cared for by non-family members and one participant lived independently. The age range of the respondents fell between 37 to 41 years old with the mean age of 38.9 years. In this group, three respondents were males and the other two were females. There were only two
ethnicities involved in this study, which Malay made up three (60.0%) of the participants and two (40.0%) were Chinese. In all cases, the significant association between the sociodemographic variables and other variables were not observed.

3.2.3.2 Oral hygiene practice of people with special needs

3.2.3.2.1 Assessment on certain aspects of oral care

Certain aspects of oral hygiene care were asked in order to assess oral hygiene practice of the participants. Having problems in performing oral health care was reported by only one participant (20.0%). Two participants who had mild physical disability reported to use devices other than toothbrush to clean their teeth while none of those with moderate physical disability did so. Interestingly, all respondents claimed that they manage to carry out toothbrushing independently apart from their physical impairment. Only 20.0% of the participants had a personal dentist who was seen regularly. Government dentists were visited by more than half of the participants (n=3, 60.0%). However, only two (40.0%) participants were seen by a dental specialist. These were described in details in Table 3.1.
Table 3.1. Oral hygiene practice of people with special needs, by gender, ethnic group and level of disability (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th></th>
<th>Problems in oral care</th>
<th>Dental care devices used other than toothbrush</th>
<th>Aspects of oral hygiene care:</th>
<th>Self oral care</th>
<th>Personal general dental practitioner</th>
<th>Government dentist</th>
<th>Seen by dental specialist</th>
</tr>
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<tbody>
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<td></td>
</tr>
<tr>
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<td>1 (33.3)</td>
<td>1 (33.3)</td>
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<td>0 (0)</td>
<td>2 (66.7)</td>
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<tr>
<td><strong>Ethnic group</strong></td>
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<tr>
<td>Malay</td>
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<td>1 (33.3)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
<td>2 (66.7)</td>
<td>2 (66.7)</td>
<td></td>
</tr>
<tr>
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<td>1 (50.0)</td>
<td>1 (50.0)</td>
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<tr>
<td>Mild physical disability</td>
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<td>1 (33.3)</td>
<td>2 (66.7)</td>
<td>1 (33.3)</td>
<td></td>
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<tr>
<td>Moderate physical disability</td>
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<td>2 (100.0)</td>
<td>0 (0)</td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
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<tr>
<td><strong>All combined</strong></td>
<td>1 (20.0)</td>
<td>2 (40.0)</td>
<td>5 (100.0)</td>
<td>1 (20.0)</td>
<td>3 (60.0)</td>
<td>2 (40.0)</td>
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</tbody>
</table>

*P<0.1
3.2.3.2.2 Frequency of daily toothbrushing

All respondents claimed to brush their teeth either twice a day or three times a day with the majority (n=4, 80.0%) of them practicing the former as indicated in Table 3.2. On the other hand, minority of the respondents (n=1, 20.0%) reported to brush their teeth three times daily.

Table 3.2. Frequency of daily tooth brushing by people with special needs, by gender, ethnic group and level of disability (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Frequency of daily tooth brushing:</th>
<th>Once</th>
<th>Twice</th>
<th>Three times</th>
<th>More than three times</th>
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<tbody>
<tr>
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<td></td>
<td></td>
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<tr>
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<td><strong>Ethnic group</strong></td>
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<tr>
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<td><strong>General health</strong></td>
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<tr>
<td>Mild physical disability</td>
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<td>0 (0)</td>
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<tr>
<td>Moderate physical disability</td>
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<td>1 (50.0)</td>
<td>1 (50.0)</td>
<td>0 (0)</td>
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<tr>
<td><strong>All combined</strong></td>
<td>0 (0)</td>
<td>4 (80.0)</td>
<td>1 (20.0)</td>
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\*P<0.1

3.2.3.2.3 Introduction to dentist

In general, patients were inspired to see a dentist mostly when they looked at the sign board of the dental clinics, which was claimed by four (80.0%) of the respondents, as presented in Table 3.3. Sixty percent had also been introduced to dentist through other medium which was not specified by any of the participants. Twenty percent sought treatment from dentists after they were introduced by neighbours or friends and the
Table 3.3. Introduction to dentist of people with special needs, by gender, ethnic group and level of disability (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th></th>
<th>Neighbour</th>
<th>Acquaintance</th>
<th>Referred by other dentists</th>
<th>Referred by medical doctor</th>
<th>Advertisement</th>
<th>Telephone book</th>
<th>Clinic signboard</th>
<th>Others</th>
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<tr>
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<tr>
<td>Male</td>
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<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (33.3)</td>
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<tr>
<td>Female</td>
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<td><strong>Ethnic group</strong></td>
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<tr>
<td>Malay</td>
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<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>3 (100.0)</td>
<td>3 (100.0)</td>
</tr>
<tr>
<td>Chinese</td>
<td>1 (50.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (50.0)</td>
<td>0 (00.0)</td>
</tr>
<tr>
<td><strong>General health</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild physical disability</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>2 (66.7)</td>
<td>1 (33.3)</td>
</tr>
<tr>
<td>Moderate physical disability</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (100.0)</td>
<td>2 (100.0)</td>
</tr>
<tr>
<td><strong>All combined</strong></td>
<td>1 (20.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (20.0)</td>
<td>0 (0)</td>
<td>4 (80.0)</td>
<td>3 (60.0)</td>
</tr>
</tbody>
</table>

*p<0.1*
same proportion of respondents found out about the dentists from advertisements in mass media. It seemed that, other choices such as, introduction by acquaintance, referred by other dentists or medical doctors and telephone book were not selected by any of the participants.

3.2.3.2.4 Frequency of dental visit

When asked about the frequency of dental visits, the majority (n=3, 60.0%) of the participants only visited a dentist when they were having dental problems as displayed in Table 3.4. Visiting dentist once a year or once in two years seemed to be practised by only one respondent.

Table 3.4: Frequency of dental visit by people with special needs, by gender, ethnic group and level of disability (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th></th>
<th>Every 6 months</th>
<th>Frequency of dental visit:</th>
<th></th>
<th>Only when having dental problems</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Once a year</td>
<td>Once in 2 years</td>
<td>Once in 3 to 4 years</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Female</td>
<td>0 (0)</td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Ethnic group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malay</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Chinese</td>
<td>0 (0)</td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>General health</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild physical</td>
<td>0 (0)</td>
<td>1 (33.3)</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate physical</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All combined</td>
<td>0 (0)</td>
<td>1 (20.0)</td>
<td>1 (20.0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

*aP<0.1
3.2.3.2.5 Reasons for not seeing dentist and barriers experienced by patients to access dental care facilities

Table 3.5 shows various reasons for the participants not to see a dentist as frequent as they should. Twenty percent of the participants visited a dentist, only when an appointment was given. Transport was a high ranking difficulty faced by 60.0% of the respondents, while high dental cost was considered by most of the participants as one of the major factors that discouraged people to see a dentist. Negative attitude such as the thought that frequent visits were not required was nominated by one participant. A belief that, no pain indicated and there was no dental problem had been the choice of 40.0% of the participants. There were other reasons stated by 40.0% of patients, even though not specified, as being the reasons for them not seeing a dentist.

3.2.3.3 Knowledge and views on oral hygiene care

3.2.3.3.1 Information and knowledge

Majority of participants (n=4, 80.0%) reported that they did not obtain any individual advice regarding oral health care. From the participants who received some advice, dentists, internet and electronic mass media such as television and radio as well as the caregivers were the sources of information. However, those who did not receive any advice claimed to learn most from self experience in cleaning their teeth.

3.2.3.3.2 Views on oral care

Generally, more than half of the respondents were not satisfied with the existing service delivered to people with special needs whereas the others felt otherwise. When they were asked to rank the level of satisfaction on various aspects of dental service as shown in Table 3.6, one was satisfied, three felt neutral and one was not satisfied with the clinic cleanliness. A majority of respondents were satisfied with the dental staff manner followed by one who felt neutral and one was not satisfied. Four participants had neutral feeling about the dental clinic location with only one was not satisfied with the location. Dental fee charged to patients had satisfied one respondent, while two gave neutral
### Table 3.5. Reasons for patients not seeing dentist, by gender, ethnic group and level of disability (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Reason for not seeing dentist:</th>
<th>Only when appointment is given</th>
<th>Transport</th>
<th>High dental fee</th>
<th>Frequent visit not required</th>
<th>Forget</th>
<th>Dislike dentist</th>
<th>Do not have any dental problems</th>
<th>Never been informed to see dentist</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1 (33.3)</td>
<td>1 (33.3)</td>
<td>2 (66.7)</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (66.7)</td>
<td>0 (0)</td>
<td>2 (66.7)</td>
</tr>
<tr>
<td>Female</td>
<td>0 (0)</td>
<td>2 (100.0)</td>
<td>2 (100.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Ethnic group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malay</td>
<td>1 (33.3)</td>
<td>1 (33.3)</td>
<td>2 (66.7)</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (66.7)</td>
<td>0 (0)</td>
<td>2 (66.7)</td>
</tr>
<tr>
<td>Chinese</td>
<td>0 (0)</td>
<td>2 (100.0)</td>
<td>2 (100.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>General health</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild physical disability</td>
<td>1 (33.3)</td>
<td>3 (100.0)</td>
<td>3 (100.0)</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Moderate physical disability</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (50.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (50.0)</td>
<td>0 (0)</td>
<td>2 (100.0)</td>
</tr>
<tr>
<td><strong>All combined</strong></td>
<td>1 (20.0)</td>
<td>3 (60.0)</td>
<td>4 (80.0)</td>
<td>1 (20.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (40.0)</td>
<td>0 (0)</td>
<td>2 (40.0)</td>
</tr>
</tbody>
</table>

aP<0.1
response about this matter and the other two were not satisfied. Domiciliary dental service was nominated by three participants as being a very good future plan in SND and two thought it was just good to be implemented.

**Table 3.6.** Level of patients' satisfaction on various aspects of dental service (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Areas of service:</th>
<th>clinic cleanliness</th>
<th>Dental staff manner</th>
<th>Location of clinic</th>
<th>Dental fee</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied</td>
<td>1 (20.0)</td>
<td>3 (60.0)</td>
<td>0 (0)</td>
<td>1 (20.0)</td>
</tr>
<tr>
<td>Neutral</td>
<td>3 (60.0)</td>
<td>1 (20.0)</td>
<td>4 (80.0)</td>
<td>2 (40.0)</td>
</tr>
<tr>
<td>Not satisfied</td>
<td>1 (20.0)</td>
<td>1 (20.0)</td>
<td>1 (20.0)</td>
<td>2 (40.0)</td>
</tr>
<tr>
<td>Not sure</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

\(^aP<0.1\)

Comparing the barriers experienced by patients with mild physical disabilities and moderate physical disabilities to access dental care facilities (Table 3.7), all participants with mild disabilities had problems with transport and financial status to deal with a dental fee. Two (66.7%) of them had nobody to accompany them to dental clinic and one (33.3%) had negative attitude towards dental service such as, would not go to dentist without given an appointment, no frequent visit required and felt that they had no dental problems which required them to go for dental visit. Patients with moderate disability appeared to be more concerned about high dental treatment costs, which was chosen by 50.0% of them while the same proportion of them was uncertain about the difficulties they were facing. All of them also mentioned about other reasons being as part of the contributing factors which prevented them from seeing a dentist.
Table 3.7. Barriers experienced by patients to access dental care facilities, by level of disability (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>障碍类别</th>
<th>轻度身体残疾</th>
<th>中度身体残疾</th>
<th>全部合计</th>
</tr>
</thead>
<tbody>
<tr>
<td>无预约无牙科访</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>1 (20.0)</td>
</tr>
<tr>
<td>无交通至牙科诊所</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
<td>3 (60.0)</td>
</tr>
<tr>
<td>高牙科费用</td>
<td>3 (100.0)</td>
<td>1 (50.0)</td>
<td>4 (80.0)</td>
</tr>
<tr>
<td>无频繁访必</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>1 (20.0)</td>
</tr>
<tr>
<td>忘记</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>不喜欢牙医</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>无牙科问题</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>1 (20.0)</td>
</tr>
<tr>
<td>牙科恐惧</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>无陪同至牙科诊所</td>
<td>2 (66.7)</td>
<td>0 (0)</td>
<td>2 (40.0)</td>
</tr>
<tr>
<td>不知道</td>
<td>0 (0)</td>
<td>1 (50.0)</td>
<td>1 (20.0)</td>
</tr>
<tr>
<td>其他原因</td>
<td>0 (0)</td>
<td>2 (100.0)</td>
<td>2 (40.0)</td>
</tr>
</tbody>
</table>

\( ^a P<0.1 \)

3.2.4 Caregivers of people with special needs

3.2.4.1 Sociodemographic variables

The sociodemographic variables for this group of participants were initially divided into six categories which included age, gender, ethnic groups, relationship with clients, highest education level and location of where the care was delivered as shown in Table 3.8. There were two age groups of participants involved. The first group was those below 54 years old, consisted of two (40.0%) and the second group was 54 years old and above, consisted of three (60.0%) participants. The age range was between 38 and 69 years old with mean age of 53 years old. Two (40.0%) represented males and three (60.0%) were females. Due to small numbers of participants, it was difficult to compare the data among the variables.
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis (Based on New Zealand Experience)

Table 3.8. Sociodemographic data of the respondents from the group of caregivers

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below 54</td>
<td>2</td>
<td>40.0</td>
</tr>
<tr>
<td>54 and above</td>
<td>3</td>
<td>60.0</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
<td>40.0</td>
</tr>
<tr>
<td>Female</td>
<td>3</td>
<td>60.0</td>
</tr>
<tr>
<td><strong>Ethnic group</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malay</td>
<td>3</td>
<td>60.0</td>
</tr>
<tr>
<td>Chinese</td>
<td>1</td>
<td>20.0</td>
</tr>
<tr>
<td>Others</td>
<td>1</td>
<td>20.0</td>
</tr>
<tr>
<td><strong>Relationship with clients</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family member</td>
<td>3</td>
<td>60.0</td>
</tr>
<tr>
<td>Non family member</td>
<td>2</td>
<td>40.0</td>
</tr>
<tr>
<td><strong>Highest education level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>3</td>
<td>60.0</td>
</tr>
<tr>
<td>College/ University</td>
<td>2</td>
<td>40.0</td>
</tr>
<tr>
<td>Master</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>PhD</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Care location</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>House</td>
<td>5</td>
<td>100.0</td>
</tr>
<tr>
<td>Residential care</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Day care centre</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>All combined</strong></td>
<td>5</td>
<td>100.0</td>
</tr>
</tbody>
</table>

The majority of the participants were Malays which made up of three of the whole group whereas one respondent was Chinese and one was from another ethnic group. Three caregivers claimed to have family relationship with the clients while the rest had no family connection. Three of them finished high school without any further qualification whereas the others were graduated from college or university. All carers reported the delivery of care to be home-based. Since there were no variety in the last variable, most data were presented based on the first five variables. Apart from that, the longest period
provided for the client was 30 years, while the minimum length of care was a year. One respondent reported that, his/her clients had good physical health without any disease or severe disability or behavioural problems, while another claimed that, the client was suffered from mild physical disability accompanied by a systemic disease or mild disability or behavioural problems. The other three were providing care for those with moderate physical disability with one or more systemic diseases or moderate behavioural problems. As reported in the previous group, there was no significant relationship between the sociodemographic variables and the tested variables.

3.2.4.2 Oral hygiene practice for clients

Various aspects of oral hygiene practice of people with special needs as observed or carried out by the caregivers were asked and tabulated in Table 3.9. One participant claimed to have some problems in providing oral hygiene care for the client, whose age was over 54 years, and had only provided care for one year. Two respondents noticed that the clients were using cleaning devices other than toothbrush. Assistance in oral care was given by one caregiver to the client who had moderate physical disability, while the rest had clients who could manage to perform their own oral care. One respondent claimed that, his client had a personal dentist who was visited regularly. A majority of the caregivers brought the clients for dental treatment at the government dental clinics. No client was seen by a dental specialist as observed by the caregivers. In addition, older and female caregivers seemed to face some difficulties in carrying out oral care for their clients. Younger and male caregivers reported encouraging the clients to use dental devices other than toothbrush.
Table 3.9. Oral hygiene practice of people with special needs as carried out by the caregivers, by age, gender, ethnic group, relationship with clients and level of education (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Aspects of oral hygiene care:</th>
<th>Problems in carrying out oral care for clients</th>
<th>Dental care devices used other than toothbrush</th>
<th>With assistance</th>
<th>Personal general dental practitioner seen by clients</th>
<th>Clients seen by government dentist</th>
<th>Clients seen by dental specialist</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below 54</td>
<td>0 (0)</td>
<td>2 (100.0)</td>
<td>0 (0)</td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>54 and above</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0 (0)</td>
<td>2 (100.0)</td>
<td>0 (0)</td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Female</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Ethnic group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malay</td>
<td>0 (0)</td>
<td>1 (33.3)</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Chinese</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Others</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Relationship with clients</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family member</td>
<td>0 (0)</td>
<td>1 (33.3)</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Non family member</td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
<td>0 (0)</td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Highest education level</strong></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>High School</td>
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<td>1 (33.3)</td>
<td>1 (33.3)</td>
<td>0 (0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>College/ University</td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
<td>0 (0)</td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>All combined</strong></td>
<td>1 (20.0)</td>
<td>2 (40.0)</td>
<td>1 (20.0)</td>
<td>1 (20.0)</td>
<td>4 (80.0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

*P<0.
Table 3.10 shows how people with special needs were introduced to a dentist, as known by the caregivers. One respondent claimed that the client was introduced to a dentist by a neighbour and similarly, one caregiver brought the client to a dentist after seeing an advertisement. Most of the caregivers observed that, a clinic sign board was the main medium to attract patients to visit a particular dental clinic. There were other methods of introduction as well, as mentioned by two caregivers.

The caregivers were also requested to provide details of the frequency of dental visits of their clients. Table 3.11 presents these data in detail. Two participants took the clients for dental visits at least once a year and the other two would only do that if the clients had dental problems. One caregiver believed to have more frequent dental visit for the clients, by doing so at least once every six months.

Table 3.12 indicates some reasons for the patients not to see a dentist regularly as required. A high proportion of the caregivers (60.0%) thought that transportation to the dental clinic, high dental fees and the clients having no dental problems requiring professional attention were the main reasons for the clients not to be brought to see a dentist. Two of them would not see a dentist without being given an appointment while others believed that frequent dental visits were not necessary. Reasons other than the given choices were stated by two caregivers but not specific. In addition, no respondent reported being given advice by dental professionals about oral hygiene care for people with special needs.

3.2.4.3 Knowledge and views about the existing dental service for people with special needs

3.2.4.3.1 Perspective of the caregivers about oral hygiene care for people with special needs

Table 3.13 presents various aspects of SND in the view of the caregivers. As expected, all participants had never come across SND before participating in this study. However, all of them believed that oral health was as important as general health. Older caregivers
### Table 3.10. Introduction to dentist of people with special needs as known by the caregivers (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Methods of introduction:</th>
<th>Neighbour</th>
<th>Acquaintance</th>
<th>Referred by other dentists</th>
<th>Referred by medical doctor</th>
<th>Advertisement</th>
<th>Telephone book</th>
<th>Clinic signboard</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neighbour</td>
<td>1 (20.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (20.0)</td>
<td>0 (0)</td>
<td>4 (80.0)</td>
<td>2 (40.0)</td>
</tr>
</tbody>
</table>

### Table 3.11. Frequency of dental visit by people with special needs as known by the caregivers (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Frequency of dental visit of the clients:</th>
<th>Every 6 months</th>
<th>Once a year</th>
<th>Once in 2 years</th>
<th>Once in 3 to 4 years</th>
<th>Only when having dental problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Only when appointment is given</td>
<td>1 (20.0)</td>
<td>2 (40.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (40.0)</td>
</tr>
</tbody>
</table>

### Table 3.12. Reasons for patients not seeing dentist, as known by the caregivers (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Reason for not seeing dentist:</th>
<th>Only when appointment is given</th>
<th>Transport</th>
<th>High dental fee</th>
<th>Frequent visit not required</th>
<th>Forget</th>
<th>Dislike dentist</th>
<th>Do not have any dental problems</th>
<th>Never been informed to see dentist</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reason for not seeing dentist:</td>
<td>2 (40.0)</td>
<td>3 (60.0)</td>
<td>3 (60.0)</td>
<td>1 (20.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>3 (60.0)</td>
<td>0 (0)</td>
<td>1 (20.0)</td>
</tr>
</tbody>
</table>
Table 3.13. Perspectives of the caregivers on oral hygiene care for people with special needs, by age, gender, ethnic group, relationship with clients and level of education (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Areas of concern:</th>
<th>Yes</th>
<th>No</th>
<th>Yes</th>
<th>No</th>
<th>Yes</th>
<th>No</th>
<th>Yes</th>
<th>No</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heard about Special Needs Dentistry service</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below 54</td>
<td>0 (0)</td>
<td>2 (100.0)</td>
<td>2 (100.0)</td>
<td>0 (0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>54 and above</td>
<td>0 (0)</td>
<td>3 (100.0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The importance of oral health as compared to general health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Below 54</td>
<td>0 (0)</td>
<td>2 (100.0)</td>
<td>2 (100.0)</td>
<td>0 (0)</td>
<td></td>
<td></td>
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<tr>
<td>54 and above</td>
<td>0 (0)</td>
<td>3 (100.0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>The importance of the existing dental service for people with special needs</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below 54</td>
<td>0 (0)</td>
<td>2 (100.0)</td>
<td>2 (100.0)</td>
<td>0 (0)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>54 and above</td>
<td>0 (0)</td>
<td>3 (100.0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The importance of facilities appropriate to accommodate people with special needs</td>
<td></td>
<td></td>
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<tr>
<td>Below 54</td>
<td>0 (0)</td>
<td>2 (100.0)</td>
<td>2 (100.0)</td>
<td>0 (0)</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>54 and above</td>
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<td>3 (100.0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
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<tr>
<td>The importance of specialist required to treat people with special needs</td>
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<tr>
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<td>2 (100.0)</td>
<td>0 (0)</td>
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<tr>
<td>54 and above</td>
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<td>3 (100.0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
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</tr>
<tr>
<td>Is domiciliary service required</td>
<td></td>
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<tr>
<td>Below 54</td>
<td>0 (0)</td>
<td>2 (100.0)</td>
<td>2 (100.0)</td>
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</tr>
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<td>3 (100.0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
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<tr>
<td>Sex</td>
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<tr>
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<td>3 (100.0)</td>
<td>3 (100.0)</td>
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<tr>
<td>Ethnic group</td>
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<tr>
<td>Malay</td>
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<td>3 (100.0)</td>
<td>0 (0)</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Others</td>
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<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
<td></td>
<td></td>
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<tr>
<td>Relationship with clients</td>
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</tr>
<tr>
<td>Family member</td>
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<td>3 (100.0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Non family member</td>
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<td>2 (100.0)</td>
<td>0 (0)</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Highest education level</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>0 (0)</td>
<td>3 (100.0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>College/ University</td>
<td>0 (0)</td>
<td>2 (100.0)</td>
<td>2 (100.0)</td>
<td>0 (0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All combined</td>
<td>0 (0)</td>
<td>5 (100.0)</td>
<td>5 (100.0)</td>
<td>0 (0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

aP<0.1
whose age was 54 and above and female caregivers were all satisfied with the existing dental service provided for people with special needs, as opposed to younger and male caregivers who were not satisfied with the service. A high percentage of participants (80.0%) claimed that the current dental facilities were not appropriate to accommodate people with special needs. On the other hand, 100.0% of them did think that this vulnerable group of the population should be treated by a dental specialist in this field. Their view on domiciliary service was reviewed and more than half of the respondents agreed that this was an appropriate approach.

3.2.4.3.2 Level of caregivers’ satisfaction on various aspects of dental service

The areas of the service which the respondents were asked to rank for their level of satisfaction is shown in Table 3.14. Two participants were satisfied with the clinic cleanliness and similarly, two of them gave neutral response to this question, while another was not satisfied. Dental staff manner was satisfactory for two respondents and neutral for the other two, while the rest of the respondents were not satisfied with the staff manner. Three agreed the location of the dental clinic did satisfy them whereas one felt neutral about it and the same number of participants was not satisfied with this. Three participants were not satisfied with the amount of dental fees while the one responded neutrally for this particular question.

Table 3.14. Level of carers’ satisfaction on various aspects of dental service (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Areas of service</th>
<th>Clinic cleanliness</th>
<th>Dental staff manner</th>
<th>Location of clinic</th>
<th>Dental fee</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied</td>
<td>2 (40.0)</td>
<td>2 (40.0)</td>
<td>3 (60.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Neutral</td>
<td>2 (40.0)</td>
<td>2 (40.0)</td>
<td>1 (20.0)</td>
<td>2 (40.0)</td>
</tr>
<tr>
<td>Not satisfied</td>
<td>1 (20.0)</td>
<td>1 (20.0)</td>
<td>1 (20.0)</td>
<td>3 (60.0)</td>
</tr>
<tr>
<td>Not sure</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>
3.2.4.3.3 Frequency of dental visits which were thought to be appropriate

Generally, all participants did not think that monthly dental appointment was appropriate. A dental visit in every three months was the choice of one participant aged over 54 years, female, and was a college/university graduate. A higher number of participants was happy to have the dental visit once in every six months for the clients and the highest proportion of this group who had only high school qualification. However, this frequency was not agreed at all by college/university graduates. Instead, all of them believed that once a year of dental visit was adequate as shown in Table 3.15.

<table>
<thead>
<tr>
<th></th>
<th>Frequency of dental visit:</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Every month</td>
<td>Every three months</td>
<td>Every six months</td>
<td>Once a year</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below 54</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
</tr>
<tr>
<td>54 and above</td>
<td>0 (0)</td>
<td>1 (33.3)</td>
<td>2 (66.7)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
</tr>
<tr>
<td>Female</td>
<td>0 (0)</td>
<td>1 (33.3)</td>
<td>2 (66.7)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Ethnic group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malay</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Chinese</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>Others</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Relationship with clients</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family member</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Non family member</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>Highest education level</td>
<td></td>
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</tr>
<tr>
<td>High School</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>College/ University</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>All combined</td>
<td>0 (0)</td>
<td>1 (20.0)</td>
<td>3 (60.0)</td>
<td>1 (20.0)</td>
</tr>
</tbody>
</table>

*p<0.1
3.2.4.3.4 The importance of certain types of dental treatment in the perspective of the caregivers

The respondents were asked to comment on the importance of certain type of dental treatments for patient with special needs as presented in Table 3.16. Dental examination and radiograph were considered important by two respondents but most (n=3, 60.0%) of them thought these treatments were not important. In contrast, all participants agreed that a dental restoration was an important part in dental treatment. Scaling and cleaning to prevent dental diseases was thought to be very important by two participants and important for the other three. Interestingly, oral hygiene instruction given to patients by a dentist was very important for two respondents and important for three of them. On the other hand, majority of participants (80.0%) felt that oral hygiene instruction given to the caregivers was important and only one said it was very important. Four caregivers were also agreed that denture fabrication was important but not important for one of them. Denture repair was considered by three respondents as important but two felt that this was not important. Two caregivers said that root canal treatment was not important and the same number of the participants said it was important, while the other one said it was very important. Extraction was categorized as an important dental treatment by all participants whereas dental implant was important for only one respondent and not important for the rest. Pain relief and emergency care were considered very important by most of the participants but important for one of them. Same number of respondents (40.0%) commented that specialist treatment was very important or important, while one said that it was not important.

3.2.5 Oral health professionals

3.2.5.1 Sociodemographic variables

The sociodemographic variables for the dentist population in this study consisted of age, gender, workplace and the length of the service of the dentists. The age range of respondents in this group was between 25 and 55 years old with mean age of 30 years old. 58.3% (n=21) of the dentists were younger than 30 years old while 41.7% (n=15) represented the dentists who were 30 years old and older. The majority of respondents
**Table 3.16.** The importance of certain types of dental treatment for people with special needs in the perspective of the caregivers (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Types of dental treatment</th>
<th>Very important</th>
<th>Importance level:</th>
<th>Not important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dental examination and X ray</td>
<td>0 (0)</td>
<td>2 (40.0)</td>
<td>3 (60.0)</td>
</tr>
<tr>
<td>Filling</td>
<td>0 (0)</td>
<td>5 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Scaling and cleaning to prevent dental diseases</td>
<td>2 (40.0)</td>
<td>3 (60.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Oral hygiene instruction to patients</td>
<td>2 (40.0)</td>
<td>3 (60.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Oral hygiene instruction to caregivers</td>
<td>1 (20.0)</td>
<td>4 (80.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Denture fabrication</td>
<td>0 (0)</td>
<td>4 (80.0)</td>
<td>1 (20.0)</td>
</tr>
<tr>
<td>Denture repair</td>
<td>0 (0)</td>
<td>3 (60.0)</td>
<td>2 (40.0)</td>
</tr>
<tr>
<td>Root canal treatment</td>
<td>1 (20.0)</td>
<td>2 (40.0)</td>
<td>2 (40.0)</td>
</tr>
<tr>
<td>Extraction</td>
<td>0 (0)</td>
<td>5 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Dental implant</td>
<td>0 (0)</td>
<td>2 (40.0)</td>
<td>3 (60.0)</td>
</tr>
<tr>
<td>Pain relief</td>
<td>4 (80.0)</td>
<td>1 (20.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Emergency care</td>
<td>4 (80.0)</td>
<td>1 (20.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Specialist treatment</td>
<td>2 (40.0)</td>
<td>2 (40.0)</td>
<td>1 (20.0)</td>
</tr>
</tbody>
</table>
were females (88.9%, n=32), while only four male dentists (11.1%) participated in this study. 50.0% (n=18) of the dentists worked at the dental clinics at the health centre, 27.8% (n=10) were based at the stand alone main dental clinics and 22.2% (n=8) were at the hospital-based dental clinics. In addition, half of the respondents had been in practice for less than five years (50.0%, n=18) and the other half had been practicing for five years and longer.

3.2.5.2 Perception about Special Needs Dentistry

3.2.5.2.1 Definition of SND

There were six characteristics included in the definition, describing people with special needs in the survey questionnaire. They were physical, intellectual, mental, medical, emotional and social impairments. All participants agreed that mental disability was a criterion that should be included in the definition of people with special needs, which was followed by physical (94.4%, n=34), intellectual (88.9%, n=32), medical (86.1%, n=31), emotional (52.8%, n=19) and social (41.7%, n=15) impairment as shown in Table 3.17. All dentists who were 30 years old and above, dentists who were based at the hospital dental clinics and those who had been in the service for five years and longer agreed that physical impairment was the criteria to be included in ‘special needs’ definition. Male dentists seemed to show the lowest frequency to agree with this condition. In contrast, intellectual disability was nominated by 100.0% of the male dentists. Medically compromised patients were considered as patients with special needs by most of the younger dentists (90.5%). Among those who chose emotional impairment as a part of special needs conditions, a majority of them were practising at the hospital-based dental clinics (80.0%) and the smallest number of dentists (37.5%) who chose this impairment was from the group of dentists practising at the main dental clinics.

It is interesting to note that there was a statistically significant difference between the view of less experienced and more experienced dentists, with 38.9% of the less experienced ones reported that emotional impairment was a criterion to be considered as a special needs condition but the more experienced dentists who shared similar view, showed almost double of this percentage (66.7%). About more than half of the dentists (60.0%) based at the hospital opted social impairment as a characteristic of people with
### Table 3.17. Criteria included by dentists, describing people with special needs, by age, gender and practice characteristics (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Include this impairment in definition of “special needs”:</th>
<th>Physical</th>
<th>Intellectual</th>
<th>Mental</th>
<th>Medical</th>
<th>Emotional</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than 30</td>
<td>19 (90.5)</td>
<td>20 (95.2)</td>
<td>21 (100.0)</td>
<td>19 (90.5)</td>
<td>9 (42.9)</td>
<td>8 (38.1)</td>
</tr>
<tr>
<td>30 or older</td>
<td>15 (100.0)</td>
<td>12 (80.0)</td>
<td>15 (100.0)</td>
<td>12 (80.0)</td>
<td>10 (66.7)</td>
<td>7 (46.7)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3 (75.0)</td>
<td>4 (100.0)</td>
<td>4 (100.0)</td>
<td>3 (75.0)</td>
<td>2 (50.0)</td>
<td>2 (50.0)</td>
</tr>
<tr>
<td>Female</td>
<td>31 (96.9)</td>
<td>28 (87.5)</td>
<td>32 (100.0)</td>
<td>28 (87.5)</td>
<td>17 (53.1)</td>
<td>13 (40.6)</td>
</tr>
<tr>
<td><strong>Workplace</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Main clinic</td>
<td>7 (87.5)</td>
<td>6 (75.0)</td>
<td>8 (100.0)</td>
<td>7 (87.5)</td>
<td>3 (37.5)</td>
<td>2 (25.0)</td>
</tr>
<tr>
<td>Health centre clinic</td>
<td>17 (94.4)</td>
<td>17 (94.4)</td>
<td>18 (100.0)</td>
<td>16 (88.9)</td>
<td>8 (44.4)</td>
<td>7 (38.9)</td>
</tr>
<tr>
<td>Hospital clinic</td>
<td>10 (100.0)</td>
<td>9 (90.0)</td>
<td>10 (100.0)</td>
<td>8 (80.0)</td>
<td>8 (80.0)</td>
<td>6 (60.0)</td>
</tr>
<tr>
<td><strong>Years of service</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 5</td>
<td>16 (88.9)</td>
<td>16 (88.9)</td>
<td>18 (100.0)</td>
<td>16 (88.9)</td>
<td>7 (38.9)</td>
<td>7 (38.9)</td>
</tr>
<tr>
<td>5 or more</td>
<td>18 (100.0)</td>
<td>16 (88.9)</td>
<td>18 (100.0)</td>
<td>15 (83.3)</td>
<td>12 (66.7)</td>
<td>8 (44.4)</td>
</tr>
<tr>
<td>All combined</td>
<td>34 (94.4)</td>
<td>32 (88.9)</td>
<td>36 (100.0)</td>
<td>31 (86.1)</td>
<td>19 (52.8)</td>
<td>15 (41.7)</td>
</tr>
</tbody>
</table>

*aP<0.1*
special needs with a very small percentage of dentists working at the main dental clinics agreed with this view (25.0%).

3.2.5.2.2 Demand for SND

Most dentists (66.7%) saw less than five patients with special needs in a typical week. Dentists who had been practising for less than five years presented the highest proportion who managed to see less than five patients in a week (77.8%) but fewer of experienced dentists would do so (55.6%). Among those who saw between five and 10 patients in a week, male dentists and the dentists worked at the main dental clinics presented the highest frequency, with no dentists at the hospital dental clinics managed to see this number of patients. However, higher number of patients would be seen by the dentists at the hospital dental clinics, in which 40.0% of them treated more than ten patients in a typical week. Female dentists seemed to be seeing more patients in a week as compared to male dentists by which 18.8% of them saw more than ten patients while none of male dentists would see the same number of patients within the same period of time (Table 3.18).

Table 3.18. Categorized mean number of patients with special needs seen in a typical week by dentists, by age, gender and practice characteristics (brackets contain percentages of dentists)

<table>
<thead>
<tr>
<th>Age group</th>
<th>Mean number of patients with special needs seen in a week:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less than 5</td>
</tr>
<tr>
<td>Younger than 30</td>
<td>14 (66.7)</td>
</tr>
<tr>
<td>30 or older</td>
<td>10 (66.7)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th>Mean number of patients with special needs seen in a week:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less than 5</td>
</tr>
<tr>
<td>Male</td>
<td>3 (75.0)</td>
</tr>
<tr>
<td>Female</td>
<td>21 (65.6)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Workplace</th>
<th>Mean number of patients with special needs seen in a week:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less than 5</td>
</tr>
<tr>
<td>Main clinic</td>
<td>6 (75.0)</td>
</tr>
<tr>
<td>Health centre clinic</td>
<td>12 (66.7)</td>
</tr>
<tr>
<td>Hospital clinic</td>
<td>6 (60.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years of service</th>
<th>Mean number of patients with special needs seen in a week:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less than 5</td>
</tr>
<tr>
<td>Less than 5</td>
<td>14 (77.8)</td>
</tr>
<tr>
<td>5 or more</td>
<td>10 (55.6)</td>
</tr>
</tbody>
</table>

| All combined               | 24 (66.7)   | 6 (16.7)         | 6 (16.7)     |

^p<0.1
Table 3.19 indicates the age range of patients seen by dentists at their practice. More than half of the dentists (53.8%) working at the hospital dental clinic would see patients with the age range between 12 and 17 but they were least treated by male dentists (37.5%). The similar scenario was reported for patients between the age of 18 and 25 where they mostly attended hospital dental clinics to seek treatment and seen by 30.8% of the dentists at this practice setting. On the other hand, only 11.1% of the respondents reported of seeing these patients at the health centre dental clinics. In contrast, adults with special needs whose age was between 26 and 60 were most likely to be seen by dentists (34.6%) based at the dental clinics at the health centres while only 7.7% of dentists practicing at the hospital dental clinics could see them. The male dentists were mostly treating elderly patients with special needs whose age were 61 years old and above (25.0%). However, none of the dentists claimed to see elderly patients at the main dental clinics.

**Table 3.19. Age range of patients seen by dentist, by age, gender and practice characteristics (brackets contain percentages of dentists)**

<table>
<thead>
<tr>
<th>Age range (year) of patients normally seen by a dentist at their practice:</th>
<th>12 to 17</th>
<th>18 to 25</th>
<th>26 to 60</th>
<th>61 and more</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than 30</td>
<td>13 (41.9)</td>
<td>5 (16.1)</td>
<td>9 (29.0)</td>
<td>4 (12.9)</td>
</tr>
<tr>
<td>30 or older</td>
<td>8 (47.0)</td>
<td>4 (23.5)</td>
<td>4 (23.5)</td>
<td>1 (5.9)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3 (37.5)</td>
<td>1 (20.0)</td>
<td>2 (25.0)</td>
<td>2 (25.0)</td>
</tr>
<tr>
<td>Female</td>
<td>18 (45.0)</td>
<td>8 (20.0)</td>
<td>11 (27.5)</td>
<td>3 (7.5)</td>
</tr>
<tr>
<td><strong>Workplace</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Main clinic</td>
<td>4 (44.4)</td>
<td>2 (22.2)</td>
<td>3 (33.3)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Health centre</td>
<td>10 (38.5)</td>
<td>3 (11.5)</td>
<td>9 (34.6)</td>
<td>4 (15.4)</td>
</tr>
<tr>
<td>Hospital clinic</td>
<td>7 (53.8)</td>
<td>4 (30.8)</td>
<td>1 (7.7)</td>
<td>1 (7.7)</td>
</tr>
<tr>
<td><strong>Years of service</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 5</td>
<td>11 (40.7)</td>
<td>4 (14.8)</td>
<td>9 (33.3)</td>
<td>3 (11.1)</td>
</tr>
<tr>
<td>5 or more</td>
<td>10 (47.6)</td>
<td>5 (23.8)</td>
<td>4 (19.0)</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>All combined(^a)</td>
<td>21 (58.3)</td>
<td>9 (25.0)</td>
<td>13 (36.1)</td>
<td>5 (13.9)</td>
</tr>
</tbody>
</table>

\(^a\)Data missing for one respondent
Dental restorations, extractions and pain relief management were delivered by all dentists working at the main dental clinics for people with special needs, as opposed to implant, where none of them provided such treatment in their practice (Table 3.20). Similarly, extractions were the most popular dental manoeuvre provided by 94.4% of dentists based at the health centre dental clinics compared to root canal treatment and implants, which were not on the list of treatment necessary for patients with special needs among dentists at this type of practice setting. All dentists at the hospital dental clinics reported of doing dental examination and provided pain relief for their patients, while very low number of them (10.0%) fabricating and repairing dentures, and doing implants for patients with special needs.

Table 3.20. Types of treatment normally delivered by dentists for patients with special needs, by practice characteristics (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Workplace:</th>
<th>Main clinic</th>
<th>Health centre clinic</th>
<th>Hospital clinic</th>
<th>All combined</th>
</tr>
</thead>
<tbody>
<tr>
<td>Examination</td>
<td>5 (62.5)</td>
<td>11 (61.1)</td>
<td>10 (100.0)</td>
<td>26 (72.2)</td>
</tr>
<tr>
<td>Restorations</td>
<td>8 (100.0)</td>
<td>15 (83.3)</td>
<td>8 (80.0)</td>
<td>31 (86.1)</td>
</tr>
<tr>
<td>Scaling and cleaning</td>
<td>6 (75.0)</td>
<td>11 (61.1)</td>
<td>9 (90.0)</td>
<td>26 (72.2)</td>
</tr>
<tr>
<td>OHIb to patients</td>
<td>7 (87.5)</td>
<td>9 (50.0)</td>
<td>8 (80.0)</td>
<td>24 (66.7)</td>
</tr>
<tr>
<td>OHIb to carers</td>
<td>5 (62.5)</td>
<td>13 (72.2)</td>
<td>9 (90.0)</td>
<td>27 (75.0)</td>
</tr>
<tr>
<td>Denture fabrication</td>
<td>5 (62.5)</td>
<td>5 (27.8)</td>
<td>1 (10.0)</td>
<td>11 (30.6)</td>
</tr>
<tr>
<td>Denture repair</td>
<td>3 (37.5)</td>
<td>4 (22.2)</td>
<td>1 (10.0)</td>
<td>8 (22.2)</td>
</tr>
<tr>
<td>Root canal treatment</td>
<td>1 (12.5)</td>
<td>0 (0)</td>
<td>2 (20.0)</td>
<td>3 (8.30)</td>
</tr>
<tr>
<td>Extraction</td>
<td>8 (100.0)</td>
<td>17 (94.4)</td>
<td>9 (90.0)</td>
<td>34 (94.4)</td>
</tr>
<tr>
<td>Pain relief</td>
<td>8 (100.0)</td>
<td>13 (72.2)</td>
<td>10 (100.0)</td>
<td>31 (86.1)</td>
</tr>
<tr>
<td>Emergency</td>
<td>6 (75.0)</td>
<td>10 (55.6)</td>
<td>8 (80.0)</td>
<td>24 (66.7)</td>
</tr>
<tr>
<td>Implant</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (10.0)</td>
<td>1 (2.80)</td>
</tr>
<tr>
<td>Specialist referral</td>
<td>1 (12.5)</td>
<td>2 (11.1)</td>
<td>3 (30.0)</td>
<td>6 (16.7)</td>
</tr>
</tbody>
</table>

aP<0.1
bOral hygiene instruction
All dentists practising at the main dental clinics claimed that patients with special needs required mostly dental restorations and tooth extractions, while root canal treatment and pain relief management were least required by patients, as nominated by only 12.5% of the dentists at this practice setting. Emergency dental treatment was voted by majority of dentists (77.8%) at the health centre dental clinics as the most common treatment required by this group of patients. On the other hand, none of them thought that pain relief was required by the patients. Scaling and cleaning, tooth extraction, and emergency dental care were chosen by all dentists at the hospital dental clinics as being the most popular treatment required by patients with special needs attending their practices. See Table 3.21.

### Table 3.21. Types of treatment normally required by patients with special needs, by dentists at their practice (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Workplace: Main clinic</th>
<th>Health centre clinic</th>
<th>Hospital clinic</th>
<th>All combined</th>
</tr>
</thead>
<tbody>
<tr>
<td>Examination</td>
<td>5 (62.5)</td>
<td>7 (38.9)</td>
<td>4 (40.0)</td>
</tr>
<tr>
<td>Restorations</td>
<td>8 (100.0)</td>
<td>15 (83.3)</td>
<td>8 (80.0)</td>
</tr>
<tr>
<td>Scaling and cleaning</td>
<td>5 (62.5)</td>
<td>13 (72.2)</td>
<td>10 (100.0)</td>
</tr>
<tr>
<td>OHI(^b) to patients</td>
<td>5 (62.5)</td>
<td>8 (44.4)</td>
<td>7 (70.0)</td>
</tr>
<tr>
<td>OHI(^b) to carers</td>
<td>5 (62.5)</td>
<td>12 (66.6)</td>
<td>6 (60.0)</td>
</tr>
<tr>
<td>Denture fabrication</td>
<td>4 (50.0)</td>
<td>7 (38.9)</td>
<td>1 (10.0)</td>
</tr>
<tr>
<td>Denture repair</td>
<td>3 (37.5)</td>
<td>2 (11.1)</td>
<td>1 (10.0)</td>
</tr>
<tr>
<td>Root canal treatment</td>
<td>1 (12.5)</td>
<td>3 (16.7)</td>
<td>1 (10.0)</td>
</tr>
<tr>
<td>Extraction</td>
<td>8 (100.0)</td>
<td>14 (77.8)</td>
<td>10 (100.0)</td>
</tr>
<tr>
<td>Pain relief</td>
<td>1 (12.5)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Emergency</td>
<td>7 (87.5)</td>
<td>15 (83.3)</td>
<td>10 (100.0)</td>
</tr>
<tr>
<td>Implant</td>
<td>5 (62.5)</td>
<td>7 (38.9)</td>
<td>5 (50.0)</td>
</tr>
<tr>
<td>Specialist referral</td>
<td>2 (25.0)</td>
<td>5 (27.8)</td>
<td>3 (30.0)</td>
</tr>
</tbody>
</table>

\(^a\)P<0.1  
\(^b\)Oral hygiene instruction
Overall, high proportion of dentists (97.5%) would prefer to consult dental paediatric specialists when in doubt about the management of patients with special needs (Table 3.22). Orthodontists were the least frequent to be consulted by the dentists regarding this matter (2.8%). Advice from the oral surgeons was sought by majority of dentists who were practising at the main dental clinics (87.5%) but they were less frequently consulted by male dentists (50.0%). There was no significant association between the sociodemographic variables and the proportion of dentists who chose dental paediatric dental specialists to guide them in the patient’s management. The data also showed that, dentists who were younger than 30 years old were most likely to seek advice from periodontists when dealing with this vulnerable group of population (28.6%), while none of male dentists had ever gained advice from them. Among those who sought advice from the orthodontists, most of them were from the main dental clinics (12.5%). Oral pathologists were consulted by 25.0% of dentists who were based at the main dental clinics and were not popular among male dentists and those practising at hospital dental clinics.

3.2.5.2.3 Criteria for referral

Although, there was no significant relationship between the proportion of dentists who chose the unavailability of the service required as a criterion considered before making referral to specialists and the sociodemographic variables, most dentists who worked at the main dental clinics (87.5%) opted for this option. See Table 3.23. It was observed that, male dentists tended to refer all patients with special needs to the specialists, as half of them had nominated this criterion, as compared to female dentists, who only 3.1% of them would refer all patients with special needs. Among those who considered patient’s request to be referred to the specialist, most dentists practising at the main dental clinics would fulfil this demand (50.0%), whereas very low frequency of dentists from health centre dental clinics would do the same thing (11.1%). In addition, all dentists at the main dental clinics (100.0%) would refer uncooperative patients to the specialist for further management. Complex medical problems experienced by the patients had been the criterion chosen by majority of dentists at the health centres to refer the patients to specialists (94.4%). Most of the dentists based at the hospital (70.0%) would consider
Table 3.22. Specialists consulted by dentists in managing patients with special needs, by age, gender and practice characteristics (brackets contain percentages of respondents nominating the specific specialist)

<table>
<thead>
<tr>
<th></th>
<th>Oral surgeon</th>
<th>Dental paediatric specialist</th>
<th>Dental specialists: Periodontist</th>
<th>Orthodontist</th>
<th>Oral pathologist</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than 30</td>
<td>16 (76.2)</td>
<td>21 (100.0)</td>
<td>6 (28.6)</td>
<td>0 (0)</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>30 or older</td>
<td>11 (73.3)</td>
<td>14 (93.3)</td>
<td>2 (13.3)</td>
<td>1 (6.7)</td>
<td>1 (6.7)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2 (50.0)</td>
<td>4 (100.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Female</td>
<td>25 (78.1)</td>
<td>31 (96.9)</td>
<td>8 (25.0)</td>
<td>1 (3.1)</td>
<td>3 (9.4)</td>
</tr>
<tr>
<td><strong>Workplace</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Main clinic</td>
<td>7 (87.5)</td>
<td>8 (100.0)</td>
<td>2 (25.0)</td>
<td>1 (12.5)</td>
<td>2 (25.0)</td>
</tr>
<tr>
<td>Health centre clinic</td>
<td>12 (66.7)</td>
<td>17 (94.4)</td>
<td>5 (27.8)</td>
<td>0 (0)</td>
<td>1 (5.6)</td>
</tr>
<tr>
<td>Hospital clinic</td>
<td>8 (80.0)</td>
<td>10 (100.0)</td>
<td>1 (10.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Years of service</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 5</td>
<td>14 (77.8)</td>
<td>18 (100.0)</td>
<td>4 (22.2)</td>
<td>0 (0)</td>
<td>2 (11.1)</td>
</tr>
<tr>
<td>5 or more</td>
<td>13 (72.2)</td>
<td>17 (94.4)</td>
<td>4 (22.2)</td>
<td>1 (5.6)</td>
<td>1 (5.6)</td>
</tr>
<tr>
<td>All combined</td>
<td>27 (75.0)</td>
<td>35 (97.2)</td>
<td>8 (22.2)</td>
<td>1 (2.8)</td>
<td>3 (8.3)</td>
</tr>
</tbody>
</table>

*aP<0.1*
Table 3.23. Criteria of patients with special needs considered by dentists, before making referral to specialist by age, gender and practice characteristics (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Criteria for referral:</th>
<th>Unavailability of the service required</th>
<th>Every patient with special needs</th>
<th>Asked to be referred</th>
<th>Complex medical problems</th>
<th>Extra care and time required</th>
<th>Psychological problem</th>
<th>General anaesthetic required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than 30</td>
<td>17 (81.0)</td>
<td>2 (9.5)</td>
<td>5 (23.8)</td>
<td>18 (85.7)</td>
<td>19 (90.5)</td>
<td>12 (57.1)</td>
<td>13 (61.9)</td>
</tr>
<tr>
<td>30 or older</td>
<td>12 (80.0)</td>
<td>1 (6.7)</td>
<td>4 (26.7)</td>
<td>13 (86.7)</td>
<td>14 (93.3)</td>
<td>8 (53.3)</td>
<td>9 (60.0)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3 (75.0)</td>
<td>2 (50.0)*</td>
<td>1 (25.0)</td>
<td>3 (75.0)</td>
<td>3 (75.0)</td>
<td>2 (50.0)</td>
<td>2 (50.0)</td>
</tr>
<tr>
<td>Female</td>
<td>26 (81.3)</td>
<td>1 (3.1)</td>
<td>8 (25.0)</td>
<td>28 (87.5)</td>
<td>30 (93.8)</td>
<td>18 (56.3)</td>
<td>20 (62.5)</td>
</tr>
<tr>
<td>Workplace</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Main clinic</td>
<td>7 (87.5)</td>
<td>1 (12.5)</td>
<td>4 (50.0)*</td>
<td>8 (100.0)</td>
<td>7 (87.5)</td>
<td>4 (50.0)</td>
<td>3 (37.5)</td>
</tr>
<tr>
<td>Health centre clinic</td>
<td>14 (77.8)</td>
<td>1 (5.6)</td>
<td>2 (11.1)</td>
<td>15 (83.3)</td>
<td>17 (94.4)</td>
<td>9 (50.0)</td>
<td>12 (66.7)</td>
</tr>
<tr>
<td>Hospital clinic</td>
<td>8 (80.0)</td>
<td>1 (10.0)</td>
<td>3 (30.0)</td>
<td>8 (80.0)</td>
<td>9 (90.0)</td>
<td>7 (70.0)</td>
<td>7 (70.0)</td>
</tr>
<tr>
<td>Years of service</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 5</td>
<td>15 (83.3)</td>
<td>2 (11.1)</td>
<td>5 (27.8)</td>
<td>16 (88.9)</td>
<td>16 (88.9)</td>
<td>9 (50.0)</td>
<td>11 (61.1)</td>
</tr>
<tr>
<td>5 or more</td>
<td>14 (77.8)</td>
<td>1 (5.6)</td>
<td>4 (22.2)</td>
<td>15 (83.3)</td>
<td>17 (94.4)</td>
<td>11 (61.1)</td>
<td>11 (61.1)</td>
</tr>
<tr>
<td>All combined</td>
<td>29 (80.6)</td>
<td>3 (8.3)</td>
<td>9 (25.0)</td>
<td>31 (86.1)</td>
<td>33 (91.7)</td>
<td>20 (55.6)</td>
<td>22 (61.1)</td>
</tr>
</tbody>
</table>

*p<0.1
patients who required extra care and longer time to manage, be referred to specialist for
dental management. However, only half of the male dentists, dentists practising at the
main dental clinics and the health centres, and those who had been in service for less
than five years might consider these characteristic as a criterion for referral. A
psychological problem was nominated as the referral criteria by most dentists at the
hospital dental clinics (70.0%), with only half of the male dentists would do so. Almost all
dentists would agree to refer patients (97.2%) for specialist’s care if general anaesthesia
was required for comprehensive dental treatment, with no significant differences in the
view of dentists from different sociodemographic groups.

3.2.5.2.4 Common dental problems

The dentists were also asked about the oral health status of people with special needs, as
presented in Table 3.24. Generally, the majority of respondents agreed that patients with
special needs had poorer level of oral health than that in other groups of the population
(80.6%). All male dentists believed that they showed poor oral health but over one third
of dentists practising at the hospital dental clinics reported that the oral health status of
patients with special needs was as good as the rest of the population, which reflected
that lower proportion of the dentists in this group agreed that the patients had poor oral
hygiene.

Table 3.25 indicates the common dental problems of patients with special needs as
observed by the dentists. Dental caries appeared to be the most common problems faced
by the patients with all female dentists, dentists working at the hospital dental clinics and
those who had been in service for less than five years said so. It was followed by
periodontal diseases which had been discovered by all dentists at the main dental clinics
to be one of the major dental problems, but only three quarters of the male dentists
thought so. A faulty prosthesis was believed to be the minor problem in patients with
special needs with only 5.6% of respondents agreed to it. Among those who agreed so,
dentists at the main dental clinics showed the higher proportion whereas none of the
male dentists and the hospital-based clinics shared the same view.
Table 3.24. Perspective of dentists about oral health status of people with special needs by age, gender and practice characteristics (brackets contain percentages of dentists)

<table>
<thead>
<tr>
<th>Poor oral health status:</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than 30</td>
<td>17 (85.0)</td>
<td>3 (15.0)</td>
</tr>
<tr>
<td>30 or older</td>
<td>12 (80.0)</td>
<td>3 (20.0)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Female</td>
<td>25 (80.6)</td>
<td>6 (19.4)</td>
</tr>
<tr>
<td>Workplace</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Main clinic</td>
<td>7 (87.5)</td>
<td>1 (12.5)</td>
</tr>
<tr>
<td>Health centre clinic</td>
<td>15 (88.2)</td>
<td>2 (11.8)</td>
</tr>
<tr>
<td>Hospital clinic</td>
<td>7 (70.0)</td>
<td>3 (30.0)</td>
</tr>
<tr>
<td>Years of service</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 5</td>
<td>14 (77.8)</td>
<td>4 (22.2)</td>
</tr>
<tr>
<td>5 or more</td>
<td>15 (88.2)</td>
<td>2 (11.8)</td>
</tr>
<tr>
<td>All combined</td>
<td>29 (80.6)</td>
<td>6 (16.7)</td>
</tr>
</tbody>
</table>

*aP<0.1

3.2.5.2.5 Exposure and knowledge about SND

Exposure and knowledge about SND received by the dentists were also examined in this study covering some particular areas of interests as shown in Table 3.26. However, there was one missing data for three variables namely, facilities accessible for patients with special needs, longer time required to treat the patients, and undergraduate exposure in SND. Firstly, half of the participated dentists agreed that they had adequate facilities at their practice to accommodate patients with special needs whereas 47.2% of them did not think the existing facilities were accessible. 94.4% of the respondents mentioned that they required longer time to manage the patients while only 2.8% did not agree with this statement. Exposure in SND during an undergraduate course was received by 50.0% of the participants but 47.2% had no exposure at all. Among those who gained the exposure, majority of them did not think that it was adequate (94.4%). However, over half of the dentists (52.8%) claimed that they were familiar with this new dental specialty while
83.3% knew about the existence of this service globally. A higher proportion of the participants (91.7%) also believed that patients with special needs should be treated by dentists who were trained in this field while the remainder did not think so. A need to develop this dental specialty in Malaysia was seen by 88.9% of the dentists whereas the rests of them did not see the need to develop such a specialty. In addition, Table 3.27 showed the confidence level of dentists in treating patients with special needs. Interestingly, majority of the dentists felt confident to manage the patients (83.3%) with 2.8% were very confident and 11.1% did not think they could handle the patients in their hands with confidence.

Table 3.25. Common dental problems of patients with special needs as observed by dentists by age, gender and practice characteristics (brackets contain percentages of dentists)

<table>
<thead>
<tr>
<th>Age group</th>
<th>Dental caries</th>
<th>Common dental problems:</th>
<th>Faulty prostheses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Periodontal diseases</td>
<td></td>
</tr>
<tr>
<td>Younger than 30</td>
<td>19 (90.5)</td>
<td>16 (76.2)</td>
<td>1 (4.8)</td>
</tr>
<tr>
<td>30 or older</td>
<td>13 (86.7)</td>
<td>14 (93.3)</td>
<td>1 (6.7)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th>Dental caries</th>
<th>Common dental problems:</th>
<th>Faulty prostheses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Periodontal diseases</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4 (100.0)</td>
<td>3 (75.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Female</td>
<td>28 (87.5)</td>
<td>27 (84.4)</td>
<td>2 (6.3)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Workplace</th>
<th>Dental caries</th>
<th>Common dental problems:</th>
<th>Faulty prostheses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Periodontal diseases</td>
<td></td>
</tr>
<tr>
<td>Main clinic</td>
<td>7 (87.5)</td>
<td>8 (100.0)</td>
<td>1 (12.5)</td>
</tr>
<tr>
<td>Health centre clinic</td>
<td>15 (83.3)</td>
<td>14 (77.8)</td>
<td>1 (5.6)</td>
</tr>
<tr>
<td>Hospital clinic</td>
<td>10 (100.0)</td>
<td>8 (80.0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years of service</th>
<th>Dental caries</th>
<th>Common dental problems:</th>
<th>Faulty prostheses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Periodontal diseases</td>
<td></td>
</tr>
<tr>
<td>Less than 5</td>
<td>18 (100.0)</td>
<td>14 (77.8)</td>
<td>1 (5.6)</td>
</tr>
<tr>
<td>5 or more</td>
<td>14 (77.8)</td>
<td>16 (88.9)</td>
<td>1 (5.6)</td>
</tr>
<tr>
<td>All combined</td>
<td>32 (88.9)</td>
<td>30 (83.3)</td>
<td>2 (5.6)</td>
</tr>
</tbody>
</table>

\(^aP<0.1\)
### Table 3.26. Exposure, knowledge and opinion of dentist about Special Needs Dentistry (brackets contain percentages of dentists)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facilities accessible for patients with special needs&lt;sup&gt;b&lt;/sup&gt;</td>
<td>18 (50.0)</td>
<td>17 (47.2)</td>
</tr>
<tr>
<td>Longer time required to treat patients&lt;sup&gt;b&lt;/sup&gt;</td>
<td>34 (94.4)</td>
<td>1 (2.8)</td>
</tr>
<tr>
<td>Undergraduate exposure in SND&lt;sup&gt;b&lt;/sup&gt;</td>
<td>18 (50.0)</td>
<td>17 (47.2)</td>
</tr>
<tr>
<td>Adequacy of exposure received&lt;sup&gt;c&lt;/sup&gt;</td>
<td>1 (5.6)</td>
<td>17 (94.4)</td>
</tr>
<tr>
<td>Familiarity in SND</td>
<td>19 (52.8)</td>
<td>17 (47.2)</td>
</tr>
<tr>
<td>Awareness about the existence of SND</td>
<td>30 (83.3)</td>
<td>6 (16.7)</td>
</tr>
<tr>
<td>Needs of specialist trained in SND to treat patients with SND</td>
<td>33 (91.7)</td>
<td>3 (8.3)</td>
</tr>
<tr>
<td>Need to develop SND in Malaysia</td>
<td>32 (88.9)</td>
<td>4 (11.1)</td>
</tr>
</tbody>
</table>

<sup>a</sup>P<0.1  
<sup>b</sup>Data missing for one respondent  
<sup>c</sup>Among those who answered ‘yes’ for undergraduate exposure

### Table 3.27. Confidence level of dentists in treating patients with special needs (brackets contain percentages of dentists)

<table>
<thead>
<tr>
<th></th>
<th>Very confident</th>
<th>Confident</th>
<th>Not confident</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 (2.8)</td>
<td>30 (83.3)</td>
<td>4 (11.1)</td>
</tr>
</tbody>
</table>

<sup>a</sup>Data missing for one respondent
3.2.5.2.6 Opinion about the development of SND service in Malaysia

The participants were asked about the most suitable location for the future special care unit, by giving them three locations to choose. Hospital-based clinics were chosen by most dentists practising at the hospital (80.0%) but were agreed by only 38.9% of dentists who had been practising for five years and more. On the other hand, the highest frequency of them (50.0%) would like to see the service to be developed at the community based-dental clinics which was also preferred by the same proportion of dentists working at the main dental clinics, while none of the male dentists chose this option. One quarter of the male dentists thought that the special care unit should be established both at the hospital and community dental clinics whereas only 10.0% dentists working at the hospitals thought so. The details are shown in Table 3.28.

Table 3.28. The suitable location for future special care unit in Malaysia recommended by dentists, by age, gender and practice characteristics (brackets contain percentages of dentists nominating that option)

<table>
<thead>
<tr>
<th>Age group</th>
<th>Hospital based</th>
<th>Community based</th>
<th>Hospital and community based</th>
</tr>
</thead>
<tbody>
<tr>
<td>Younger than 30</td>
<td>13 (61.9)</td>
<td>5 (23.8)</td>
<td>3 (14.3)</td>
</tr>
<tr>
<td>30 or older</td>
<td>6 (40.0)</td>
<td>7 (46.7)</td>
<td>2 (13.3)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th>Hospital based</th>
<th>Community based</th>
<th>Hospital and community based</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>3 (75.0)</td>
<td>0 (0.0)</td>
<td>1 (25.0)</td>
</tr>
<tr>
<td>Female</td>
<td>16 (50.0)</td>
<td>12 (37.5)</td>
<td>4 (12.5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Workplace</th>
<th>Hospital based</th>
<th>Community based</th>
<th>Hospital and community based</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main clinic</td>
<td>3 (37.5)</td>
<td>4 (50.0)</td>
<td>1 (12.5)</td>
</tr>
<tr>
<td>Health centre clinic</td>
<td>8 (44.4)</td>
<td>7 (38.9)</td>
<td>3 (16.7)</td>
</tr>
<tr>
<td>Hospital clinic</td>
<td>8 (80.0)</td>
<td>1 (10.0)</td>
<td>1 (10.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years of service</th>
<th>Hospital based</th>
<th>Community based</th>
<th>Hospital and community based</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 5</td>
<td>12 (66.7)</td>
<td>3 (16.7)</td>
<td>3 (16.7)</td>
</tr>
<tr>
<td>5 or more</td>
<td>7 (38.9)</td>
<td>9 (50.0)</td>
<td>2 (11.1)</td>
</tr>
</tbody>
</table>

*P<0.1
Table 3.29 presents the type of training that the dentists would like to pursue to develop their skills in SND. Attending courses in SND was the most popular medium voted by 61.1% of dentists, followed by being involved in the SND dental team (36.1%), undergoing distance learning (22.2%) and trained as an ancillary worker in SND (5.6%). The data also reported that 19.4% of the participants were not interested in SND. Most of the male dentists (75.0%) and those practising at the main dental clinics (75.0%) were interested to attend courses in SND while half of the dentists working at the health centres did not have the same interest. The less experienced dentists, who had been working for less than five years showed the most interest to participate in SND dental team (50.0%) while none of male dentists would like to do so. Distance learning appeared to be highly nominated by the dentists at the main dental clinics (37.5%) and again male dentists showed no interest at all in this learning method. The same applied for male dentists who would not prefer to be trained as ancillary workers but the highest frequency of main clinic dentists (12.5%) thought this was appropriate to develop their skills. Older dentists whose age 30 and above (26.7%) had been the majority who had no interest at all in SND whereas only a small percentage of younger dentists (14.3%) claimed that they were not interested in this field.

3.2.6 Policy makers

3.2.6.1 Sociodemographic variables

The sociodemographic variables for the policy makers consisted of age, gender, portfolios and length of service in the Ministry. The age range of respondents was between 36 and 56 years old with mean age of 48 years old. They were then divided into two age groups, whereby four (50.0%) of them were younger than 48 years old and the rest were 48 years old and older. Female respondents comprised of the majority of the participants (n=7, 87.5%) while there was only one male respondent, 12.5%. Even though, initially, the respondents were expected to represent three types of major portfolios in the Oral Health Division which included Malaysian Dental Council (MDC), Oral Health Care Policy and Oral Health Care units, there was none who represented MDC. There were seven (87.5%) respondents who held the posts in Oral Health Care Policy unit and one (12.5%) holding the post in Oral Health Care unit. Similarly, seven (87.5%) of them had been
Table 3.29. Types of training in SND in dentists’ best interest, by age, gender and practice characteristics (brackets contain percentages of dentists nominating that option)

<table>
<thead>
<tr>
<th></th>
<th>Courses</th>
<th>Distance learning</th>
<th>Types of training: Ancillary workers</th>
<th>Dental team</th>
<th>Not interested</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than 30</td>
<td>13 (61.9)</td>
<td>6 (28.6)</td>
<td>2 (9.5)</td>
<td>9 (42.9)</td>
<td>3 (14.3)</td>
</tr>
<tr>
<td>30 or older</td>
<td>9 (60.0)</td>
<td>2 (13.3)</td>
<td>0 (0)</td>
<td>4 (26.7)</td>
<td>4 (26.7)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3 (75.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0.0)</td>
<td>1 (25.0)</td>
</tr>
<tr>
<td>Female</td>
<td>19 (59.4)</td>
<td>8 (25.0)</td>
<td>2 (6.3)</td>
<td>13 (40.6)</td>
<td>6 (18.8)</td>
</tr>
<tr>
<td><strong>Workplace</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Main clinic</td>
<td>6 (75.0)</td>
<td>3 (37.5)</td>
<td>1 (12.5)</td>
<td>3 (37.5)</td>
<td>2 (25.0)</td>
</tr>
<tr>
<td>Health centre clinic</td>
<td>9 (50.0)</td>
<td>4 (22.2)</td>
<td>1 (5.6)</td>
<td>7 (38.9)</td>
<td>3 (16.7)</td>
</tr>
<tr>
<td>Hospital clinic</td>
<td>7 (70.0)</td>
<td>1 (10.0)</td>
<td>0 (0)</td>
<td>3 (30.0)</td>
<td>2 (20.0)</td>
</tr>
<tr>
<td><strong>Years of service</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 5</td>
<td>11 (61.1)</td>
<td>4 (22.2)</td>
<td>2 (11.1)</td>
<td>9 (50.0)</td>
<td>4 (22.2)</td>
</tr>
<tr>
<td>5 or more</td>
<td>11 (61.1)</td>
<td>4 (22.2)</td>
<td>0 (0)</td>
<td>4 (22.2)</td>
<td>3 (16.7)</td>
</tr>
<tr>
<td>All combined</td>
<td>22 (61.1)</td>
<td>8 (22.2)</td>
<td>2 (5.6)</td>
<td>13 (36.1)</td>
<td>7 (19.4)</td>
</tr>
</tbody>
</table>

\(^aP<0.1\)
in the service for more than ten years and one (12.5%) had served the Ministry between five and ten years. For most data, significant association between sociodemographic variables and other measured variables were not indicated in this study.

3.2.6.2 Perception about Special Needs Dentistry

3.2.6.2.1 Definition of SND

As asked previously to the oral health care professionals, the same six characteristics describing people with special needs were included in the questionnaires for policy makers to assess their views on the definition of people with special needs. Physical impairment was chosen by all participants, as the criterion should be considered in describing people with special needs, as shown in Table 3.30. Mental impairment was the second most chosen by the participants as a criterion of special needs nominated by seven (87.5%) respondents. All participants from those who were younger than 48 years old, male policy maker, those from Oral Health Care Policy unit and had been in the service between five and ten years had chosen this option, while none from the Oral Health Care unit agreed with this criterion. It was followed by medical impairment as being one of the criteria of special needs conditions, whereby it had been chosen by six (75.0%) respondents. All male policy makers, those from the Oral Health Care unit and those who had been practising between five and ten years had nominated this criterion. Intellectual and social impairments had fallen next in the row of the characteristic of people with special needs with five (62.5%) participants chose this option. Two of the older group of the respondents but one male policy maker, one Oral Health Care unit’s representative and those who had been in the service for less than ten years thought that intellectual disability was a characteristic of special needs, whereas, less than half of the participants (45.7%) who had been in the service for more than ten years felt that social impairment should be included in the criteria. Emotional impairment was chosen by half of the participants, voted by all males, the Oral Health Care unit’s respondents and those who had less experience, but only three females and those from the Oral Health Care Policy unit shared the same thoughts.
Table 3.30. Criteria included by policy makers, describing people with special needs, by age, gender and practice characteristics (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Include this impairment in definition of “special needs”:</th>
<th>Physical</th>
<th>Intellectual</th>
<th>Mental</th>
<th>Medical</th>
<th>Emotional</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than 48</td>
<td>4 (100.0)</td>
<td>3 (75.0)</td>
<td>4 (100.0)</td>
<td>3 (75.0)</td>
<td>2 (50.0)</td>
<td>2 (50.0)</td>
</tr>
<tr>
<td>48 or older</td>
<td>4 (100.0)</td>
<td>2 (50.0)</td>
<td>3 (75.0)</td>
<td>3 (75.0)</td>
<td>2 (50.0)</td>
<td>3 (75.0)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>Female</td>
<td>7 (100.0)</td>
<td>4 (57.1)</td>
<td>6 (85.7)</td>
<td>5 (71.4)</td>
<td>3 (42.9)</td>
<td>4 (57.1)</td>
</tr>
<tr>
<td>Portfolio</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malaysian</td>
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<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
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<td>7 (100.0)</td>
<td>5 (71.4)</td>
<td>3 (42.9)</td>
<td>4 (57.1)</td>
</tr>
<tr>
<td>Oral Health Care Policy</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>Years of service</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between 5 and 10</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>10 or more</td>
<td>7 (100.0)</td>
<td>4 (57.1)</td>
<td>6 (85.7)</td>
<td>5 (71.4)</td>
<td>3 (42.9)</td>
<td>4 (45.1)</td>
</tr>
<tr>
<td>All combined</td>
<td>8 (100.0)</td>
<td>5 (62.5)</td>
<td>7 (87.5)</td>
<td>6 (75.0)</td>
<td>4 (50.0)</td>
<td>5 (62.5)</td>
</tr>
</tbody>
</table>

*P<0.1
Table 3.31. Perspectives of policy makers in various aspects of SND, by age, gender and practice characteristics (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Aspects of SND in policy makers' perspective:</th>
<th>Familiarity</th>
<th>Awareness</th>
<th>Specialist required in SND</th>
<th>Increase in demands for SND</th>
<th>Domiciliary service development</th>
<th>Readiness of MOH for the development of SND</th>
<th>Special facilities for SND</th>
<th>Involvement of other organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than 48</td>
<td>2 (50.0)</td>
<td>3 (75.0)</td>
<td>3 (75.0)</td>
<td>4 (100.0)</td>
<td>4 (100.0)</td>
<td>3 (75.0)</td>
<td>4 (100.0)</td>
<td>4 (100.0)</td>
</tr>
<tr>
<td>48 or older</td>
<td>4 (100.0)</td>
<td>4 (100.0)</td>
<td>4 (100.0)</td>
<td>4 (100.0)</td>
<td>3 (75.0)</td>
<td>2 (50.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>Female</td>
<td>6 (85.7)</td>
<td>6 (85.7)</td>
<td>6 (85.7)</td>
<td>7 (100.0)</td>
<td>6 (85.7)</td>
<td>5 (71.4)</td>
<td>6 (85.7)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td>Portfolio</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oral Health Care Policy</td>
<td>5 (71.4)</td>
<td>6 (85.7)</td>
<td>6 (85.7)</td>
<td>7 (100.0)</td>
<td>6 (85.7)</td>
<td>5 (71.4)</td>
<td>7 (100.0)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td>Oral Health Care</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>Years of service</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between 5 and 10</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>10 or more</td>
<td>5 (71.4)</td>
<td>6 (85.7)</td>
<td>6 (85.7)</td>
<td>7 (100.0)</td>
<td>6 (85.7)</td>
<td>4 (57.1)</td>
<td>6 (85.7)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td>All combined</td>
<td>6 (75.0)</td>
<td>7 (87.5)</td>
<td>7 (85.7)</td>
<td>8 (100.0)</td>
<td>7 (87.5)</td>
<td>5 (62.5)</td>
<td>7 (87.5)</td>
<td>6 (75.0)</td>
</tr>
</tbody>
</table>

aP<0.1
3.2.6.2.2 Aspects of SND in the view of policy makers

The perspective of policy makers about Special Needs Dentistry was looked at in various aspects as indicated in Table 3.31. The participants were asked about how familiar they were with SND, and all respondents who were 48 years old and older, from the Oral Health Care unit and had five to ten years experience in the service, claimed that SND was not new to them, as opposed the male dentist who thought that he was not familiar with SND. Almost all of the participants (n=7, 87.5%) from various sociodemographic groups were aware about the existence of SND in other parts of the world. The same number of respondents also believed that patients with special needs should be managed by specialists trained in this field. Therefore, all participants agreed that there was a need to develop the service in Malaysia. Similarly, 87.5% respondents believed that there was an increase in demands for the service in Malaysia. The development of domiciliary service was thought to be necessary by five respondents. However, only half the older age group of participants said so. In addition, majority of respondents (n=7, 87.5%) felt that the Ministry of Health has fully prepared for the development of this new field in dentistry in Malaysia and this could be supported by the provision of special facilities in the future special care unit to accommodate people with special needs which was agreed by 75.0% (n=6) of them. Again, all participants agreed that involvement of other organizations in charge of this vulnerable group of population in liasing with oral health care service was vital.

3.2.6.2.3 Needs and demands for SND service

Increasing needs and demands for SND service were the main reasons for the development of this specialty as shown in Table 3.32. Several areas were offered in order to see the policy makers’ point of views regarding these aspects of the development of the service. Since people with special needs had been long managed by Oral Surgeons and Dental Paediatric specialists, an increase in their current workload was seen by five (62.5%) respondents as the factor of the development of SND service. The male policy maker and those from the Oral Health Care unit claimed that patients with special needs should be attended by experts in this field. An increase in the population of people with special needs was reported to be one of the reasons for this important development in
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis
(Based on New Zealand Experience)

Table 3.32. Reasons for a need to develop SND service in Malaysia, by age, gender and practice characteristics (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Reasons for development:</th>
<th>Increase in workload of Paediatric Dental Specialist and Oral Surgeon</th>
<th>SND should be handled by experts in this field</th>
<th>Increase in population of people with special needs</th>
<th>A need of expansion of dental scopes in Malaysia</th>
<th>None is available now</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than 48</td>
<td>2 (50.0)</td>
<td>3 (75.0)</td>
<td>2 (50.0)</td>
<td>3 (75.0)</td>
<td>1 (25.0)</td>
</tr>
<tr>
<td>48 or older</td>
<td>3 (75.0)</td>
<td>3 (75.0)</td>
<td>3 (75.0)</td>
<td>3 (75.0)</td>
<td>2 (50.0)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>Female</td>
<td>4 (57.1)</td>
<td>5 (71.4)</td>
<td>4 (57.1)</td>
<td>5 (71.4)</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td>Portfolio</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oral Health Care Policy</td>
<td>4 (57.1)</td>
<td>5 (71.4)</td>
<td>4 (57.1)</td>
<td>5 (71.4)</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td>Oral Health Care</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>Years of service</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between 5 and 10</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>10 or more</td>
<td>5 (71.4)</td>
<td>6 (85.7)</td>
<td>5 (71.4)</td>
<td>6 (85.7)</td>
<td>3 (42.9)</td>
</tr>
<tr>
<td>All combined</td>
<td>5 (62.5)</td>
<td>6 (75.0)</td>
<td>5 (62.5)</td>
<td>6 (75.0)</td>
<td>4 (37.5)</td>
</tr>
</tbody>
</table>

*P<0.1

the dental service by five respondents. It was also seen by six participants as the right time to expand the scope of dental specialty in Malaysia. Lower proportion of participants (n=4, 37.5%) thought that the unavailability of the service at the moment was the reason for the development of SND. Interestingly, none of the participants who were in the service between five to ten years agreed with these suggested purposes.
3.2.6.2.4 Support provided by the Ministry of Health in the development of SND

The policy makers were also asked about possible methods of support which would be provided by the Ministry for general dental practitioners who had growing interest in the field of SND as described in Table 3.33. All respondents reported that scholarships should be given to the general dental practitioners who had known interest in SND to obtain formal training and to become specialist in this area. A majority of them (n=7, 87.5%) were also agreed that, providing continuing professional development course for the dental officers could assist them to gain confidence. It would be wise for the manager at the clinics where the dentists were practising to release them for certain number of hours to attend broad based training in SND as agreed by six policy makers but none of them who had been in the service for more than five years but less than ten years shared the same thought. Providing good career pathway for the specialist in SND was believed by majority of respondent as a good medium to attract more dentists to develop their interest in SND.

3.2.6.2.5 Role of disability support association in liaising with SND service

The importance of the involvement of the disability support association in managing oral health care of people with special needs was reviewed, taking into account four basic roles of the associations related to dentistry presented in Table 3.34. Since, there was no significant difference in the view of the policy makers in association with the sociodemographic variables, only the combined result will be presented. Providing support to clients to access dental facilities and training programmes for the caregivers in carrying out oral hygiene care for the clients, were nominated by all respondents as the major roles of the disability support associations. It was followed by the provision of assistance in performing good oral hygiene care and working closely with the Ministry of Health to promote oral care for people with special needs to the community which had been chosen by majority of participants (n=7, 87.5%).
Table 3.33. Support provided by the Ministry of Health Malaysia for dental officers who are interested in SND, by age, gender and practice characteristics (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Scholalrship for formalized training</th>
<th>Support provided by MOH: Providing continuing professional development course</th>
<th>Support provided by MOH: Permission to attend broad based training</th>
<th>Good career pathway</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than 48</td>
<td>4 (100.0)</td>
<td>4 (100.0)</td>
<td>2 (50.0)</td>
</tr>
<tr>
<td>48 or older</td>
<td>4 (100.0)</td>
<td>3 (75.0)</td>
<td>4 (100.0)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>Female</td>
<td>7 (100.0)</td>
<td>6 (85.7)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td>Portfolio</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oral Health Care Policy</td>
<td>7 (100.0)</td>
<td>6 (85.7)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td>Oral Health Care</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>Years of service</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between 5 and 10</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>10 or more</td>
<td>7 (100.0)</td>
<td>6 (85.7)</td>
<td>6 (85.7)</td>
</tr>
<tr>
<td>All combined</td>
<td>8 (100.0)</td>
<td>7 (87.5)</td>
<td>6 (75.0)</td>
</tr>
</tbody>
</table>

*P<0.1

3.2.6.2.6 Future expectation in SND service in Malaysia and various issues related to SND in policy makers' perspective

Table 3.35 indicates the expectation of policy makers toward SND service in Malaysia in the near future. All respondents seemed to believe that there would be a good future for the service and two of them also expected the demand for the service will continuously increase. Certain issues regarding the service which were believed to contribute to the development of SND, were asked to the policy makers. Seven statements were given in the questionnaire as presented in Table 3.36, and the policy makers were required to
choose whether they agreed with the statements or vice versa. The first six statements had been agreed by all participants. Firstly, the service for a high risk patient to be provided within the hospital environment but those who are undergoing maintenance phase and low risk needs can be managed at community dental clinic. Secondly, easy access to dental care facilities by people with special needs should be taken into consideration in the plan of future dental clinics or special care units. Appropriate referral guidelines should be developed if referral of patients required from medical site to dental

Table 3.34. Role of disability support associations in liaising with SND service, by age, gender and practice characteristics (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Roles of disability support associations:</th>
<th>Support to access dental facilities</th>
<th>Assistance in performing good oral hygiene care</th>
<th>Training the caregivers</th>
<th>Working closely with MOH to promote oral hygiene care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than 48</td>
<td>4 (100.0)</td>
<td>3 (75.0)</td>
<td>4 (100.0)</td>
<td>4 (100.0)</td>
</tr>
<tr>
<td>48 or older</td>
<td>4 (100.0)</td>
<td>4 (100.0)</td>
<td>4 (100.0)</td>
<td>3 (75.0)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>Female</td>
<td>7 (100.0)</td>
<td>6 (85.7)</td>
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<tr>
<td>Portfolio</td>
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<td></td>
</tr>
<tr>
<td>Oral Health Care Policy</td>
<td>7 (100.0)</td>
<td>6 (85.7)</td>
<td>7 (100.0)</td>
<td>6 (85.7)</td>
</tr>
<tr>
<td>Oral Health Care</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>Years of service</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between 5 and 10</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
<td>1 (100.0)</td>
</tr>
<tr>
<td>10 or more</td>
<td>7 (100.0)</td>
<td>6 (85.7)</td>
<td>7 (100.0)</td>
<td>6 (85.7)</td>
</tr>
<tr>
<td>All combined</td>
<td>8 (100.0)</td>
<td>7 (87.5)</td>
<td>8 (100.0)</td>
<td>7 (87.5)</td>
</tr>
</tbody>
</table>

*P<0.1
Table 3.35. Future of Special Needs Dentistry service in Malaysia as expected by the policy makers (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Expected future of Special Needs Dentistry service:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Good/ Needed/ Positive</td>
<td>8 (100.0)</td>
</tr>
<tr>
<td>May increase in demand</td>
<td>2 (25.0)</td>
</tr>
<tr>
<td>Cannot see the future at this stage</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

\(^a\)P<0.1

Table 3.36. Policy makers’ view regarding various issues on Special Needs Dentistry service (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Issues regarding SND</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>The service for high risk patients to be provided within the hospital environment but those who are undergoing maintenance phase and low risk needs can be managed at the community dental clinic</td>
<td>8 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>The plan for any future dental clinics should consider the accessibility for people with special needs</td>
<td>8 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Appropriate referral guidelines should be worked out from medical site to dental site and from general dental practitioner to specialist in SND</td>
<td>8 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>A network should be developed by the specialist in SND with the medical colleagues and other organizations in order to introduce the service to the community</td>
<td>8 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Caregivers should be formally trained in managing the dental care for people with special needs</td>
<td>8 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>The dental auxiliary staff should have training in handling people with special needs</td>
<td>8 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Guideline on the dental management of patients with special needs should be provided for the general dental practitioner and medical practitioner</td>
<td>7 (87.5)</td>
<td>1 (12.5)</td>
</tr>
</tbody>
</table>

\(^a\)P<0.1
site and from general dental practitioner to specialist in SND. It was then followed by developing a network between the specialists in SND and medical colleagues as well as other organizations in order to introduce the service to the community. In addition, caregivers should be formally trained in managing the home dental care for people with special needs, and training should also be given to dental auxiliary staff in handling these patients at the clinic level. Apart from that, 87.5% (n=7) reported that the guidelines on the dental management of patient with special needs should be provided for the general dental and medical practitioners.

In addition, Table 3.37 indicates barriers that were thought to discourage people with special needs to access dental care. Transportation and lack of awareness about oral health care of people with special needs among the caregivers were the main barriers of patients to access dental care facilities as agreed by 87.5% (n=7) of respondents. Besides that, half of the participants felt that financial constraints, location of the dental clinics which were far from home, lack of skills and knowledge of the dental practitioners in managing this group of patients and a health system which was not easily accessible by people with special needs were the contributing factors for patients not to have regular dental visits. On the other hand, less than half of respondents (37.5%, n=3) mentioned that complex health and disability as one of the barriers.

3.2.7 Disability support group representative

3.2.7.1 Sociodemographic variables
The sociodemographic variables for this group of participants were initially divided into three major categories, age, gender and workplace. However, since all the participants who returned the survey form were from one centre, there was no variety in the workplaces, therefore, some of the data were presented based only on age and gender, or only the combined measurements were highlighted due to the absence of significant association between the measured variables and the sociodemographic variables resulting from a small sample size. The minimum age of the respondents was 28 years while the maximum age was 48 years old, with mean age of 34. Therefore, in order to facilitate the analysis, the participants were divided into two age groups as shown in Table 3.38.
### Table 3.37. Barriers to oral health care facilities as seen by the policy makers (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial constraints</td>
<td>4 (50.0)</td>
<td>4 (50.0)</td>
</tr>
<tr>
<td>Transportation</td>
<td>7 (87.5)</td>
<td>1 (12.5)</td>
</tr>
<tr>
<td>Location of the dental clinics</td>
<td>4 (50.0)</td>
<td>4 (50.0)</td>
</tr>
<tr>
<td>Lack of awareness about oral health care among caregivers</td>
<td>7 (87.5)</td>
<td>1 (12.5)</td>
</tr>
<tr>
<td>Complex health and disability issues</td>
<td>3 (37.5)</td>
<td>5 (62.5)</td>
</tr>
<tr>
<td>Lack of skills and knowledge of dental practitioners</td>
<td>4 (50.0)</td>
<td>4 (50.0)</td>
</tr>
<tr>
<td>A health system which is not easily accessible by people with special needs</td>
<td>4 (50.0)</td>
<td>4 (50.0)</td>
</tr>
</tbody>
</table>

\( \text{P}<0.1 \)

The younger age group was categorized as below 34 years while the older age group was those whose age was 34 and above. The group of below 34 years consisted of two (40.0%) participants and three (60.0%) represented the older age group. Male comprised of 20.0% \( (n=1) \) of the respondents whereas, 80.0% \( (n=4) \) were females. All respondents were working at Rumah Sinar Harapan or Community Rehabilitative Centres and there was no respondent from Down Syndrome Association or Persatuan C.H.I.L.D (Caring and Helping Individuals Learn and Develop) as expected earlier.

#### 3.2.7.2 Perspective about the existing dental service for people with special needs

3.2.7.2.1 Support provided by the organization

Table 3.39 shows the types of disability which often referred to Taman Sinar Harapan and the Community Rehabilitative centres. Mental impairment was the most common condition referred to the centre as nominated by all participants. Physical disability was ranked as the second most common condition to be referred, chosen by 80.0% of the participants. Three respondents reported that people with intellectual disability were also
Table 3.38. Sociodemographic data of the respondents from the representatives of disability support groups

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below 34</td>
<td>2</td>
<td>40.0</td>
</tr>
<tr>
<td>34 and above</td>
<td>3</td>
<td>60.0</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>20.0</td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>80.0</td>
</tr>
<tr>
<td>Workplace</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Association</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rumah Sinar Harapan/Community Rehabilitative Centre</td>
<td>5</td>
<td>100.0</td>
</tr>
<tr>
<td>Social Welfare</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Department</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All combined</td>
<td>5</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 3.39. Types of disability which often referred to Taman Sinar Harapan and the Community Rehabilitative Centre (brackets contain percentage)

<table>
<thead>
<tr>
<th>Type of disabilities/impairments</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>4 (80.0)</td>
</tr>
<tr>
<td>Intellectual</td>
<td>3 (60.0)</td>
</tr>
<tr>
<td>Mental</td>
<td>5 (100.0)</td>
</tr>
<tr>
<td>Emotional</td>
<td>2 (20.0)</td>
</tr>
<tr>
<td>Social</td>
<td>2 (20.0)</td>
</tr>
</tbody>
</table>
sent to the centres for training. Emotional and social impairments were the least common type of disabilities which were referred to the rehabilitative centres as only two respondents discovered about these conditions in their clients.

The participants were asked to report on the types of support the centres were offering and types of support often requested by the community, as presented in Table 3.40. Financial support was given by two centres. Similarly, the same number of centres provided social support to the clients. Full residential care was offered by most of the rehabilitative centres whereas two centres supported the clients in looking for jobs. In addition, more than half of the centres offered vocational training for those in needs. On the other hand, all centres were often asked to provide full residential care for people with special needs. Financial support was requested by this vulnerable group of population from two centres and one centre was asked for some kind of social support. None of the centres discovered people requested for job search support and vocational training.

Table 3.40. Types of supports given and requested at Taman Sinar Harapan and the Community Rehabilitative Centre (brackets contain percentage)

<table>
<thead>
<tr>
<th>Support often given</th>
<th>Support often requested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Financial</td>
<td>2 (40.0)</td>
</tr>
<tr>
<td>Social</td>
<td>2 (40.0)</td>
</tr>
<tr>
<td>Full time residential care</td>
<td>4 (80.0)</td>
</tr>
<tr>
<td>Job search</td>
<td>2 (40.0)</td>
</tr>
<tr>
<td>Vocational Training</td>
<td>3 (60.0)</td>
</tr>
</tbody>
</table>
The involvement of the organizations in oral health care for people with special needs

The involvement of the organizations in oral health care for people with special needs was assessed in various aspects of activities. The activities and the response obtained from the centres are listed in Table 3.41. None of the centres reported of organizing any event related to dentistry regularly. However, three centres claimed to make some arrangement with the nearby dental clinics for the clients to have dental check up. In contrast, lower proportion of respondents (20.0%) did have daily personal care checklist for clients including dental care. Dental care assistance and oral hygiene care training to the caregivers were not part of the programme provided by any of the centres.

Table 3.41. Program related to dental care organized at Taman Sinar Harapan and the Community Rehabilitative Centres for people with special needs (brackets contain percentage)

<table>
<thead>
<tr>
<th>Program</th>
<th>Yes (n) (%)</th>
<th>No (n) (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual dental event</td>
<td>0 (0)</td>
<td>5 (100.0)</td>
</tr>
<tr>
<td>Arrangement for dental visit with the nearby dental clinics</td>
<td>3 (60.0)</td>
<td>2 (40.0)</td>
</tr>
<tr>
<td>Daily personal care checklist filled by the caregivers</td>
<td>1 (20.0)</td>
<td>4 (80.0)</td>
</tr>
<tr>
<td>Dental care assistance</td>
<td>0 (0)</td>
<td>5 (100.0)</td>
</tr>
<tr>
<td>Oral hygiene care training to the caregivers</td>
<td>0 (0)</td>
<td>5 (100.0)</td>
</tr>
</tbody>
</table>

3.2.7.2.3 Views on various aspects of SND

Certain areas of dental service were offered for respondents to comment as indicated in Table 3.42. All participants agreed that dental health was equally important as general health. A similar response was given by all respondents when asked about dental care of people with special needs which should be delivered by the specialist in SND field. The
Table 3.42. Views of the representatives of the support group disability about the existing dental service for people with special needs, by age and gender (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Areas of concern:</th>
<th>Dental health is equally important as general health</th>
<th>Dental care of people with special needs should be managed by the specialist in that field</th>
<th>The necessity of domiciliary service for the clients</th>
<th>Agree with the development of SND service in Malaysia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below 34</td>
<td>2 (100.0)</td>
<td>0 (0)</td>
<td>2 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>34 and above</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
<td>3 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
<td>1 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Female</td>
<td>4 (100.0)</td>
<td>0 (0)</td>
<td>4 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>All combined</td>
<td>5 (100.0)</td>
<td>0 (0)</td>
<td>5 (100.0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

\(^{a}P<0\)
development of domiciliary service and SND service in Malaysia were thought to be appropriate by all respondents. Also, as far as the dental care was concerned by the support group, government dentists were the major care providers for people with special needs.

Certain issues related to people with special needs which should be addressed by the government and might discourage them from accessing dental care facilities were also raised up in the questionnaire for the respondents to review. As shown in Table 3.43, total general health problems, dental health problems, and difficulties to find suitable jobs were nominated as the main issues chosen by all respondents. Four representatives found that requiring assistance in activities of daily living was another major problem related to people with special needs. It was then followed by issues like being neglected by family members and the community, difficulties in accessing health service, social stigma faced by family members and the last but not least, the financial constraints were considered by three participants as prudent to be looked in depth.

**Table 3.43.** Issues related to people with special needs which discourage them from accessing dental care (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Areas of concern</th>
<th>Yes</th>
<th>No (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neglected</td>
<td>3 (60.0)</td>
<td>2 (20.0)</td>
</tr>
<tr>
<td>Assistance in activity of daily living</td>
<td>4 (80.0)</td>
<td>1 (20.0)</td>
</tr>
<tr>
<td>Total general health problems</td>
<td>5 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Dental health problems</td>
<td>5 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Difficulties to access health service</td>
<td>3 (60.0)</td>
<td>2 (20.0)</td>
</tr>
<tr>
<td>Social stigma</td>
<td>3 (60.0)</td>
<td>2 (20.0)</td>
</tr>
<tr>
<td>Difficult to find a job</td>
<td>5 (100.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Financial constraint</td>
<td>3 (60.0)</td>
<td>2 (20.0)</td>
</tr>
</tbody>
</table>
Other areas of concern were the views of the participants on the existing dental service delivered for people with special needs as indicated in Table 3.44. Three respondents agreed that the current dental fee was high and unaffordable by people with special needs. A lack of experience of the general dentists in managing people with special needs was another major concern in the service as mentioned by two participants. Similarly, two reported about lack of communication between patients and dentists, transportation issues to dental clinic and limited access to dental care facilities.

Table 3.44. Views on dental care project for people with special needs (brackets contain percentages of respondents nominating that option)

<table>
<thead>
<tr>
<th>Areas of concern</th>
<th>Yes</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High dental fee</td>
<td>3 (60.0)</td>
<td>2 (40.0)</td>
</tr>
<tr>
<td>Lack of experience of the general dentist in managing people with special needs</td>
<td>2 (40.0)</td>
<td>3 (60.0)</td>
</tr>
<tr>
<td>Lack of communication between patient and dentist</td>
<td>2 (40.0)</td>
<td>3 (60.0)</td>
</tr>
<tr>
<td>Transport to dental clinic</td>
<td>2 (40.0)</td>
<td>3 (60.0)</td>
</tr>
<tr>
<td>Limited access to dental care facility</td>
<td>2 (40.0)</td>
<td>3 (60.0)</td>
</tr>
</tbody>
</table>
4 CHAPTER FOUR

4.1 DISCUSSION

This project investigated five groups of participants which were the major stakeholders in the field of SND, people with special needs, caregivers, oral health professionals, policy makers and disability support group representatives. A mixed-methods research design was adopted in the form of semi-structured interviews and observation, as well as a census survey. The analysis of the data resulted in the identification of areas which required some particular concern in the development of the SND service in Malaysia with regard to oral hygiene practice of people with special needs, knowledge and views on oral hygiene care for people with special needs, barriers experienced by people with special needs to access dental care facilities, criteria included to define people with special needs in Malaysia and referral criteria and lastly, the knowledge and exposure received by oral health practitioners in managing people with special needs. Owing to the differences in the data collection and limited number of similar studies, a direct comparison was not possible for certain areas of concern. However, where the similarities were noted with other recent studies, these will be highlighted in the text which follows.

4.1.1 Methodological Issues

As described earlier, this study used combination of qualitative and quantitative approaches to better understand a research problem. It is also called mixed-methods research which is best used when neither approach is sufficient alone. Since SND is a relatively new area of specialty in Malaysia, collecting the literature from the similar target groups was difficult and almost none was available. Therefore, adopting the qualitative study in the form of semi-structured interviews provided the background information on the perspectives of the stakeholders in SND and overcame the difficulties faced by the researcher in obtaining this information from the literature. The quantitative part was expected to strengthen the findings of the qualitative part by producing statistical report with correlations. By using this method, the study could be built up based on the strength of both the qualitative and quantitative research methods. Therefore, a complete picture of the research problem could be provided. In addition, this
mixed-methods complemented a result from one type of research to another. In this circumstance, a qualitative research alone would tend to be less helpful through its selectivity in reporting whereas purely quantitative research tended to be less helpful through its oversimplification of causal relationship. As for this present study, the strength was from the qualitative component as it was rarely done for the target population and shunned by many researchers for some reason. This could minimize the weak points in the quantitative components which suffered from low response rate. On the other hand, this required training in both methods and working with multiple teams which certainly increased the cost of the study. In addition, this method is still very new to dental research related to SND.

In the qualitative phase of the study, 55 participants were interviewed in which 21 of them were New Zealanders and the other 34 were from Malaysia. The number of people who were willing to be interviewed was much less than that of the potential participants which had been initially approached. Time constraints, distance between where the researcher was based and the location of the participants, the availability of the participants within the time that the interviewer was in Malaysia and travelling issues of the interviewer, were the limitations involved in collecting the qualitative data. In addition, the reader should bear in mind that there were other factors, such as communication, the patient’s educational background and the impairments that the participants lived with, which might have influenced the delivery and validity of the information. The interviewer, in any possible situation had modified the dialogue to match the participant’s level of understanding, in an attempt to cover a wide range of disabilities for this study and to gain as much input as possible. Some bias of the information given by participants especially those from the groups of people with special needs, caregivers and disability support group representatives did exist, in order to impress the interviewer whom they knew to be a dentist. From observation by the interviewer, the information was given based on what they thought was the best practice rather than the actual scenario they were practising.

Since, this was the first study of its kind in Malaysia, therefore, to attract the involvement of the eligible participants in the quantitative part (answering survey questionnaire) was
challenging. Approaching private organizations and individuals with special needs as well as the caregivers were disappointing. They either refused to participate or did not return the questionnaire in the time allowed or could not be contacted during follow up. A second wave of the questionnaires improved the number of respondents for certain groups such as oral health professionals and policy makers but failed to gain the same result for the rest of the groups of participants. Again, time constraints, distance, communication and cost were the difficulties faced by the researcher, resulted in disappointing number of responses. The major aim of the quantitative phase was to examine whether the themes identified from the interviews applied to the majority of the targeted population or were unique to certain individuals. Even though, the response rate was only 17.0%, which was far below expectation, it has to be accepted to allow the completion of the course thesis. Therefore, the study might not fully represent the entire group of population. The small sample size created difficulties with statistical power in quantitative data and indicated lack of interest and knowledge of the Malaysian population in SND. Nevertheless, it identifies a worrying lack of awareness about the importance of oral hygiene care for people with special needs at both the domestic and professional level, and this warrants further action.

4.1.2 Findings

4.1.2.1 Oral hygiene practice of people with special needs

People with special needs who were involved in this study were mainly suffering from physical disabilities, either mild or moderate which might or might not be accompanied by other medical conditions. People with intellectual disabilities were excluded from this study to ensure that the participants could understand and answer the survey questionnaires by themselves, as required. Even though 80.0% of the respondents were cared for by caregivers, many were capable of performing the oral hygiene care on their own which indicated that, their manual dexterity was not affected. So far, there was no study in Malaysia which aimed to look at oral hygiene practise of adults with physical disabilities, which led to the difficulties in comparing the results obtained with other studies comprising of similar population. The mean age of participants in this study was 38.9 years old. Most data which was currently available focused on younger (children and
adolescent) and older (more than 65 years old) age group. There was one study carried out in India by Patro BK in 2008 which looked at oral hygiene practices in similar age group of population but without any disabilities.65 Another study done by Shoaib M in Pakistan was designed to determine the oral hygiene status and brushing habits of individuals with special needs having sensory and physical disabilities but in younger population with age ranges between six and 17 years old.66 Azrina et al 2007 carried out a qualitative study which investigated oral hygiene practices among the visually impaired adolescents in Malaysia which could be categorized as an oral health project related to people with physical disabilities.67 In addition, there was no significant difference in the number of females and males participants as well as among the ethnic groups due to a very small sample size.

As mentioned in the previous text, apart from the participants’ physical disabilities, all respondents managed to perform oral hygiene care independently and only one of them was having problems in cleaning his teeth because of the difficulties to remove food debris from interdental areas. It shows that, having physical disabilities may not restrict someone from performing routine oral hygiene care independently as long as the manual dexterity is intact. In addition, this study showed that, having a personal dentist was not important as there was only one participant who saw a particular dentist regularly, with majority of them (60.0%) visited government dentists randomly. This could be related to the current situation in Malaysia that the government dentists working in the community are easily accessible at any time at no cost for people with special needs if they are the holders of disability card, issued by the Social Welfare Department. This resulted in private dentists being rarely preferred or used by this group. Dental devices other than toothbrush were used by two participants from those with mild physical disabilities which indicated that they were aware of other cleaning devices available to clean the teeth. Unfortunately, details of the devices were not collected on the questionnaire. These findings were consistent with the data collected from the caregivers group who majority of them (80.0%) reported that their clients, either with mild or moderate physical disabilities could perform dental cleaning without assistance. Similarly, clients were brought to see government dentists by 80.0% of the caregivers and only one client was reported to have a personal dentist.
From the data, it was also found that older caregivers (54 years and above) who had only provided care for a short period faced some difficulties in performing oral care for the clients as opposed to younger caregivers who reported no difficulties and seemed to be motivated by encouraging their clients to use supplementary devices other than a toothbrush as necessary. Only small number of participants were seen by dental specialists (n=2, 40.0%) and according to the caregivers, none of their clients had ever been seen by dental specialist. This could be associated with factors such as general dentists are capable of managing many people with special needs, there is no need for referral to specialist or the absence of specialist in SND in Malaysia. However, these factors can result in negligence of dental care of this vulnerable group of population with unmet treatment needs.

Brushing teeth twice or three times a day was reported by all of the people with special needs in this study, with majority of them (80.0%) brushed at least twice daily. Similar finding was reported by Azrina et al, 2007. A report from a study concerning people from the same age group also consistent with the results obtained from this project. In addition, people with mild physical disabilities were found to brush less frequently than people with moderate disabilities. However, there was no significant age, sex and ethnic differences found in the brushing practice between those with mild and moderate physical disabilities.

The question regarding the method of selecting dentists was included in the survey form in order to identify the best mechanism to introduce people with special needs to SND service in Malaysia. It was suggested by this study that the signboard of dental clinics played an important role to attract people to seek for dental care at a particular dental practice. Information from neighbours and friends was also useful for a small number of respondents from this group. It was followed by information gained from various form of advertisements in mass media. The data from the caregivers also yielded the same trend of findings. There was no other study available to compare the results. The reason for clinic signboard to be such a popular medium was because it could be easily seen and provided exact and direct information about the dental service provided and the location of the clinic. However, from the results, clinic signboard might not be the only mechanism
of introduction, as some of the respondents who chose this method had also nominated other mechanisms of introduction. Unfortunately, they did not specify the methods in their answer as requested.

An interesting finding was that most of people with special needs would only see dentist when they were having dental problems, as claimed by 60.0% of people with special needs and 40.0% of the caregivers. One reported seeing a dentist at least once a year and another 20.0% visited dentist once in two years. The figure was slightly different from the data given by the caregivers whereby 40.0% of them would bring the client to dentist at least once a year and the other 20.0% did that at least once in six months. The trend of seeing dentist when the problem arose was also reported in other studies.\textsuperscript{68, 69} Unfortunately, this attitude may not only applicable for people with special needs but also lives in a normal population.

\textbf{4.1.2.2 Knowledge and views on oral hygiene care for people with special needs}

Lack of knowledge about effective oral hygiene care related to specific conditions that the people with special needs were suffering from, was obvious when 80.0% of respondents claimed that they did not obtain any individual advice regarding oral health care. This result might be associated with the high proportion of participants who only sought for dental care when only they were having dental problems. Lack of experienced dentists and willingness of general dentists to manage people with special needs could also be the contributing factors for the patients not receiving adequate dental advice as reported by Pradhan A. in her study, which aimed to investigate factors influencing the oral health status of adults with physical and intellectual disabilities.\textsuperscript{70} Therefore, self learning experience was the important medium of education for these people. Advice obtained by the other 20.0% of participants was mainly from dentists, internet, radio and television which were consistent with the research findings undertaken by Sixsmith J., et al.\textsuperscript{71} Sumi also reported that majority of the caregivers at the Japanese nursing homes gained information about oral care of the elderly through mass media which suggested the future importance of mass media in education and other activities to promote oral care.\textsuperscript{72} The types of advice claimed to be received from radio and television were likely to be the information provided through dental product advertisement and possibly from health
related programmes. Even though the internet can provide huge amount of information required, it may not be accessible to all people with special needs, as it requires extra equipments, cost and knowledge especially for those living at rural areas where internet access is limited.

As expected, the term SND or dental care for people with special needs was very unfamiliar to all caregivers participating in this study, as compared to other specialties in dentistry. Owing to lack of promotion and marketing of SND service, this new field of specialty might not be recognizable by a lay person even though it had been long provided within the community. Nonetheless, the importance of oral hygiene care was ranked equally to that of general health by all the respondents from the caregivers group as well as the disability support representatives, which was a good sign that the caregivers and the key workers were aware about the effects of poor dental health to individuals. A previous study done in Japan regarding the attitudes to oral care among the caregivers at nursing homes also found that 99.9% of the caregivers recognized the importance of oral care and 96.0% showed some interest in oral care.

A review of people with special needs satisfaction level for the existing dental service indicated that 60.0% of respondents were not satisfied with the service they were receiving, particularly with the government dental services. In this study, no significant differences were observed between the satisfaction scores and background variables, which was consistent with the results obtained by Hashim R, 2005 from his study which investigated patients' satisfaction with dental services in Ajman University, United Arab Emirates. However, from caregivers' data, older caregivers and females were most satisfied with the service provided as opposed to the younger and male caregivers. Similar finding was reported by Stege by which patients over the age of 60 tended to be more satisfied with their dental care than younger patients and Gopalakrishna and Mummaleni found that women expressed greater levels of satisfaction with dental care than men.

This could be described as due to their greater exposure to dental services which modified their expectations. On the other hand, in a study by Lahti et al., older patients were less satisfied with the dental service but younger patients usually had better oral health status than the older population which made their dental experience less
The Development of Special Needs Dentistry Service in Malaysia - A Situational Analysis
(Based on New Zealand Experience)

stressful.\textsuperscript{76} Jacob J., et al., who measured service quality of public health dental service in Kelantan, Malaysia found that there was no significant association between patient satisfaction and age, gender, marital status or personal income.\textsuperscript{77}

Further, in the present study, few responses from people with special needs were satisfied with the clinic cleanliness which was supported by less than half of the caregivers. This technical quality is difficult to compare with other studies as it depends on peoples’ subjective view on particular practices which might be influenced by other factors. Dental staff manner was satisfactory for majority of respondents (people with special needs and caregivers) which has been shown by various studies as an important element in evaluating dental care services.\textsuperscript{78, 79} This interpersonal factor can be described as personality and communication skills of dental personals. Effective communication skills have been shown by Mellor and Milgrom to limit patient dissatisfaction and so preventing liability claims.\textsuperscript{80}

The location of the dental clinic appeared to be non problematic for majority of respondents which could be supported by the dental health system in Malaysia where community dental clinics are distributed close to the community, be it in rural or urban areas. This was opposite from the view of policy makers, half of whom thought that the location of the dental clinic and a health system which was not easily accessible would be the problems for patients in accessing dental care. These contradictory views might result from the opinion of the policy makers who viewed the issues from different perspective. An absence of an appropriate referral system for people with disabilities was referred by the policy makers as a health system which was not easily accessible.

On the other hand, although not significant, quite considerable numbers of the participants were not satisfied with the fee charged for dental treatment. It is a surprising finding, as to the author’s knowledge, people with special needs in Malaysia can receive free dental treatment at the government dental clinics as noted previously or if some payment is required e.g dental prostheses, the cost is still less than that in private practice. Domiciliary dental service was explained in the questionnaire as a dental service provided at home facilities or residential institution, and was supported by most of the participants and all representatives of the disability support group, which could be a good
future plan in the development of SND. Unfortunately, most of the data available in terms of dental patient satisfaction do not specifically address people with special needs to make this study comparable to the other studies.

Looking at the attitude of caregivers about appropriate dental visits required for people with special needs, even though not significant, there was an association between the frequency of dental visits and the level of education of the caregivers. College or university graduates seemed to believe that once a year dental visit was adequate enough for people with special needs. In contrast, those with only high school qualification did believe that dental visits should be done at least once in six months. However, those who agreed on one dental visit in a year also stated that, the frequency could vary depending on the clients’ needs for dental treatment.

As described earlier, people with special needs tended to seek dental treatment only when they had some dental problems. Dental problems in this context could be commonly related to acute dental pain which required urgent care and immediate pain relief. This was consistent with the view of the caregivers who categorized pain relief and emergency care as very important. The caregivers’ awareness about the importance of preventive dental measures such as oral hygiene instruction (OHI) and, scaling and cleaning were also observed in this study. Regular preventive oral health care can improve the health of persons with disabilities with little effort and great long term benefit. However, restorative dental treatments, tooth extraction, prostheses fabrication and specialist treatment were also reported as important as the preventive care. More complex treatments such as root canal treatment and implants were not considered suitable for people with special needs from the view of the caregivers. On the other end, much simpler preventive care such as dental examination and diagnostic radiograph were categorized as not important.

4.1.2.3 Barriers experienced by patients to access dental facilities

Accessing dental care facilities can be difficult for people with special needs regardless of their disabilities. Various previous studies have shown that many issues are involved leading to difficulties in obtaining dental care in this group of people. These are
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis
(Based on New Zealand Experience)

commonly related to knowledge, attitude and experience.\textsuperscript{83-85} However, there are inconsistent findings from studies addressing access to dental care for a person with disabilities. Al Agili et al., found that, 85.0\% of parents reported their children with disabilities had received some form of dental care and Bourke et al. found only 10.0\% of parents whose children with cerebral palsy had difficulties in obtaining dental care.\textsuperscript{86, 87}

This is supported by Russell & Kinirons who reported 60.0\% of adults with cerebral palsy in their study were regular dental attenders.\textsuperscript{88} On the other hand, Finger and Jedrychowski discovered that almost half of the respondents (parents of children with handicapping conditions) having difficulties to access dental care facilities for their children.\textsuperscript{89}

In this study, it was suggested that, people with mild physical disability had more problems with transport and financial status to access dental care. Also, transportation along with lack of awareness about the importance of oral hygiene care were voted by the policy makers as being the major barriers for accessing dental care. Having no one to accompany them to dental clinic was another contributing factor which limit their access to dental clinic as reported by 66.7\% of them. Negative attitudes such as no dental visit without given appointment, frequent visits not required and would only seek dental care when any problem arose were reported by a small number of participants in this group. In contrast, people with moderate disability were more worried about high dental charge than anything else. There was no significant difference regarding the same issues when comparing the view of the caregivers and people with special needs.

The fact that, transportation is the major difficulty for people with physical disabilities can be explained by non user friendly public transport in Malaysia for people with special needs. Public transport with wheelchair access is almost impossible to find especially for those who live in rural areas. Also, this may be true in cases of persons with disabilities who do not have access to a private vehicle. Even though, not significant, transportation problems have been reported to play a role in limiting access to dental care by another study as well.\textsuperscript{90} This problem may be interrelated to financial constraints where the cost of taxis is expensive or they often rely on others to accompany them for dental appointments.\textsuperscript{91} A concern regarding the fee charged by dentist can be associated with
low income of people with disabilities since they are often unemployed and live on a government benefit. On the other hand, negative attitude towards dental service is not unique to people with special needs but also exists in the general population which can lead to avoidance behaviours such as cancelling or missing appointments. A belief that they have nothing wrong with their teeth and thus dental visit is not required has also been demonstrated by other studies.\(^{86, 92-94}\)

Factors related to dental care providers may also discourage people with disabilities from seeking dental care. While most persons with disabilities do not require special modifications and receive dental care from their communities as proven by Waldman & Perlman,\(^{95}\) some dentists from the current study did think that, the existing facilities in their practice were not adequate enough to accommodate this group of patients. Therefore, lack of adequate facilities may not be a true barrier. However, the majority of the participated dentists in the present study agreed that longer time was required to manage people with special needs, and that would discourage them from providing care for this group of the population. Burtner et al. in 1990 reported similar results, while O’Donell and Tesini & Fenton, demonstrated that treatment time was patient dependent.\(^{81, 96, 97}\) Besides that, lack of skills and knowledge of the dental practitioners in managing this vulnerable group of population could be another contributing factor that prevents people with special needs from receiving appropriate dental care as reported by some of the policy makers in this study. Lack of skills and knowledge might lead to the unwillingness of the dentists to treat this group of patients. In addition, lack of communication resulted in poor understanding about the client’s dental problem by the caregiver, poor diagnosis by the oral health professionals, and inconsistent information from the caregivers and the clients. All of these would lead to poor patient management.

### 4.1.2.4 Criteria included to define people with special needs and referral criteria of people with special needs

This particular section examined the factors used by oral health professionals about why they call an individual as a person with special needs. It is prudent to determine the criteria of patients with disabilities who require referral to specialist in SND. Inappropriate referral of patients, by general dental practitioners and other health professionals to
dental specialists often occur due to misunderstanding of the type of patients who are treated by specialists in SND and a lack of information regarding the patient’s special need in the referral letter. While some patients can be treated by general dentist, certain patients may benefit most in the specialist care environment though a recent study has shown that only a small proportion of patients needed to see a dental specialist.

In the present study, six characteristics were included in the questionnaire in which the participants were free to choose the specific criteria based on their view and knowledge which would fit in the definition of people with special needs. Mental, physical, intellectual and medical impairments were placed at the higher rank to be the criteria included by the dentist and policy makers. In contrast, emotional and social impairments were placed at the bottom of the list and mostly recognized as a special needs condition by dentists who worked at the hospital environment and had longer working experience.

This finding may be related to the current dental care delivery system in Malaysia where patients with special needs are traditionally referred to specialist dental clinics at the hospital but they may not be necessary treated by a dental specialist. Instead, depending on their dental problems and severity of their disabilities, they could only be managed by the registrar or house surgeon under specialist supervision if required. According to United States Department of Education 2004, someone can be diagnosed with emotional impairment if he/she exhibiting one or more of the following characteristics over extended period of time and to a marked degree can adversely affect the educational performance. The characteristics include an inability to learn which cannot be explained by intellectual, sensory or health factors, an inability to build or maintain interpersonal relationship with peers and teachers, inappropriate types of behaviour or feeling under normal circumstances, a general pervasive mood of unhappiness or depression and a tendency to develop physical symptoms or fears associated with personal or school problems. Schizophrenia is also categorized as an emotional impairment. In addition, a dictionary definition of ‘social’ is something related to spending time and meeting other people for pleasure. Therefore, failure to develop a relationship and interaction with
other people can be defined as social impairment, which may or may not be accompanied by other types of disabilities.

These two types of impairments have only been clarified in depth recently. Thus, some people may not aware that these conditions should be categorized as special needs conditions, and more often, an individual may present with more than one type of impairments. On the other hand, Ministry of Health Malaysia defines people with disabilities as ‘an individual who is unable to carry out the activities of daily living due to mental or physical impairments’. Visual, hearing, physical, intellectual, behavioural impairments and communication problem are the characteristics included in this definition.

It is important to note that, even though all the characteristics chosen by the dentists and policy makers can be accepted and included to describe people with special needs in Malaysia, it is not necessary to refer all of them to specialist in SND for dental care. Therefore, criteria for referral must be specified so that the general dentists will have clear guidelines which patient to be referred and when the referral is required. Based on the preference of the specialist, these criteria may be unique to each country or even specific to each centre. For example, Dental Special Needs Flinders Medical Centre only provides treatment for patients with complex medical conditions and the types of care provided have also been specified. This is indeed very useful for general dental practitioners when they need to refer the patients with special needs.

In the present study, it was strongly suggested that patients who required dental treatment under general anaesthesia, those with complex medical problems and uncooperative patients should be referred to receive treatment under specialist care. This is consistent with the finding reported by Hennequin et al. in 2000. Other criteria such as the unavailability of the service required at the attended practice, patients with significant psychological problems and if extra care and time needed to manage the patients were also outlined by a lesser number of dentists in this study as criteria for referral. Under certain circumstances, patients might ask to be referred to specialist and it appeared that dentists working at the main dental clinic mostly would consider this request. Main dental clinics in Malaysia are usually located in the major cities in every
state where the population is concentrated. The number of patients who seek treatment can be very high which results in a long waiting list. Therefore, it is not surprising to find the dentists from these centres referring patients to specialist considering the workload they have. This may be at times causing inappropriate referral especially by less experienced dentists. Apart from that, male dentists seemed to have less interest in treating people with special needs as in this study, 50.0% of male dentists would refer all patients with special needs to specialist. Considering the fact that SND is a new field of dentistry particularly in Malaysia, the development of patient and treatment specific guidelines in relation to the acceptable definition of people with special needs would be necessary to ensure their dental treatment needs are well met. It seems that, from this finding, the general dentists in Malaysia will need to be guided and educated about appropriate time and situation to make referral.

4.1.2.5 Demands for SND service and support provided for the development of the service

Generally, demands for the SND service can be measured by variables such as the number and age range of patients with special needs who attend the dental clinics. Types of dental treatment delivered and requested may also reflect the needs and demands for the service. Even though, there was no previous study in Malaysia which assessed the demand for SND service, studies from other parts of the world have shown that poor oral hygiene status is experienced by adult and children with disabilities. Kamatchi et al. reported that, among a group of hearing impaired individuals who had been examined for oral hygiene and periodontal status, 70.0% of them required dental treatment. Further support is found in a study by Folakemi and Oredugba to determine oral health care knowledge and practices of a group of deaf adolescents in Lagos, although only 12.0% of the sample had received dental care, 90.0% were willing to have a dental check up. Another study which looked at the treatment requirements of children and adolescents with cerebral palsy, mental retardation and visual disorders in four special schools in Athens, Greece, suggested that treatment needs regarding both primary and permanent dentitions were extremely high in all groups of individuals. In this present study, it was found that patients with disabilities were mostly seen by dentists working at the hospital.
based dental clinics and also by female dentists, who managed to see more than ten patients in a typical week with the age range of 12 to 25 years old. Referring to this number of patients attending the dental clinics, the demand and needs for SND service are definitely there. Because of the higher proportion of female dentists in Malaysia, in almost all areas, they will outnumber the male dentists. However, older patients with special needs are more likely to seek treatment from dentists at the health centres than that at the hospital. It may be due to the location of the dental clinics at the health centre which are more reachable for patients, whereas hospital-based dental clinics are functioning on a referral basis and more difficult to access.

Regarding the types of treatment delivered and required by dentists at the three different practice settings, tooth restorations, extractions and pain relief management appeared to be the most common dental treatment provided at the main dental clinics but most of the time, dental restorations and tooth extractions were the types of treatment required in this setting. Similarly, dental extraction was the most common treatment delivered whereas emergency dental treatment was mostly required by the patients at the dental clinics based at the health centre. In contrast, dental examination and pain relief management were carried out by all participated dentists at the hospital based dental clinics but scaling and cleaning, tooth extractions and emergency dental care were thought to be mostly required by the patients. In almost all instances, root canal treatment and implants were not the treatments of choice for the patients with special needs. Even though, the treatment delivered and required, mentioned by the dentists were somewhat variable, when patients required emergency dental care and pain relief management, tooth restorations, extractions or scaling and cleaning would be the appropriate management. Apart from that, there was no significant association between the practise setting and the types of treatment delivered or required.

In people with disabilities, treatment for dental caries often results in dental extraction of otherwise restorable teeth. This decision is frequently necessary due to limited support, financial or co-operation reasons. Hennequin et al. revealed that, instead of monitoring caries, dentists tended to be proactive and choose to treat when dealing with people with disabilities. In some cases, due to the inability of the patients to cooperate with the
dentists during the clinical assessment appointment, accomplishment of thorough dental examination, radiographic assessment and diagnosis was difficult to achieve. Adding to this problem is the limited ability to express pain or describe the symptoms which lead to diagnosis by elimination.

In addition, in this present study, dental caries and periodontal diseases were the major dental problems experienced by people with special needs, recorded by the dentist. As proven by previous studies, people with disabilities have higher rates of dental caries than the general population.\textsuperscript{108-110} This is consistent with a study conducted by the Special Olympics which reported that people with mental retardation had poorer oral health, more untreated caries and a higher prevalence of gingivitis and other periodontal diseases than the general population.\textsuperscript{64} On the other hand, some dentists who were practising at the hospital based dental clinics found that the oral health status of people with special needs was as good as the rest of other population. This may be true because dentists at the hospital dental clinics in Malaysia do not usually see patients for primary care. Patients have to be referred by other oral health professionals or medical practitioners in order to get access to hospital dental care. General dental practitioners are encouraged to treat basic dental needs such as scaling and cleaning or restorations as much as they can possibly do before they send the patients to the hospital. Therefore, the cases seen at the hospital level are not the ‘fresh’ ones unless the patients are referred directly by the medical practitioners. Apart from that, because of complex medical conditions and disabilities, patients who present at the hospital dental clinics often have regular dental appointments. Thus, their oral hygiene is closely monitored by the oral health professionals.

Due to the absence of specialists in SND, specialists from other disciplines are often consulted especially by younger and less experienced dentists in managing people with disabilities. Dental paediatric specialists appeared to be the most popular professionals to be consulted followed by the oral surgeons in this study. The responsibilities of the dental paediatric specialists who treat children with special needs requiring dental care are sometimes carried out through to their young adult age before they are released from the dental paediatric list. Because of the familiarity of the dental paediatric specialist in
dealing with such patients in their childhood, it can make the consultation much easier. Other specialties, such as periodontists, orthodontists and oral pathologists are consulted depending on the individual cases. Interestingly, in this study, higher proportion of younger dentists preferred to gain advice from periodontists regarding patients with special needs. This could be related to the higher awareness of the younger dentists about the importance of periodontal care amongst patients with special needs.

As repeatedly stated in the literature, there are many reasons for focusing on the needs for oral health care for people with disabilities. The growth of senior citizen population in the nation particularly those with medical conditions and disabilities, will increase the demand for dental care among the frail elderly. Dental problems including poor oral hygiene, poorly fitting dentures and loss of some or all of their teeth are common for this population. In addition, lack of knowledge and awareness about oral hygiene care, physical limitations to perform personal prevention practices, oral problems exacerbated by medical problems, side effects of medications and disability itself accompanied by the unwillingness and lack of training of the dentists to deal with complex medical, social and behavioural problems are limitations which need to be addressed to improve the oral health status of people with special needs.

Even though closing the gaps of the oral health disparities in this group of people can be achieved by other methods, Malaysia has taken an initial step by training specialists in this field which can later be the professional coordinator/case manager in coordinating the relevant programmes for people with special needs. This action is consistent with the view of policy makers who thought these patients should be attended by specialists trained in this field. In addition, the need to expand the scope of dentistry in Malaysia, an increase in the population of special needs and an increase in workload of other specialists (dental paediatric specialists and oral surgeons) who are currently involved in the management of this group of patients, are seen as the contributing factors for the need to develop SND. Malaysia also believes that through the development of SND service, the mission to improve the awareness and oral health status of this group of the population will become a reality.
This can be further supported by the willingness of the Ministry of Health to sponsor the government dentists who have an interest in specialist training in SND which is only currently available overseas. The future specialists in this field are also expected to conduct continuing professional development programmes and broad base training to assist the general dentist exploring this new branch of dentistry. Another way to attract more dentists to develop their interest in SND is to create a good career pathway for the specialist in SND as agreed by majority of the policy makers. While Ministry of Health has already developed an initial plan to ensure the development of SND is on the correct path, cooperation from other individuals or organizations involved in the delivery of care for people with special needs can be very helpful to support the community-based system of the service.

There are many forms of disability supports which can be provided for individual with disabilities. In Malaysia, the disability support groups can either be the private or governmental organizations. Their roles vary depending on the objectives of the organizations. Supports such as aids or devices, homemaker services, home care services, attendant services, home modifications, transportation, skills development, access to information in multiple formats or income support may be required on individual basis. In the Ninth Malaysian Plan (9MP), support for people with disabilities is focused, so that their rights to live in dignity and self respect are promoted and protected. This has been outlined in details in the Persons with Disabilities Act 2008 which aims to ensure their rights to an inclusive society, greater access to education and vocational training, employment, barrier free environment as well as access to ICT. With regards to the supports offered by the disability support groups participated in this study, residential care and vocational training were mostly offered by the centres. Financial, job search and social support were also provided by some centres as reported by the respondents. Lack of awareness and information about the support available compounded by social stigma lead to people with disabilities being stranded at home without an opportunity to develop self skills to live independently. The caregivers would rather seek full residential care and financial support than social support, job search service or vocational training to improve the quality of life of the care recipients.
Apart from active involvement of the organizations in the provision of various forms of support for this vulnerable group of population, their participation in dental health support is still lacking. It is obvious when none of the centres reported organizing any programmes related to dental care for the clients. However, some centres managed to make some arrangement with the nearby dental clinics for the clients to have dental checks. These findings are not unusual as several other studies have also reported inadequacies in dental care at long term care facilities\cite{115-117}. Training the caregivers in daily cleaning and monitoring oral health was not part of the responsibilities of the organizations. Although, ensuring the staff receive such training should be included in the written plan of the facilities, as suggested by the policy makers in this study, the absence of formal training programme for the caregivers in oral health care of people with disabilities causing some limitations to achieve the desired outcome. However, by working closely together with the Oral Health Division, Ministry of Health Malaysia, should improve the access to information of the staff about oral hygiene care in various aspects of disabilities.

### 4.1.2.6 Exposure and knowledge about SND

Managing people with special needs require extra skills and confidence from the dentists that are current. Patience and empathy should always be part of the service and are required even more than that in non disabled patients\cite{47}. Most studies involving graduated dentists indicate limited knowledge and preparation to treat patients with special oral health care needs. In this present study, half of the participants from oral health professional groups reported receiving some kind of exposure in managing people with special needs during undergraduate study but most believed that it was inadequate. It is not a surprised finding as similar response was documented in a recent study where 50.0% of the participated dentists reported no clinical training in the care of patients with special needs and 75.0% claimed they had little or no preparation for the care of these patients\cite{118}. A study on dental hygienist education about dental care for people with special needs also showed similar results\cite{119}. Even if, a small number of the respondents in this study obtained the dental degree from overseas universities, the forms of exposure they received were no different from that of those graduating locally. It could either be a
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis
(Based on New Zealand Experience)

slot of lecture about SND in the whole curriculum or rarely, observing the tutors managing the patient with special health care needs. In the US, more than half of the dental schools provide less than five hours classroom presentation and three quarter of the schools provide zero to five percent of treatment time for people with special needs.\textsuperscript{120} In Canada, the curricula of the dental schools regarding the content and time devoted to treating patients with special needs are not standardized.\textsuperscript{121} However, the dental school graduates are required to be given experience in the management of the medically compromised patients or patients with disabilities or chronic conditions by the Commission on Dental Accreditation of Canada.\textsuperscript{121} It seems that, inadequacy of knowledge and exposure in oral health care needs for people with disabilities among the oral health professionals does exist and this requires special attention and collaboration from various parties to improve the situation.

Despite of the lack of knowledge and training, the majority of the dentists were aware about the existence of SND globally and they believed that the patients who required special health care needs must be treated by the specialist trained in this field. This led to the need for the development of SND in Malaysia as agreed by most of the participants. This is consistent with the growing consensus of a career structure needed for person working in this field. Even though, some of the oral health care providers in Malaysia have been specially trained to provide the service for children with special needs since the programme was launched in 1993,\textsuperscript{122} specialized training for general dentists in managing adults with disabilities has just been introduced recently.

Reviewing the interest of general dentists in this field is crucial to plan for future training suitable to the oral health care providers. Courses in SND seemed to be the most popular choice amongst the general dentist, which should be initiated immediately after the fully trained specialists in SND complete their training. This may be the simplest way to introduce the service to the oral health practitioners and can then be followed by the creation of a dental team responsible for the oral health care of this group of people. Male dentists and those working at the main dental clinics had the most interest to attend courses in SND and more of less experienced dentists were willing to take the responsibilities in the SND team. Distance learning and training of ancillary workers, were
nominated by less than a quarter of the participated dentists which indicated that, these types of training, although possible, it may not attract a lot of attention. In addition, older dentists revealed less interest in participating in providing care for people with special needs. Lack of interest may be resulted from the absence of established career structure for general dentists working in institutional settings who provide care for adult patients with disabilities, not just in Malaysia but also in United States, Canada and other parts of the world. Currently, Dentistry for Persons with Disabilities is provided through the field of Paediatric Dentistry whereby the career structure is clearer and well established. Interestingly, low interest and skills in the provision of oral health care for this group of individuals did not affect the level confidence of the dentist in managing the patients. The majority reported they were confident enough to deal with people with special needs in their practice.

Considering the future plan of the SND service, appropriate dental facilities which are easily accessible by this group of the population must be incorporated and looked at in detail before the special care unit can be established at a particular location. In many instances, people with behavioural problems and intellectual disabilities require oral sedation for oral examination and treatment. Adding to this, Hennequin et al. reported that, there was minority of people with disabilities who were uncooperative and unreceptive to sedation and gentle restraint, required general anaesthesia for dental care. Along with their medical problems, they might be more appropriately seen at hospital setting. Consistent with the dentists’ point of view, hospital-based setting was chosen to be the preferred location for the future special care unit. However, senior dentists would like to see the unit developed at the community-based clinic for reasons such as it will be easily accessible for patients as well as easier to promote and market the service to the community.

On the other hand, policy makers believed that the service for high risk patients should be provided within the hospital environment but those who are undergoing maintenance phase and low risk needs can be managed at the community dental clinic or private settings. Although necessary, services catered at both centres can only be provided when the number of specialists in this field is adequate. Initially, due to insufficient
governmental financial support, lack of trained specialist in this field and the current health system, hospital setting seems to be more suitable than the community setting. In Great Britain, Community Dental Service (CDS) or salaried primary care dental service is responsible to treat majority of people with profound disabilities if they fulfil the local acceptance criteria which encompass the usual SND categories. Through this service, domiciliary care, sedation, and in many localities, general anaesthetic services are provided. In contrast, the SND service in Australia and New Zealand is mainly delivered at the hospital environment even if the major care providers are public dental officers in the hospital. This is further supported by the recognition of several dentists as specialist in hospital/SND in New Zealand and postgraduate dental programme in SND in both New Zealand and Australia. Lastly, in the US, there are no specific individuals who address the comprehensive dental needs of adults with special needs. Traditionally, persons with special needs requiring sedation and general anaesthesia utilized the services of hospital affiliated training programmes but with the introduction of the title “board-certified”, the provision of medically equivalent credentials for qualified dentists that attest to their training, experience and education, and knowledge has become necessary in order to obtain hospital, academic, federal and state privileges.
CHAPTER FIVE

5.1 CONCLUSION

5.1.1 Future recommendations for the development of SND services in Malaysia

Based on the analysed data and findings of this study, the first step that should be taken by the Ministry of Health of Malaysia in the development of SND in Malaysia, is to introduce the service to the community so that it will become known and can be utilized by the defined population. With the presence of pioneer specialists in SND, it is expected that oral health promotion for people with special needs can be further extended to cover areas of building healthy public policies, creating a supportive environment, strengthening community action, developing personal skills or re-orientating health services in the pursuit of oral health goals in line with the concept of health promotion defined in the Ottawa Charter for Health Promotion in the first international conference on health promotion in 1986 by World Health Organization (WHO). The specialists along with the policy makers must rely on each other as a team to build a plan of promoting and marketing the service.

In the plan, first and foremost, the knowledge and education on SND for the general dentists and medical practitioners working with MOH should be strengthened as they are the primary care providers and the likelihood that they will be the first person to see the patients is very high. Therefore, the definition of an adult with special needs should be made clear to oral health care providers and also to their medical counterparts. Short courses or seminars on SND seem to be appropriate and should be made easily available to the general dentists who participate in the future. The contents of the course should include the treatment modifications on a case-to-case basis, preventive care plan, skills and communication as well as training of auxiliary staff in handling the affected individuals. As for the medical counterparts, they have to be educated in oral health and oral health issues for people with special needs as their knowledge in this area is likely to be insufficient. This will assist them to make the appropriate referrals to the dental division. In addition, screening procedures and guidelines for managing people with
disabilities must be established to assist the general dentists to work effectively with this group of people. On the other hand, referral to specialists is required if cases are complex and difficult to manage at the community-based setting and fit with the local criteria specified by the specialists.

Secondly, coherent strategic policy at regional level with formal structures for oral health promotion must be developed. This should incorporate regional coordination of ongoing activities involving integration of dental and other health services. At an individual level, people with special needs and their caregivers should be given access to information and services available. Knowledge and information can be channelled through the mass media in various ways such as television and radio programmes or commercial advertisements which can cover wide groups of the population. This will increase public awareness and therefore, more will be expected to come forward and seek for dental care. Environmental barriers such as transport and non user-friendly dental premises to people with disabilities must be considered, and coordination with other relevant organizations is essential to ensure this mission is successful.

In addition, formal training programmes for staff working in institutions regarding oral health care for people with disabilities must be established. With a documented training programme, there will be no excuse for them not to include, at least tooth brushing twice daily for the care recipients in their routine checklist and included in their busy schedule. The attitude of nursing and care staff towards oral health care will influence the oral hygiene status of these people, particularly those who are totally dependent to others to carry out their activities of daily living. Therefore, a paradigm shift and evolution in thinking about dental care are mandatory.

Last but not least, domiciliary services may be necessary to be developed once SND service has been well established and an adequate number of specialists working in this field has been achieved. This particular service can be provided for those with severe mobility or psychiatric problems. However, the dental treatment provided in the domiciliary visit is restricted to simple procedures such as dental examination, simple restoration or extraction or denture fabrication. This can be facilitated by having a formal register of the individuals of special needs, so that they can be visited at home if
necessary. On the other hand, the social stigma perceived by the family members may be further escalated with the establishment of such a register as more parties can identify these individuals. This may result in manipulation of their conditions for the benefits of other irresponsible parties which in turn might cause distress to the affected individuals and family members. A systematic approach to implementing this sort of service is crucial as multiple external factors may interfere with the service delivery.

5.1.2 Lessons learnt
This study has tried to shed light on the concept of SND in Malaysia among the various groups of stakeholders who are generally involved in the care of people with special needs including the affected individuals. Many issues related to oral health care of people with special needs had been discovered and addressed which aimed to reach the objectives. The completion of this research project will assist the Ministry of Health Malaysia to define SND from local perspectives which are suitable to the Malaysian population and the health system. Information associated with education and knowledge, support required to improve access to dental care, the challenges and recommendations/guidelines to make SND a reality have been successfully outlined. The disabled people in Malaysia in particular will gain optimal benefits from this current and exciting development in dentistry.

More dental practitioners are expected to develop their interest in the SND field through the training pathway as it becomes more established, as well as the initiative of the Ministry of Health to support the career development of the specialist in SND in line with other existing dental specialties in the near future. To ensure a continuing development in this rewarding field of dentistry, research in SND should be encouraged and incorporated in planning, development, and monitoring of the specialty. Thus, future studies should investigate the oral health status of adults with disabilities in Malaysia from various parameters, such as caries experience and periodontal status which is currently lacking. Information on barriers and local access to dental care for this group of population should be investigated in greater detail so that the oral health care disparities can be reduced. Another area requiring further research is the quality of dental services for persons with disabilities by exploring areas related to clinical determinants of quality dental treatment and the timeliness, efficiency, and effectiveness of available dental services.
There are many ethical issues related to this area of health care and few questions or problems can be addressed in a yes/no, black or white manner. The autonomy of an individual is of paramount concern in planning their care but the lawyers and ethicists are as yet unable to establish a robust but flexible framework to ensure that decision making will ensure a positive outcome for each individual. Communication, responsibility, guardianship and social beliefs all impact in our work. It is acknowledged that the law in the area of Disability Awareness is recent, evolving and already subject to revision. This is to be applauded, but also requires an acknowledgement that the changes over the last decade have been huge and have required a paradigm shift in thinking or even begin to implement the changes. Not all affected parties are able to move at the same rate; but all are aware that many well meaning, informed positive acceptable and common sense solutions used in the past will no longer stand up to scrutinize if challenged. Thus, details investigation and attention are required to explore these areas of concern in the future development of SND service in Malaysia.
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Appendix 1. Semi-Structured Questions For Key Informative Interview
For the New Zealand Participants

1. CAREGIVERS / PATIENTS

For Caregivers

i) ‘Name...eg John’, when did you start looking after the patient?

ii) Do you enjoy it?
   A lot
   Sometimes
   Sort of
   Not really

iii) Do you have any idea how someone with special needs should be helped in cleaning their teeth? Have you ever been taught or attending any course/talk/seminar about it? How do you do this?

iv) What is your opinion about dental care for people with special needs?

v) How effective the dental services for people with special needs in New Zealand?

vi) Do you think it could be improved? How?

vii) Do you think enough is done to promote oral health for people with special needs?

viii) What do you think are the major barriers for patients with special needs to access dental care? How could this be improved?

ix) How satisfied you are with the dental service for people with special needs in New Zealand?

For Patients

i) “Name of patient...eg James”, How clean are your teeth just now? (Different photos displaying different types of dental condition will be used whenever appropriate to assist participants answering this question)

ii) What do you use to clean your teeth at home? (Different types of oral hygiene aids will be shown to participants e.g. toothbrush, mouthwash, floss, toothpick, interdental toothbrush etc)

iii) Has anyone ever taught you how to clean your teeth at home or at school?

iv) How many times in a year you go for a dental check up? Do you like going to the dental clinic? Why?

v) Do the dentist and the dental staff treat you well at the clinic? What do they do on your teeth?

vi) Who tell you about looking after your teeth?

vii) Do you have any difficulties with coming to dental clinic, for example transport, cost, accompanying person, distance)?

viii) Are you satisfied with the dental service given to you now?

ix) What could we do to make our service better and easier for you?
2. ORAL HEALTH PROFESSIONAL

i) What is your definition of patient with special needs?

ii) How many on average, patients with special needs do you see and treat per week at your practice?

iii) What is your perception of their oral hygiene?

iv) What criteria do you consider before referring the patient to dental specialist?

v) What are the common dental problems of patient with special needs?

vi) Do you have any kind of exposure in treating patient with special needs? If yes, is it adequate enough?

vii) What is your opinion about Special Needs Dentistry Service in New Zealand?

viii) Is there any particular area that requires special attention with regards to SND?

ix) How do you think it should be improved?

x) Do you think the oral health promotion and support for people with special needs is adequate?

xi) Do you have anything to add?

3. DISABILITY SUPPORT GROUPS

i) What kind of support do you provide for patient with special needs?

ii) Do you conduct any programme relevant to oral health care for people with special needs and the caregivers? If yes, how do you do you do this? If no, do you have any intention or plan to carry out the programme?

iii) Do you think the involvement of other stakeholders in oral health promotion for people with special needs is essential? What organizations should be involved and what are their roles?

iv) Are you aware of the existence of SND service in New Zealand? What is it and where it is available?

v) What do you think are the major barriers of SND patients to access oral health care? How could it be improved?

vi) Do you think oral health care for people with special needs should be taken care of by general dentist or dental specialist? Why?

vii) Do you think New Zealand government has provided good community care for people with special needs? Why?

viii) Do you feel that a home dental visit service is necessary to be a useful part of special needs dentistry in New Zealand? Why?

ix) Do you have anything else to add?
4. POLICY MAKER

i) How do you define an individual as a patient with special needs?

ii) What is the current system you have in dealing with the health of people with special needs? (financial, social support, community support)

iii) New Zealand is one of the first countries which acknowledged Special Needs Dentistry as a dental specialty in 2003 by Dental Council of New Zealand. Do you have any background information?

iv) Ideally, how do you think, SND should be practised in New Zealand and why?

v) With the development of SND service in New Zealand since 2003, do you see any change or improvement in the oral health status of people with special needs?

vi) In what particular fields do you think SND should be improved?

vii) What is your role in promoting oral health care for people with special needs? What have the MOH done in this matter?

viii) How do other stakeholders play a role in oral health care of people with special needs? How important is their involvement?

ix) With transfer of individuals with special needs from long stay institutions to community care, what are the major changes in delivery of general and especially oral health care?

x) What do you think are the major barriers of SND patients to get access to oral health care? How could this be improved?
Appendix 2. Semi-Structured Questions For Key Informative Interview For the Malaysian Participants

1. **CAREGIVERS (i to x) / PATIENT (xi to xx)**

   **For caregivers**
   - i) When did you start looking after the patient?
   - ii) Do you enjoy it?
   - iii) Do you have any idea how the tooth cleaning of patient with special needs should be performed? Have you ever been taught or attending any course/talk/seminar about it?
   - iv) How do you perform the tooth cleaning for them now?
   - v) What is your perception in oral health care of people with special needs?
   - vi) Do you have any idea what special need dentistry is?
   - vii) Do you think dental treatment for people with special needs should be carried out by general dental practitioner or dental specialist? Why?
   - viii) Do you think the oral health promotion for people with special needs is adequate?
   - ix) What do you think are the major barriers of SND patients to get access to oral health care? How could it be improved then?
   - x) How satisfied you are with the SND service in Malaysia?

   **For Patients**
   - xi) What do you think about your teeth, how clean do you think it is? (Different photos displaying different types of dental condition will be used whenever appropriate to assist participants answering this question)
   - xii) How do you clean your teeth/mouth at home? (Different types of oral hygiene aids will be shown to participants e.g. toothbrush, mouthwash, floss, toothpick, interdental toothbrush etc)
   - xiii) Has anyone teach you how to clean your teeth before?
   - xiv) How often do you go for dental check up? How do you like about the dental service given to you?
   - xv) Do you think you should get better service? If yes, why do you say so?
   - xvi) Do you get enough information about looking after your teeth and how do you get the information now?
   - xvii) What are the difficulties you have to come to dental clinic, for example transport, cost, accompanying person, distance)? How do you want it to be done to make it easier for you?
   - xviii) Who do you like to see to get your teeth checked? (Normal dentist/ your own dentist or specialist, why?)
   - xix) Are you satisfied with the dental service given to you now?
   - xx) Would you like to make any other comments?
2. ORAL HEALTH PROFESSIONAL
   i) What is your definition of patient with special needs?
   ii) How many in average, patients with special needs do you see and treat per week at your practice?
   iii) What is your perception of their oral hygiene?
   iv) What criteria do you consider before referring the patient to a dental specialist?
   v) What are the common dental problems of patient with special needs?
   vi) Do you have any kind of exposure in treating patients with special needs? If yes, is it adequate enough?
   vii) What is your opinion about the development of Special Needs Dentistry Service in Malaysia?
   viii) Is there any particular area that requires special attention with regards to SND?
   ix) How do you think SND should be practised?
   x) Do you think the oral health promotion and support for people with special needs is adequate?

3. DISABILITY SUPPORT GROUPS
   i) What are the major units of your support for people with special needs?
   ii) Do you conduct any programme relevant to oral health care for people with special needs and the caregivers? If yes, how do you do this? If no, do you have any intention or plan to carry out the programme?
   iii) Do you think the involvement of other stakeholders in oral health promotion for people with special needs is essential? What organizations should be involved and what are their roles?
   iv) What is your opinion regarding the development of SND service in Malaysia?
   v) What do you think are the major barriers of SND patients to get access to oral health care? How could it be improved?
   vi) If you are required to advise patient with special needs in how to perform tooth cleaning, would you be able to do that? How confident are you?
   vii) How important is oral health care compared to general health care of people with special needs? Why?
   viii) Do you think oral health care for people with special needs should be taken care of by General Dental Practitioner or dental specialist? Why?
   ix) Do you think the government has looked after people with special needs well enough? Why?
   x) What is your view regarding the domiciliary service as part of SND service in Malaysia? Any particular area that requires special attention?

4. POLICY MAKER
   i) How do you classify an individual as a patient with special needs?
   ii) What is the current system you have in dealing with the oral health of people with special needs? (financial, social support, community support)
   iii) Is there a need to develop special needs dentistry in Malaysia?
   iv) How do you think ideally, SND should be practised in Malaysia and why?
v) What is your role in promoting oral health care for people with special needs? What have the MOH done in this matter?

vi) What do you think is the role of the disability support associations in liaising Special Needs Dentistry service?

vii) How do other stakeholders play a role in oral health care of people with special needs? How importance is their involvement?

viii) What do you think are the major barriers of SND patients to get access to oral health care? How could it be improved then?

ix) Do you think oral health status of people with special needs will be much better if they are residing in an institution? Why?

x) How do you see the future of SND service and the career pathway of SND specialist?
Appendix 3. Survey Questionnaire For People with Special Needs

UNIVERSITY Otago

DEPARTMENT OF ORAL DIAGNOSTIC AND SURGICAL SCIENCES

ORAL HEALTH CARE FOR PEOPLE WITH SPECIAL NEEDS IN MALAYSIA – A SITUATIONAL ANALYSIS AND THE DEVELOPMENT OF SPECIAL CARE DENTISTRY

SURVEY QUESTIONNAIRE FOR PEOPLE WITH SPECIAL NEEDS

This survey is carried out to look at the attitude of people with special needs and care givers to the relative importance of oral health care for individuals with special needs. You are free to use friend/family member to help you understand and answering the questions.

Part A Personal Information

1. How long have you been supported by your caregivers?

   □ Year □ Months

2. How do you evaluate your overall health?

   □ In good physical health (No significant illnesses or disabilities).
   □ Mildly physical impaired. (Have only minor illnesses and/or disabilities )
   □ Moderately physically impaired (Have one or more diseases or disabilities)
   □ Severely physically impaired (Have one or more illnesses or disabilities Which are either severely painful or life threatening)
   □ Totally physically impaired (Confined to bed and requiring full time Medical assistance or nursing care)

What is the relationship between you and the caregiver?

Family member
Please specify (e.g mother, father, sister) ...................................................

Non family member
Please specify (e.g social care worker, friends) ............................................
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis
(Based on New Zealand Experience)

3. Age? □ Years old
4. Gender? □ Male □ Female
5. Ethnicity? □ Malay □ Chinese □ Indian □ Others

Part B  Oral Hygiene Practice for the patients

1. Do you have any difficulty in cleaning your teeth?
   Yes □ No □

2. If yes, why do you find it difficult?

3. How many times do you clean your teeth in a day?
   Once □
   Twice □
   Three times □
   More than three times □

4. Do you have special tooth cleaning device other than toothbrush?
   Yes □ No □
   If yes, please state the type of device used: ________________________
   Was the device recommended by the dentist or any other health professionals?
   Yes □ No □

5. How do you perform the oral hygiene care?
   Self tooth brushing □
   Tooth brushing performed by caregiver □
6. Do you have a dentist whom you visit on regular basis?

Yes [ ] No [ ]

7. How did you find the dentist?

- Referral by friend/ neighbour [ ]
- Referral by acquaintance [ ]
- Referral by another dentist [ ]
- Referral by doctor [ ]
- Advertisement [ ]
- Phone book [ ]
- Saw office/ sign [ ]
- Other [ ]

8. How often do you visit the dentist for check up?

- Every 6 months [ ]
- At least once a year [ ]
- At least every 2 years [ ]
- At least once every 3-4 years [ ]
- It depends, just when I have trouble [ ]

9. Do you see a private dentist or a government dentist?

Private [ ] Government [ ]

10. Is your dentist a specialist? Yes, go to Q No 11, otherwise go to Q 12

Yes [ ] No [ ] Don’t know [ ]
11. If yes, which discipline?

- Oral Surgeon

- Paediatric Dentist (specialist who deals with children dental health)

- Oral Pathologist (Specialist who deals with diseases in the mouth other than tooth disease)

- Periodontist (Gum specialist)

- Orthodontist (Specialist who helps straightened the teeth)

- Others, please specify: ____________________

12. The most common reason for not going to dentist?

- I do go for regular check-up

- Transportation

- The cost of care

- I don’t need to go very often

- I forget to go

- I don’t like dentist

- There is nothing wrong with my teeth

- Others

Please specify.................................................................................................................

Part C Perception of need for Special Needs Dentistry service, oral hygiene attitude and knowledge

1) Dental information and education

1. Did you get any advice on oral hygiene care for the people with special needs?

   Yes [ ]

   No [ ]

2. Who gave you the advice?

   [ ]
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis
(Based on New Zealand Experience)

The dentist

The medical doctor

The dental nurse at school

The caregiver

Through internet/ television/ radio

Through personal experience

ii) Opinion about the existing dental service

1. Are you satisfied with the service given by your dentist?
   Yes ☐ No ☐
   Give reason for your answer:

   __________________________________________________________________________

2. Does the dental clinic you have visited have satisfactory facilities for individuals with special needs?
   Yes ☐ No ☐

3. How satisfied are you with the following:
   a. Overall cleanliness of the clinic

   Satisfied ☐ Neutral ☐ Unsatisfied ☐ Not sure ☐

   b. Friendliness and courtesy of the staff

   Satisfied ☐ Neutral ☐ Unsatisfied ☐
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis
(Based on New Zealand Experience)

Not sure  

c. Convenience of location for you  
Satisfied  
Neutral  
Unsatisfied  
Not sure  

d. Cost to you  
Satisfied  
Neutral  
Unsatisfied  
Not sure  

4. What do you think about home dental visit?  
Essential  
Valuable  
Helpful  
Optional  
Not needed  

iii) Barriers to access the dental care facilities  

1. The most common reason for not going to a dentist?  
Only go for regular check-up if appointment received  
I have no transport to go to dental clinic  
The dental cost is expensive  

235
<table>
<thead>
<tr>
<th>Reason</th>
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<tr>
<td>I don't need to go very often</td>
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<tr>
<td>I forget to go</td>
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<tr>
<td>I don't like the dentist</td>
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<tr>
<td>There is nothing wrong with my teeth</td>
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<tr>
<td>Scared of dentist</td>
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<td>No one available to accompany me to see dentist</td>
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<td>Do not know</td>
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<td>Other</td>
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**THANK YOU FOR YOUR PARTICIPATION**
Appendix 4. Survey Questionnaire For the Caregivers

UNIVERSITY OF OTAGO

DEPARTMENT OF ORAL DIAGNOSTIC AND SURGICAL SCIENCES

THE DEVELOPMENT OF SPECIAL NEEDS DENTISTRY SERVICE IN MALAYSIA - A SITUATIONAL ANALYSIS (BASED ON NEW ZEALAND EXPERIENCE)

SURVEY QUESTIONNAIRE FOR CAREGIVERS OF PEOPLE WITH SPECIAL NEEDS

You may tick more than one answer for each question where appropriate.

Part A Personal Information

1. How long have you been caring of the client?
   [ ] Year  [ ] Months

2. How do you evaluate their overall health?
   [ ] In good physical health (No significant illnesses, disabilities or behaviours).
   [ ] Mildly physical impairment. (Have only minor illnesses, disabilities and/or behaviours)
   [ ] Moderately physically impaired (Have one or more diseases, disabilities or behaviours)
   [ ] Severely physically impaired (You have one or more illnesses, disabilities or behaviours which are either severely painful or life threatening)
   [ ] Totally physically impaired (Confined to bed and requiring full time medical assistance or nursing care)

3. What is the relationship between you and the client?
   Family member
   Please specify (e.g mother, father, siblings).................................................................

237
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis
(Based on New Zealand Experience)

Non family member
Please specify (e.g social care worker, friends)............................................. □

4. Age? □ Years old
5. Gender? □ Male □ Female
6. Ethnicity? □ Malay □ Chinese □ Indian □ Others
7. Please indicate the highest level of education that you have completed?
   High School Graduate □
   College Graduate □
   Master □
   Ph.D. □
8. Where do you look after the client?
   My own home □
   Institution □
   Day Care □

Part B  Oral hygiene practice for the client
9. Do you have any difficulty in cleaning the client’s teeth?
   Yes □ No □
10. If yes, what makes it difficult?

11. How many times do you clean the client’s teeth in a day?
    Once □
    Twice □
<table>
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<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>12. Does the client have special dental cleaning device other than toothbrush?</td>
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<tr>
<td>Yes</td>
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<td>No</td>
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<tr>
<td>If yes, please state the type of device used:</td>
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<tr>
<td>Was the device recommended by the dentist or any other health professional?</td>
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<td>Yes</td>
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<tr>
<td>No</td>
<td></td>
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<tr>
<td>13. How do you perform the tooth cleaning for your client?</td>
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<tr>
<td>Client performs the tooth brushing</td>
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<tr>
<td>Tooth brushing performed by me</td>
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<td>14. Does the client have a dentist whom he/she visits on regular basis?</td>
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<td>Yes</td>
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<td>No</td>
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<td>15. How did the client find the dentist?</td>
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<td>Referral by friend/ neighbour</td>
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<td>Referral by acquaintance</td>
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<td>Referral by another dentist</td>
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<td>Referral by doctor</td>
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<td>Saw office/ sign</td>
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<tr>
<td>Other</td>
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</tbody>
</table>
16. How often does the client visit the dentist for check up?

- Every 6 months  
- At least once a year  
- At least every 2 years  
- At least once every 3-4 years  
- It depends, just when he/ she has trouble

17. Does he/she see private dentist or government dentist?

- Private  
- Government

18. Is the dentist a specialist? Yes, go to Q No11, otherwise go to Q12

- Yes  
- No  
- Don’t know

19. If yes, in which discipline?

- Oral Surgeon  
- Paediatric Dentist (specialist who deals with children dental health)  
- Periodontist (Gum specialist)  
- Orthodontist (Specialist who helps straightened the teeth)  
- Oral Pathologist (Specialist who deals with diseases in the mouth other than tooth disease)  
- Others, please specify: ____________________________  
- Do not know

20. The most common reason for not going to dentist?

- Only go for regular check-up if appointment received  
- Transportation  
- The cost of care
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis
(Based on New Zealand Experience)

21. Do you get any advice on oral hygiene care or providing tooth cleaning for the people with special needs?
   Yes ☐ No ☐

22. Have you ever come across the term Special Needs Dentistry?
   Yes ☐ No ☐

23. If yes, what do you understand about Special Needs Dentistry?
   What? ________________________________________________

24. Do you think oral hygiene care is as important as taking care of general health? If yes, why?
   Yes ☐ No ☐
   Why? ________________________________________________

25. Are you satisfied with the service given by the dentist? Why?
   Yes ☐ No ☐
   Why? ________________________________________________

26. Does the dental clinic you visit have adequate facilities for individuals with special needs?
   Yes ☐ No ☐

27. How satisfied are you with the following:
a. Overall cleanliness of the clinic:

- Satisfied
- Neutral
- Unsatisfied
- Not sure

b. Friendliness and courtesy of the staff:

- Satisfied
- Neutral
- Unsatisfied
- Not sure

c. Convenience of location for you:

- Satisfied
- Neutral
- Unsatisfied
- Not sure

d. Cost to your client:

- Satisfied
- Neutral
- Unsatisfied
- Not sure

28. How often do you think the patient should go for dental visit?

- Monthly
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis
(Based on New Zealand Experience)

Every three months

Every six months

Yearly

29. How important do you think the dental treatment listed below for the people with special needs?

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Essential</th>
<th>Valuable</th>
<th>Unimportant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Check up/ X-ray</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fillings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleaning to prevent mouth disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instructions of cleaning teeth to patient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instructions of cleaning teeth to caregivers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dentures to replace teeth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denture repair and adjustment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Root canal treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tooth removal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tooth implant</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dental to relieve pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency dental treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dental services provided by specialist</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

30. Do you think dental treatment for people with special needs should be provided by dental specialist?

Yes [ ]
No [ ]

31. Do you think a home dental visit is very helpful?

Yes [ ]
No [ ]

THANK YOU FOR YOUR PARTICIPATION
Appendix 5. Survey Questionnaire For Oral Health Professionals

UNIVERSITY
Otago

DEPARTMENT OF ORAL DIAGNOSTIC AND SURGICAL SCIENCES

THE DEVELOPMENT OF SPECIAL NEEDS DENTISTRY SERVICE IN MALAYSIA - A SITUATIONAL ANALYSIS (BASED ON NEW ZEALAND EXPERIENCE)

THE VIEW OF ORAL HEALTH PROFESSIONALS IN MALAYSIA

You may tick more than one answer for each question where appropriate.

PART A  PERSONAL INFORMATION

1. Age
   
   [ ] years old

2. Gender
   [ ] Male  [ ] Female

3. Your workplace:
   [ ] Main dental clinic
   [ ] Community dental clinic in health centre
   [ ] Hospital based dental clinic

4. No of year in service:
   [ ] Less than 5 years
   [ ] Between 5 – 10 years
   [ ] More than 10 years
PART B PERCEPTION ABOUT SPECIAL NEEDS DENTISTRY

i) Definition of patient with special needs

5. How do you classify an individual as a special needs patient?
   (You may have more than one answer)

   - Those with physical impairment
   - Those with intellectual impairment
   - Those with mental impairment
   - Those with medical impairment
   - Those with emotional impairment
   - Those with social impairment

ii) Demand for SND service

6. How many patients with special needs (based on your answer for above question) on average do you see in a week?
   
   - Less than 5
   - Between 5-10
   - More than 10

7. What are the age range of patients with special needs do you see in the clinic?
   
   - Between 12 to 17
   - Between 18 to 25
   - Between 26 to 60
   - More than 60

8. What are the common treatment that you deliver for them?
   
   - Check up/ X-ray
   - Fillings
9. What kind of dental treatment do they usually require?

- Check up/ X-ray
- Fillings
- Cleaning to prevent mouth disease
- Instructions for cleaning teeth to patient
- Instructions for cleaning teeth to caregivers
- Dentures to replace teeth
- Denture repair and adjustment
- Root canal treatment
- Tooth removal
- Treatment to relieve dental pain
- Emergency dental treatment
- Tooth implant
- Dental services provided by specialist
Dental services provided by specialist

10. If you need to refer the patient with special needs for routine treatment, who would you contact for advice?

- Oral Surgeon
- Paediatric Dentist
- Oral Pathologist
- Periodontist
- Orthodontist
- Others, please specify: _______________________

iii) Criteria for referral

11. When do you think the patient needs to be referred to a specialist?

- When the treatment offered is not available at the clinic
- Every patient with special needs should be referred
- When the patient asks to be referred
- Lack of cooperation from the patient
- Patient with complex medical problems
- Patients who need more attention and require extra time to manage
- Patients with severe psychiatric problems
- Patients who need dental treatment under General Anaesthesia
iv) Common Dental Problems

12. Do you think people with special needs have poorer oral health than the rest of the population?

Yes ☐ No ☐

13. What are the common dental problems of patients with special needs?

Dental caries ☐
Periodontal problems ☐
Faulty denture ☐

v) Exposure and knowledge about Special Needs Dentistry

14. Do you have facilities accessible for patient with special needs at your clinic?

Yes ☐ No ☐

15. Do you need longer time in treating patients with special needs?

Yes ☐ No ☐

16. How confident you are when dealing with patients with special needs?

Very confident ☐
Confident ☐
Not confident ☐

17. Did you have any kind of exposure to treat adults with special needs in your undergraduate course?

Yes ☐ No ☐

18. If yes, do you think it was adequate enough?

Yes ☐ No ☐
19. Are you familiar with Special Needs Dentistry?

Yes [ ]  No [ ]

vi) Opinion about the development of Special Needs Dentistry Service in Malaysia

20. Are you aware of the existence of Special Needs Dentistry in other countries of the world?

Yes [ ]  No [ ]

21. What do you understand about the term 'Special Needs Dentistry'?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

22. Do you think dental treatment for people with special needs should be organized by a specialist trained in that field?

Yes [ ]  No [ ]

23. Is there a need to develop special needs dentistry in Malaysia?

Yes [ ]  No [ ]

24. If yes, why?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

25. If SND is developed in Malaysia, should it be practised in hospital or in community clinic?

Hospital based [ ]  Community based [ ]

26. Are you interested in training in Special Needs Dentistry?

Courses [ ]
The Development of Special Needs Dentistry Service in Malaysia – A Situational Analysis
(Based on New Zealand Experience)

Distance teaching
Ancillary workers
Dental teams
Others
Not interested

27. How do you think SND is different from other dental specialties?
Please give your comment:

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

THANK YOU FOR YOUR PARTICIPATION
Appendix 6. Survey Questionnaire for Policy Makers

UNIVERSITY OTAGO

DEPARTMENT OF ORAL DIAGNOSTIC AND SURGICAL SCIENCES

THE DEVELOPMENT OF SPECIAL NEEDS DENTISTRY SERVICE IN MALAYSIA- A SITUATIONAL ANALYSIS (BASED ON NEW ZEALAND EXPERIENCE)

SURVEY QUESTIONNAIRE FOR DENTAL OFFICERS AT THE ORAL HEALTH DIVISION, MINISTRY OF HEALTH MALAYSIA

You may tick more than one answer for each question where appropriate.

PART A PERSONAL INFORMATION

1. Age
   □ □ □ years old

2. Gender
   □ Male □ Female

3. Your portfolio:
   □ Oral Health Care Policy
   □ Oral Health Care
   □ Malaysian Dental Association

4. No of years in service:
   □ Less than 5 years
   □ Between 5 – 10 years
   □ More than 10 years
PART B PERCEPTIONS ABOUT SPECIAL NEEDS DENTISTRY

i) Definition of patients with special needs

5. How do you classify an individual as a special needs patient?

- Those with physical impairment
- Those with intellectual impairment
- Those with mental impairment
- Those with medical impairment
- Those with emotional impairment
- Those with social impairment

ii) Needs and demands for Special Needs Dentistry service

6. Are you familiar with Special Needs Dentistry?

   Yes [ ]    No [ ]

7. Are you aware of the existence of Special Needs Dentistry in other countries of the world?

   Yes [ ]    No [ ]

8. What do you understand about special needs dentistry?

   [ ]

9. Do you think dental treatment for people with special needs should be supervised by a specialist trained in that field?

   Yes [ ]    No [ ]
10. Is there a need to develop special needs dentistry in Malaysia?

Yes [□]  No [□]

11. If yes, why?

- Increase in workload of Paediatric Dental Specialists and Oral Surgeons who are currently treating people with special needs [□]
- The dental management of people with special needs should be handled by expert professionals in this field [□]
- The number of people with special needs is increasing [□]
- A need for expansion of dental specialty scope in Malaysia [□]
- None is available now [□]

Others, please specify: __________________________________________________________
________________________________________________________________________
________________________________________________________________________

12. Do you expect the demands for oral health care for individual with special needs will increase in the foreseeable future?

Yes [□]  No [□]

If yes, why?

13. Should a domiciliary service be developed concurrently with the development of Special Needs Dentistry to cater oral health care for individuals with special needs?

Yes [□]  No [□]

iii) Support provided by the government in the development of SND

14. Is the Oral Health Division, MOH ready for the development of SND?

Yes [□]  No [□]

253
15. Do special needs dentists require special facilities and equipment to deliver the service?

Yes [ ] No [ ]

If yes, could you please list down the appropriate facilities and equipment required:

[ ]

[ ]

[ ]

16. Do you agree with other organizations involvement in managing the oral health care for individuals with special needs regarding oral health promotion, education as well as the service delivery?

Yes [ ] No [ ]

Why?

[ ]

[ ]

[ ]

17. How should dental officers who are interested in Special Needs Dentistry be supported?

Scholarship for formalized training [ ]

Providing continuous professional development [ ]

Permission to attend broad based training relevant to SND [ ]

Good career pathway [ ]

18. What do you think is the role of the disability support associations in liasing with Special Needs Dentistry service?

Providing support so that the individual with special needs could get access to oral health care [ ]

To assist them in performing good oral health care [ ]

To assist the caregivers in learning to carry out the oral health care for people with special needs [ ]

To work together with Oral Health Division in promoting oral health for people with special needs [ ]
iv) Future planning for SND service

19. How do you see the future of Special Needs Dentistry service?

- Good/ Needed/ Positive

- May increase in demand

- Cannot see the future at this stage

20. Do you agree with the statements below?

Y for Yes, N for No

- The service for high risk needs patients to be provided within the hospital environment but those who are undergoing maintenance phase and at low risk needs can be managed at the community dental clinic

- The plans for any future dental clinics should consider the accessibility for people with special needs

- Appropriate referral system should be worked out from medical site to dental site and from general dental practitioner to specialist in SND

- A network should be developed by the specialist in SND with the medical colleagues and other organizations in order to introduce the service to the community

- Caregivers should be formally trained in managing the dental care for people with special needs

- The dental auxiliary staff should have training in handling people with special needs

- Guideline on the dental management of special needs should be provided for the general dental and medical practitioners
v) Barriers to oral health care

21. What are the common barriers to oral health care for individual with special needs?

- Financial constraints
- Transportation
- Location of the dental clinic
- Lack of awareness about oral health care among the Caregivers
- Complex health and disability issues
- Lack of skills and knowledge of the dental practitioners
- A health system which is not easily accessible by people with special needs

Others, please specify.................................................................................................................

THANK YOU FOR YOUR PARTICIPATION
Appendix 7. Survey Questionnaire for Disability Support Group Representatives

THE DEVELOPMENT OF SPECIAL NEEDS DENTISTRY SERVICE IN MALAYSIA - A SITUATIONAL ANALYSIS (BASED ON NEW ZEALAND EXPERIENCE)

THE VIEW OF DISABILITY SUPPORT GROUPS

You may tick more than one answer for each question where appropriate.

PART A PERSONAL INFORMATION

1. Age
   - [ ] years old

2. Gender
   - [ ] Male
   - [ ] Female

3. Your workplace:
   - [ ] Malaysian Down Syndrome Association
   - [ ] Sinar Harapan House
   - [ ] Department of Community Welfare Malaysia

PART B PERCEPTIONS ABOUT SPECIAL NEEDS DENTISTRY

i) Support Provided

4. What disability commonly presents at your centre:
   - [ ] Those with physical impairment
   - [ ] Those with intellectual impairment
   - [ ] Those with mental impairment
Those with emotional impairment

Those with social impairment

5. What support(s) that is/ are provided by your centre?

Financial support

Social support

Full time residential support

Job search support

Training/ teaching/vocational

6. What support frequently asked by the individual with special needs?

Financial support

Social support

Full time residential support

Job search support

Training/ learning

Others, please specify

ii) Involvement in oral health care for people with special needs

7. Does your centre conduct any programme relevant to dental health care for individual with special needs?

Yes ☐ No ☐

8. If yes, what are the programmes?

Organizing an event related to dental health on regular basis ☐

Making arrangement with nearby community dental clinic ☐

Client’s personal care checklist to be filled by the caregiver ☐
Dental support

Staff education with regards to dental care

iii) Opinion about the existing dental service for people with special needs

9. Do you think oral hygiene care is as important as taking care of general health?
   Yes ☐  No ☐

   Why?

10. Do you think dental treatment for people with special needs should be provided by dental specialist?
    Yes ☐  No ☐

11. How essential is home dental visit for individual with special needs?
    (Please circle a number from 1 to 10 below)

    1 2 3 4 5 6 7 8 9 10

    Less important More important

12. What is/are your major concern/s regarding the individual with special needs?
    Being neglected ☐
    Need assistance in carrying out their daily routine activities ☐
    General health conditions ☐
    Dental health conditions ☐
    Difficult access to general and dental health care ☐
    Social acceptance for them to live in the community ☐
    Job search ☐
Financial support

13. What is your view regarding oral health care project for individuals with special needs?

Dental treatment is expensive
Inexperienced dentist
Lack of communication between dentist and patients
Difficult transportation
The facilities are difficult to access

14. Do you take the individual with special needs under your care to the government or private dental clinic?

Government dental clinic
Private dental clinic

15. Do you support the development of Special Needs Dentistry service in Malaysia?

(Special Needs Dentistry concerned with the improvement of individuals and groups in society who have a physical, sensory, intellectual, mental, medical, emotional or social impairment or disability or, more often, a combination of a number of these factors.)

Yes
No

Why?

THANK YOU FOR YOUR PARTICIPATION