

2008 Qualitative Evaluation of the Oral Health Promotion
Intervention Project for the Eastern Health Board Area, in the
Republic of Ireland.

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In order to protect the anonymity of parents and professionals who took part in this study, including focus groups and one-to-one interviews, **ALL names and personal details have been altered.**

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Executive Summary

The original aim of the oral health initiative was to reduce the need for the dental treatment of children with disabilities by implementing a team approach to oral health education. This meant not only incorporating oral health education within the workload of the whole dental team but within the workload of every healthcare professional that may come into contact with the children and their parents. To facilitate this approach seven hundred ancillary workers and healthcare professionals were given advice and training in oral health promotion. In addition, oral health promoters were trained and employed to give one-to-one advice to parents regarding their child's oral healthcare.

The aim of the qualitative evaluation was to:

- Explore parent and professional perceptions of oral health
- Address how collaborative working between different disciplines may be impeded by current procedural practices, legislative and organisational constraints, and budgetary systems and boundaries
- Explore how parent's needs change after the birth of a child with disabilities
- Summarise the scope of the recent oral health initiative and consider the impact on children with disabilities

The area chosen for the pilot intervention fell within the boundaries of the Eastern Health Board; County Louth, County Monaghan, County Cavan and County Meath. Therefore, staff and parents within these counties were interviewed for the evaluation study which took place between May and July 2008.

A purposive sample was chosen with one researcher interviewing 15 parents or carers of children on a one-to one basis in a location of their choosing. In addition, four professionals, from a variety of backgrounds; voluntary, health and social care and ancillary care, were also interviewed on a one-to-one basis and three

focus groups, with a mixture of professionals, ranging in number from 3 -10 took place.

The study found that parents and non-dental professionals required appropriate information in order to make choices and decisions regarding the oral health of children with disabilities. When non-dental professionals were interviewed they disclosed that there was not enough tailored and appropriate information to meet their needs. In some instances non-dental professionals wanted more knowledge on syndromes and how oral health may be implicated. Careful attention needed to be paid to the taken-for-granted use of dental terminology which non-dental professionals may find intimidating and which leaves them feeling irritated and isolated. There needed to be greater availability of oral health educational materials for teaching purposes for non-dental professionals. An exploration needed to be made for the commercial production of more interactive sugar boards and cartoon style teaching aids to facilitate non-dental professionals working with children with disabilities.

Parents found the oral health instruction useful and gained a great deal from the one-to-one sessions with the oral health promoters. The favourable responses could be directly attributed to the oral health promoters, who exhibited the requisite personal qualities for working effectively with parents. However, some parents appeared confused indicating that information needed to be tailored to parent's needs, reinforcement provided where necessary, and the use of tick-box questionnaires used with discretion.

Professional tensions were highlighted and related to work load and different ways of working. For example, some teams work trans-disciplinary and use the social model whilst others prefer a more compartmentalised approach relying on a medical model of care.

Many parents were fighting and pleading for services which are not accessible, adequate, appropriate or equitable as promised in policy. The daily demands of caring for a child with disabilities meant that most parents were tied to a day-to-day existence and the greater the level of impairment, the higher the number of

demands. The burden of care was placed squarely on the shoulders of parents, and depending on the level of their child's disability, they are performing the role of medical professionals (but without training) in addition to the often secondary but just as important, role of being a parent. The effect on family life was often stressful. This had an effect on oral health because parents were spending their energy and resources on accessing priority services to fulfil their child's immediate needs, leaving oral health a low priority.

Non-dental professionals also had a more medicalised view of oral health and dentistry and rather than seeing the dental services as promoters of oral health first and treating dental disease second, there was a tendency to see services as being in place to treat dental disease. Working more collaboratively and the provision of training was required in terms of syndromes and disorders, and their link with oral health may assist other disciplines and non-dental professionals in acknowledging the importance of oral health and its relation to general health and vice versa. However, just introducing oral health promotion, without its biological and social origins and implications provided little impetus for non-dental professionals to view oral health as part of general health and vice versa.

Oral health was struggling to be seen as part of general health and it was only when crisis situations occur with children with disabilities that services were frantically fire fighting to address the issues. The existing gap in dental service provision has widened with fluoridation not solving the oral health problems, particularly for children with more profound needs. Creating a specialist service for children with disabilities was creating its own problems with visits being duplicated and parents and children seeing different dental professionals for the same procedures and becoming confused by the process. This may be a contributory factor for some parents refusing to engage with services.

There were many barriers related to procedures for accessing oral health services, and when a parent did manage to access the services a further barrier may occur in relation to delays in being seen. The independent assessment of individual need was already creating problems in areas where it has been implemented because of the length of time between assessment and receiving services. The restructuring

of services was creating a burden upon non-dental staff already working above capacity and struggling with the demands of their work. Oral health had become relegated to a position of little importance and a whole child approach was not being taken by all services.

Budget constraints were affecting joint working because non-dental professionals were overstretched, feeling that they only had the capacity to carry out day-to-day work with parents and children rather than participate in networking meetings and further training in other areas such as dental.

There needs to be greater integration of the dental services as a whole with early intervention teams and the rest of the healthcare and social services. More oral health promoters and dentists need employing to address the deficit in services. Schools need to be targeted as areas of oral health promotion. There needs to be an awareness campaign throughout the whole of Ireland on the importance of oral health and its relationship with general health. A greater input into supporting parents with services, alongside oral health services creating relationships with parents from the birth of their first child may foster parent's engagement with oral health services.

The existing oral health initiative was well conceptualised, and has made a difference for many parents. However, a lack of knowledge concerning the structural, procedural, and budgetary barriers coupled with insight into the daily demands on parents caring for children with disabilities perhaps meant that achieving the aims of the plan could not be a total success from the outset.

Background to the report and policy contextualisation

Promoting health is not a new idea and as a named practice has risen steadily since the Canadian publication ‘A New Perspective on the Health of Canadians’ (Lalonde 1974). This report emphasised the necessity of interventions to prevent disease rather than reliance on medicine to treat and cure disease. However, the move within health promotion practice encompasses a more holistic approach, not just a disease focused approach but rather one that concentrates on the whole person in order to gain optimum health for the individual, and with a greater consideration for the determinants of health (World Health Organisation 1986, 2002).

Treatment services alone are perceived as insufficient in dealing effectively with disease, and the rise in health promotion may be directly accredited to the perceptions of these limitations. Amongst the various healthcare services to have recognised this fact are the dental services, and the acknowledgment that dental treatment alone will not successfully alleviate the causes of dental disease, or their links with other medical conditions (Daly et al 2002). Arguments have been made for a return to the underlying determinants of health as a crucial area that requires addressing before any long term improvements in healthcare (Tones and Green 2004). Health promotion may therefore be seen as the means by which the underlying determinants of oral health may be tackled in order to improve oral health within the population.

Education has long been seen as an important influence in health promotion and they have often been compared as having a great deal of overlap and being one and the same thing (Tones 1990). However, some authors prefer to view education as part of health promotion and promotion as an umbrella term for a range of educational and health promoting activities (Ewles and Simnett 2003, Laverack 2004). In terms of effective oral health education as part of a health promotion plan then a clearly defined structure is often required, focusing on the needs of a target group with an evaluation process built in to inform a review process whereby any lessons learnt can inform future action (Watt and Fuller 1999).

The target group for this study were children with disabilities, who as a marginalised group have a high and often unmet need, for treatment (Vignehsa et al., 1991, Halberg et al 2004, Halberg et al., 2005, Nunn 2006). Linked to this need is the inescapable fact that many children with disabilities may live below the poverty margin and also have medical impairments which a deteriorating oral health can exacerbate, or exert an effect on the child's quality of life (Hollister and Weintraub 1993, Petersen 2005). For many children with profound disabilities the only option for dental care is when a crisis occurs and they are hospitalised for and in-patient general anaesthetic and dental treatment is carried out (Russell and Kinirons 1993, Nunn *ibid.*).

The Disability Act (Government of Ireland 2005) was the basis for the Sectoral Plan (Department of Social and Family Affairs 2006) to be guided by the principles of '*equity, people-centredness, quality and accountability in the delivery of health services [...] for people with disabilities*' (p, 11). Some of the recommendations for all health services were to:

- Engage with everyone in the wider community to improve health
- Work with those in the health system who have a role to play in improving health
- Evaluate services so that resources are used to best effect

Taken from the Sectoral Plan (2006), page 11.

Therefore, the main thrust of policy appears to be the inclusion of everyone in the community and health system to play a part in improving health, a more community focussed approach as proposed by the World Health Organisation (WHO 1986). Dental services must therefore include agents in the wider community, including those within the health care system to promote engagement with children with disabilities and to take a more holistic perspective of their health care by incorporating their oral health care as part of their general health plan.

1.1 Aims and coverage of the research

The original aim of the oral health initiative was to reduce the need for the dental treatment of children with disabilities by implementing a team approach to oral health education. This meant not only incorporating oral health education within the workload of the whole dental team but within the workload of every healthcare professional that may come into contact with the children and their parents. To facilitate this approach seven hundred ancillary workers and healthcare professionals were given advice and training in oral health promotion. In addition, oral health promoters were trained and employed to give one-to-one advice to parents regarding their child's oral healthcare. Quite simply, it was envisaged that every parent, healthcare and voluntary sector worker involved in the life of a child with disabilities would collaborate and co-operate with each other, thereby becoming partners in their oral health care.

The aim of the qualitative evaluation was to:

- Explore parent and professional perceptions of oral health
- Address how collaborative working between different disciplines may be impeded by current procedural practices, legislative and organisational constraints, and budgetary systems and boundaries
- Explore how parent's needs change after the birth of a child with disabilities
- Summarise the scope of the recent oral health initiative and consider the impact on children with disabilities

The research did not seek to explicitly look at the quality of the services offered (even though this would be inevitably tied to parent's experiences). It was also beyond the scope of the research to make regional comparisons, to make any detailed analysis of service provision, or to evaluate any other programme or initiative. The emphasis was on providing a detailed description of parent and professional experiences in relation to oral health care.

1.2 Selection of Area

The area chosen for the pilot intervention fell within the boundaries of the Eastern Health Board; County Louth, County Monaghan, County Cavan and County Meath. Therefore, staff and parents within these counties were interviewed for the evaluation study which took place between May and July 2008.

1.3 Sample

A purposive sample was chosen with one researcher interviewing 15 parents or carers of children on a one-to one basis in a location of their choosing. The parents and carers were involved with the early intervention team in the Republic of Ireland; who implements services for children aged 0-6 years. Some parents had one child with disabilities; other parents had two or three children with disabilities. In addition, four professionals, from a variety of backgrounds; voluntary, health and social care and ancillary care, were also interviewed on a one-to-one basis and three focus groups, with a mixture of professionals, ranging in number from 3 -10 took place.

1.4 Interviews and focus groups

Interviews were arranged by the oral health promoters working in the Eastern areas; they had already established a good rapport with the parents and one-to-one interviews were arranged. All interviews took between forty minutes and two hours depending on what the parent wanted to discuss. Focus groups were declined by parents due to childcare and time pressures coupled with the need for privacy. The majority of parents requested that the interviewer travel to them because this fitted in with their existing childcare and lifestyle arrangements.

Interviews with professionals usually lasted about an hour. An hour was also allocated for the focus groups, which were productive when multidisciplinary teams became aware of the job pressures their colleagues faced. The interviewer travelled to the professional's place of work, or for focus groups the professionals met in an agreed room in the area where they worked. Difficulties appeared when

arranging interviews and focus groups with professionals because they felt that they were being tested, and were under pressure with their job roles, in fact many professionals refused to participate. At the time of study, the Heath Service Executive was in a state of flux; there was an embargo on all staff, job vacancies were not being filled, and people were unsure of their job status. These factors undoubtedly affected the data collection.

Participants	Type of Interview	Type of interview
	One-to-one	Focus groups
Number of Parents	15	0
Number of Professionals	4	3

Table 1: Distribution of interviews

1.5 *Narrative and ethnographic methods*

A narrative approach to interviewing was employed this was mainly to unpick the many layers of subjective meanings within professional and parent's stories, this particular approach is well suited to discovering the confusions, ambiguities and contradictions that are a part of everyday experience (Plummer 2001). All interviews were tape recorded with the permission of the interviewees and tapes were destroyed immediately after transcription. Only the interviewer is aware of the identities of the interviewees and any personal identifying characteristics have been altered so that they are not directly traceable to the individuals concerned.

The full content of the stories remains private and unavailable for general consumption. The interviewer saw herself as part of the interview situation and was guided by ethnographic principles, recording her thoughts, feelings and observations after the interviews as field notes, and using them to reflect on her interpretations after transcription. The interviewer also used her counselling experience to guide her observations, thoughts and feelings. This process involves a high degree of reflection to understand and separate emergent feelings, transferred during interactions with other people, from ones own feelings (Rogers 1980).

1.6 *Data Analysis*

Analysis of the transcribed interviews was inductive. The transcripts were read, and re-read and then compared and contrasted with areas in existing dental, medical, sociological, and psychological research. Themes and categories emerged from the stories that people told. The themes were triangulated with the researcher's observations, and other stories told by parents and healthcare professionals, this was similar to the process of grounded theory and established methods within qualitative research (Glaser and Strauss 1967, Strauss and Corbin, 1990, Strauss and Corbin 1997, Glaser 1998).

1.7 *Classification of barriers*

A core aim of the research was to identify disabling barriers that prevented children with disabilities from achieving optimum oral health, and to provide a greater understanding and possible solutions to these barriers. In order to achieve clarity by the term barrier I have divided them into groups:

- Organisational – structural
- Organisational - procedural
- Budgetary

Splitting organisational barriers into two halves allows us to indicate where the barrier lies; central government and policy, or local delivery. However, sometimes this is not an easy distinction and some barriers may have a central root if they stem from the design of government directed policy. One example is the result of local delivery such as; co-ordination of services, resource shortages (staff, appropriate services/facilities, budget size), structure and function of staff roles within an organisation, lack of collaboration and co-operation around information sharing and liaison, inconsistency of services, financial planning and prioritisation.

1.8 *Terminology employed*

For the sake of clarity the term professional is used to denote anyone who is employed by the HSE (either directly or indirectly), it may cover dental care professionals, dental practitioners, health education officers, physiotherapists, psychologists, speech and language therapists, occupational therapists, public health nurses, community nurses, family social workers, and parent support workers. ‘Services’ is intended as an umbrella term to cover a range of services and type of services received which ranged from

- Dental
- Physiotherapy
- Occupational therapy
- Psychology
- Speech and Language therapy
- Paediatrics
- Advocacy
- Physical equipment or adapted equipment for use in the home

Similarly, anything physical, sensory, cognitive, or a mixture of any of the three is given the term ‘impairment’ in preference to ‘special needs’. This term originates from the disability literature and is the preferred term used by people with disabilities.

1.9 *Social model of disability*

The social model of disability was used as a framework; this places barriers firmly in the realm of society rather than within the individual, or directly resulting from impairment or personal circumstances. The social model of disability does not seek to problematise the individual; rather it seeks to outline the disabling barriers within society that prevent an individual (in this study) from accessing and receiving services equally with the mainstream population.

1.10 Structure of the report

The report is divided into a further four short chapters:

Chapter 2 focuses communicating oral health; availability of information, knowledge of and surrounding oral health, and parent involvement in choice and decision-making.

Chapter 3 focuses on perspectives on parenting concentrating on parents in relation to oral health, parenting a child with disabilities; daily challenges, family life and support, and non-dental professional perspectives of dentistry and oral health.

Chapter 4 presents an overview on barriers in relation to oral health, divided into:

- structural barriers pertaining to service structure and delivery
- procedural barriers relating to bureaucracy, form filling and the recently implemented statutory statement of need
- Budgetary barriers relating to staff shortages, embargo on staff, difference in areas, and travel

Chapter 5 concludes and gives recommendations

Communicating Oral Health

Chapter Summary

Parents and non-dental professionals require appropriate information in order to make choices and decisions regarding the oral health of children with disabilities. When non-dental professionals were interviewed they disclosed that there was not enough tailored and appropriate information to meet their needs. In some instances non-dental professionals wanted more knowledge on syndromes and how oral health may be implicated. Careful attention needs to be paid to the taken-for-granted use of dental terminology which non-dental professionals may find intimidating and which leaves them feeling irritated and isolated. There needs to be greater availability of oral health educational materials for teaching purposes for non-dental professionals. An exploration needs to be made for the commercial production of more interactive sugar boards and cartoon style teaching aids to facilitate non-dental professionals working with children with disabilities.

Parents found the oral health instruction useful and gained a great deal from the one-to-one sessions with the oral health promoters. The favourable responses could be directly attributed to the oral health promoters, who exhibited the requisite personal qualities for working effectively with parents. However, some parents appeared confused indicating that information needed to be tailored to parent's needs, reinforcement provided where necessary, and the use of tick-box questionnaires used with discretion.

Professional tensions were highlighted and related to work load and different ways of working. For example, some teams work trans-disciplinary and use the social model whilst others prefer a more compartmentalised approach relying on a medical model of care.

Introduction

Within this chapter, the relationship between professionals and with parents is explored in relation to oral healthcare. It explores how oral health is communicated to parents and non-dental professionals, considers how information is presented, the content of the information, delivery, organisational issues concerning delivery of information, and models of good practice.

In many health promotion initiatives, mass media is used as a tool because it is cost effective (Noar 2006). The most widely used media in health promotion is print based and includes magazines, leaflets and newspapers. Print based media provides information, creates and articulates meanings and sets agendas for influencing health behaviours and changing attitudes (Corcoran 2007). However, even though there are examples of print based media in promoting awareness raising there is little evidence to suggest that it actually alters behaviour (Humphris and Field 2004, Dyer et al. 2005). Initiatives that take the wider environment into consideration and using a settings based approach, stemming from the Ottawa Charter for Health Promotion (WHO 1986), alongside other approaches by addressing the 'whole problem' rather than isolated parts is the preferred approach. A setting based approach can either take place in a setting, for example the dental surgery, or a setting can be used in a wider sphere and environment, target groups, and policy become part of the whole approach and health promotion becomes integrated into everyday activities and organisations adapt and evolve to achieve healthy setting status.

Availability of relevant information or lack of it clearly limits options for parents especially when they may be seeking strategies to cope with stressful situations (Mitchell and Sloper 2000). One example is lack of oral health awareness, leading to a deteriorating dentition in a child with disabilities; the child may experience additional pain and a crisis situation requiring a general anaesthetic may occur. This places an added burden and extra worry on the parent and a reactive situation whereas oral health awareness from an early age could enable the parent to proactively manage the situation and avoid the crisis and general anaesthetic.

2.1 Content of Information

One aspect that has been worked on in the oral health initiative is the content and delivery of information for parents and professionals. Over seven hundred professionals took part in training for oral health in order for them to have the requisite knowledge for discussion with parents. There were contrasting responses to the training:

Professional 1:

“Well I did my training last year and we did about teeth, plaque and also little summaries for Williams syndrome, Downs’ syndrome and more information on oral health would have been a lot more useful for these types of groups would have been useful, particularly for the Downs population. I think sugar and tooth paste and other things I knew overall but it was useful to have someone confirm it. [...] we don’t know about associated syndromes with cleft lip and palate but I think they get left because even within community they get left concerning their oral health because I think that causes fear in some nurses [...].”

Professional 2:

“Again a lot of the information was useful, there was a lot of information in the packs, perhaps too much, but the picture of the sugar hits was useful and some of the information, especially for children with Downs syndrome.”

Professional 3:

“Just that when we did the course there were many terms that we didn’t understand like the word caries and it took a while for us to work out what the words meant and when we did it was goodness caries means decay and why couldn’t they have said that in the first place. But we already knew a lot but the terminology we didn’t [...].”

Professional 4:

“[...] There was a lot of resentment coming on the course because we are so busy, and telling us we had to attend when we could have perhaps read the same amount in a pack would have been more useful, but then I suppose a lot of people would not have bothered with the pack, but maybe fewer information [...]”

Professional 5:

“[...] if we get asked questions we don't know and the training has helped, alongside the refresher teams.”

Professional 6:

“[...] I have an interest in oral health so I already knew most of what I was told, I suppose it's good to be refreshed but I didn't learn anything new, or anything I wasn't doing already [...]”

These healthcare professionals want more tailored and appropriate information for their needs. For example, many staff members felt that more specific information concerning syndromes and their relationship with oral health would have been useful. Little attempt was made to ascertain the existing knowledge of non-dental staff before training and this resulted in some staff not learning anything new and feeling irritated. This irritation increased when dental knowledge was taken for granted and unfamiliar dental terminology was used, leaving non dental staff feeling isolated and inadequate. Even though 71% of Ireland has fluoridated water, there was a paucity of knowledge concerning fluoride and which areas in Ireland had a fluoridated water supply. Resentment was voiced in more than one meeting concerning being forced to go to oral health training sessions when staff felt overburdened with their existing roles.

However, a different perspective was voiced by parents concerning content and delivery of information.

Parent 2:

“The diagrams were definitely useful because they kind of showed you'd be having your lunch and then chocolate or something after and leaving decay in the

mouth. [...] I was giving him decay all day long, whereas now I give him it all in one go and then give him a break. [...] But the most thing that I've learnt is that I was giving him drink during the day to keep up his fluids and I was giving him an awful lot of Ribena and I kind of stopped that to give him a break and just give him the water which he'll take. So I don't know why I gave him the juice to start off with. But that's the main thing I've probably kind of learnt."

Parent 4:

"I had to go and meet and the health promoter, she gave me loads of information on the sugar in the food and when to give them treats and when not to give them treats and the types of sugar that could cause damage which was really interesting because you don't really know about all the hidden stuff [...]"

Parent 8:

"it was common sense a lot of it, don't give them rubbish, keep the teeth washed, I had done it with my other children, not giving them sugary stuff [...]"

Parent 9:

"Talked to me about diet but nothing I didn't know already and it really wasn't an issue [...]"

Parent 10:

"[...] well I was giving them sweet stuff all day long, I didn't know that and she was saying that if you eat sweet stuff continually then the sugar build up in your mouth causes decay but I didn't know that. Sure I thought it was very interesting when she was showing the amount of sugar in Cola and sweets and different things and some sweets are healthy like the natural sugar company and that."

Parent 11:

"That's how I went to the session with (health promoter) and went through the whole care for his teeth and that's where I found out about the sugar, the four hits a day you know, the whole lot."

Parent 14:

“I couldn’t believe how much sugar was in certain foods [...] I found it interesting that when they are brushing (health promoter) said to brush the gum as well and I would never have stopped them from rinsing out. [...] I was amazed about the Australian natural confectionery as to how much sugar was in them. But it’s the things that you don’t think about, the drinks.”

Parent 6:

“Like they were asking me a million questions and I was trying to watch her (daughter). They gave me a questionnaire to fill in before and I ticked it off and then she (health promoter) went through it with me like what she drinks and eats and using toothpaste and not be using too much and stuff that I already knew [...]”

Parent 1:

“[...] I think that seeing her and she was good with the information and she had a box of stuff as well with her to show me what had sugar in and how much sugar, how many teaspoons that were in each thing and it surprised me some of them as to how much was in like medicines and I found that useful. I learnt a lot that day from stuff that I thought was ok [...]”

Many parents interviewed found the one-to-one sessions with the oral health promoters useful and interesting, adapting their knowledge accordingly for the whole family. However, some parents appeared confused as to the content of oral health advice, others admitted they had ‘forgotten’ much of what they had been told, and a few indicated that they learnt very little from the sessions and this perhaps highlights the need to tailor information specifically by exploring the needs of parents, to avoid the routine use of tick box questionnaires, and to provide reinforcement at intervals.

2.2 Presentation of information

Parents and non dental professionals discussed useful information and how it was presented.

Professional 7:

“You know in terms of oral health one thing has had the biggest impact here and that is our sugar board, it is one of the most looked at things by children parents and anybody coming in to do training. Ours is a DIY version and if there was money to spend on something then that is the most useful, it is the most visual. I don't think I've seen parents pay any notice to leaflets, but the sugar board has maximum impact.”

Professional 5:

“We use bags with sugar cubes in and fats and get them to do the number of cubes in something like a bag of jelly babies, 66 cubes of sugar, when they see it in terms of cubes of sugar it makes them think, but they all loved the oral health thing.”

Professional 2:

“To be honest we are so busy it is sometimes difficult to add (oral health) and would it be cost effective to produce a slim line DVD to show tooth brushing? Unless you see it happening it can be difficult to explain to a parent [...] The community nurses and we found that flip charts with cartoon characters on them instead of real kids with rotten teeth are sometimes more useful to work with.”

Professional 9:

“[...] part of that would be talking about oral health and all that, we've a flip chart and there's one page that shows a mouth, or teeth that haven't been cared for and brushed and a nice mouth of teeth and talk around that but if we have concerns we would refer [...] The flip chart is difficult to use, come and have a look at it for teaching purposes.”

Professional 7:

“We have problems with language barriers with Middle Europeans [...] The dental needs of young children are great but parents fear their child attending the dentist [...] “

Non dental professionals found the sugar board useful, alongside cartoon characters for educational purposes. The flip chart that has been produced for

teaching purposes is not user friendly, the illustrations and information are useful for dental professionals but is threatening, not easy to read, contains medical and technical jargon and is therefore not appropriate for non dental professionals and parents. Most non-dental professionals wanted more readily available oral health educational materials that could be adapted for different individuals and communities to meet their needs.

2.3 Delivery of Information

Some parents and professionals considered oral health to be the domain of the dentist, hygienist, dental nurse and oral health promoter. Professionals felt that parents would be happier receiving dental information from a dental care provider rather than a physiotherapist or speech therapist.

Professional 2:

“I feel that perhaps parents are more inclined to listen to a dental professional about their oral health and that’s the place where they should be going because I have a hard time seeing where oral health fits in with psychology.”

Professional 5:

“[...] We have an oral health leader in the team who keeps us up to date. When you are talking about the social model and we need to work in this way so that families get the most out of us [...]”

However, there is no evidence from the parents to suggest that they would prefer the dentist to be giving them oral health advice in comparison to a speech therapist or physiotherapist. This statement may be fuelled by the workload that professional 2 experiences on a daily basis and rather than admit oral health causes more conflict in the working day the blame is externalised to the parents.

In contrast, professional 5 works in a transdisciplinary environment; so for example a speech and language therapist may undertake some physiotherapy and perhaps more importantly the team do not have job titles so parents don’t expect to be working on just one aspect of their child’s needs. All these team members

work with the social model. This is in opposition to a medical model of care whereby care is compartmentalised into clinical factors and there is little consideration for the ‘whole’ person. This highlights a tension for delivering oral health promotion because different ways of working influence how and what types of information are delivered or withheld.

These three parents had seen a community social worker, an occupational therapist, a speech therapist, and did not suggest that they had a problem being given oral health advice by non dental professionals.

Parent 10:

“I saw the lady through Enable Ireland and got more leaflets which were good but I knew a lot of the information already. But other than that I haven’t come across anything else”.

Parent 7:

“[...] So what I’m using at the moment is, the OT girl here gave it to me, they’re long sticks with a pink sponge on the top [...]”

Parent 2:

“[...] I went to see the speech therapist and she advised me to get him off the bottle and onto a cup as quickly as possible to help with his speech [...]”

Parent 3:

“And I know it’s nothing to do with today but (oral health promoter) has been a tower right through, she would be the first person I would lift the phone to and have a good whinge, she would be the first I would do it to, she’s super.”

Parents did respond favourably to one-to-one advice from the oral health promoters and interviews highlighted that the promoters had built trusting relationships with many of the parents. These personal qualities indicated that the oral health promoters had an approachable and understanding manner, effective communication skills and respect for parent’s concerns about their child generally, not just in relation to oral health care.

Parents indicated that they wanted the best for their children, needing reassurance, and expressing concern that dentists were qualified to deal with children with disabilities in that they had an understanding that each child was an individual

Parent 10:

“They’ve been good like but...These people who are dealing with our kid are they are trained to deal with kids with special needs?”

Health care professionals also expressed difficulties with the dental professionals because they felt that specific training was needed if they were dealing with children with disabilities.

Professional 9:

“Dental isn’t trained in sensory integration and that would help us, if we are giving oral health advice the least they can do is get an overview of our ways of working and they are in the best position for things like oral aversion to help us with sensory integration as part of their visits [...]”

This professional is aiming for collaborative working and a more transdisciplinary approach, she is fully aware that professions can become compartmentalised and work within their discipline rather than across disciplines. This emphasises the need for dental to work across disciplines, exploring how they can enable other disciplines by working collaboratively.

Parents and Oral Health

Chapter Summary

Parents of children with disabilities may be diverse in their experiences, but in terms of oral health care the priorities of many parents centre on their immediate concerns, hopes and wishes for their child. Many parents are fighting and pleading for services which are not accessible, adequate, appropriate or equitable as promised in policy. The daily demands of caring for a child with disabilities means that most parents are tied to a day-to-day existence and the greater the level of impairment, the higher the number of demands. The burden of care is placed squarely on the shoulders of parents, and depending on the level of their child's disability, they are performing the role of medical professionals (but without training) in addition to the often secondary but just as important, role of being a parent. The effect on family life is often stressful. This has an effect on oral health because parents are spending their energy and resources on accessing priority services to fulfil their child's immediate needs, leaving oral health a low priority.

Non-dental professionals also have a more medicalised view of oral health and dentistry and rather than seeing the dental services as oral health promoters there is a tendency to see services as being in place to ameliorate dental decay.

Working more collaboratively and the provision of training is required in terms of syndromes and disorders, and their link with oral health may assist other disciplines and non-dental professionals in acknowledging the importance of oral health and its relation to general health and vice versa. However, just introducing oral health promotion, without its biological and social origins and implications provides little impetus for non-dental professionals to view oral health as part of general health and vice versa.

3.1 *Accessing Services*

Parents of children with disabilities have a diversity of experiences, similar to parents of children without disabilities (Fisher and Goodley 2007). However, many parents experience a financial impact when they have a child with disabilities (Dowling and Dolan 2001). For example, parents may find it harder to maintain full-time employment, or their housing may be inadequate for their child's needs and spending on basic needs may increase, leaving parents struggling to meet the level of debt incurred (Emerson and Hatton 2007). Other studies have identified that parents of children with disabilities spend twice as much as parents of children without disabilities on items and services for their child (Dobson et al. 2001).

In addition to the worry concerning finances, many parents of children with disabilities experience a lack of practical and emotional support at a time of transition when, depending on the level of impairment, they may be struggling with services, and feeling isolated and marginalised as a result of social attitudes (Dobson et al. *ibid.*). Other worrying factors may be related to the diagnosis, or lack of one. Receiving a diagnosis is often the point from which parents can begin to regain some control, start to think about their futures, and gain an insight into the nature of their child's disability. Crucially, and with the advent of the new assessment of need a diagnosis enables parents to gain access to services and benefits.

When a parent has a child with any impairment then most early intervention services have a tendency to concentrate on the medical and developmental needs of the child (Lonner et al. 1994). However, services often fail to address the family support needs of that child; this fails to recognise the duality of the role of the parent: carer and parent. In many instances children with profound needs are discharged into the care of their parents with medical equipment, oxygen cylinders and tube feeding equipment. This places the burden of care on the learning resources and energy skills of the parents, and in Ireland support for parents and respite care is severely under funded (Ling and O'Sioráin 2005). Accessing

services may prove problematic and parents may engage in a struggle in order to obtain services for their child (Greco et al. 2004). There may also be problems with physically accessing services due to their geographical location and transport restrictions (Smith 1996, Johnson 2003). Despite the importance of oral health in terms of a whole person approach, it may be that because of the multitude of barriers in their lives parents have tendencies to place oral health quite low on their list of priorities for their child.

The following narratives highlight the pressures of daily living on parents of children with profound impairments.

3.2 *Parent's experiences*

Sinead

<p>Diagnosis</p>	<p>Michelle was diagnosed just at birth and she spent five months when she was born, well 4, 4 and a half months in hospital, she had heart surgery. So when she was 10 weeks old she had a good 8 hour long surgery, a procedure done in a hospital in Northern Ireland. She was born on the border and then went straight up there.</p>
<p>Learning resources and skills of parents</p>	<p>She has been tube fed from birth through her nose and we had to look after the tube to start with and that took place for over a year she had severe oral aversion. If I touched her, if I took her to the hospital at about 5 months old if I put my finger on her tongue, or her lip, it would initiate a gag reflex and vomiting. So that tube feeding went on for a year through the nose.</p>
<p>Burden of care</p>	<p>All day and through the night we were up. We were feeding her right through the night at one stage for a few months through the tube, just up all night with her. I hated the gastrostomy tube I have to say, from day 1 she had, she didn't have the vomiting but she had continual gagging, day and night, like an old man. You know that trying to clear her, first thing in the morning? That procedure was done in a hospital 100 miles away. So we had to travel there every week, twice a week because she had continuous infections, yeah last summer we spent away in a blitz because we couldn't go out of the door with her, couldn't even take her...</p>
<p>Oral care</p>	<p>In terms of her oral care, she had no teeth at that stage. Funnily enough, she didn't have teeth from birth until she was 18, 19 months, 20 months actually. So the work that I was doing with her orally was to try and desensitise I had a load of pretty kind of things, I had a z vibe which is the size of a pencil and is a tiny like massager which you massage her mouth and then eventually, I think it took a year of that to try and get into her mouth and then maybe do a little bit of work and I would then use a little finger tip little rubber things. Michelle's the type that gets fed up very quickly so you've got great work doing that for a few weeks then you can't even go near her with it. So they were the only 2 things that I was using with her. The toothbrush I found, even though she didn't have teeth I was massaging the gums and doing that kind of work. But to be honest, her oral care is a very small part of our everyday life. I just look forward to her eating.</p>

<p>Daily pressures and lack of support</p>	<p>I've an appointment for her every day this week, I'm in Northern Ireland tomorrow, the Lourdes Wednesday, Thursday I've occupational therapy, and Friday speech therapy which we are doing privately. Saturday we are doing private OT and that's my week. Week done. There's a lot of work so the teeth are only just starting to feature. You are battling with the health board, you are battling, there's no support at all, no partnership for all the people that are involved in Michelle's care there's letters from here, there was no progress and I was so stressed I had very little speech, the OT, having to fight all the time. In terms of professionals it's usually all developmental stages, there's no lightness to be honest with you. The first visits to the paediatrician she listed everything that Michelle could possibly get as an adult, finishing off with Alzheimer's and I was like any good news, you know? I'm in a system with services until Michelle gets to six and then they take the services all away and I'm back to fighting on a daily basis. We've already taken out a bank loan to fund some of her treatment privately, but what if we couldn't do that?</p>
<p>Information</p>	<p>I might read it but maybe not straight away, or take them to bed. Or I use the internet and up to a month ago I started I would have Michelle's own file with her information, so I know where her stuff is for information if I need to go and look for it and I have easy access and anything that will help Michelle I will read.</p>
<p>Family life</p>	<p>We've had a heck of a tough 2 years but she lights up, she lights up my life we just adore her so much, you know, the fact that she has gone through so much, it's just like wow, yes. You don't think that you could be strong to do it, but you do it, even Rebecca had it tough you know, she was just left, not that she was left but she was pushed everywhere to be minded while I was off with the doctors and it's only now that's she's starting to enjoy family life. It was a medical house before, that's all we talked about; Michelle, her feeding, and nobody outside your own home understands what is going on, family included, they hadn't a clue.</p>

Marie

<p style="text-align: center;">Diagnosis</p>	<p>Things only kicked in when we got to a different hospital and I had a paediatrician here and I didn't get on with him because he had a really bad attitude and we were having various tests for her and I asked what would happen if the test came back and we had no idea and he said oh I don't know, it's out of my hands. Just like that and when we went to the different hospital he was like this child's not leaving until I find out what is wrong and he should really have diagnosed her with developmental delay because he had been seeing her since she was 6 months and by the time we got to the other hospital she was nearly a year and she wasn't sitting up. So it was only when we got there that we got stuff sorted out.</p>
<p style="text-align: center;">Learning resources and skills of parents</p>	<p>I mean she wasn't eating and you are in and out of hospital all the time and he kept saying she had gastro and so I was cleaning the house all the time and he was asking did I sterilise bottles and all this sort of stuff and I was sterilising things like a million times and you'd even be using the Milton sterilising them and sterilising them again because there was all this going on.</p>
<p style="text-align: center;">Burden of care</p>	<p>I thought it was just because she was getting sick all the time and she was in and out of hospital a lot and he was sending me away saying try and get the food into her but didn't once say she had developmental delay. When she went into hospital she would pick up everything that the other kids had and there was actually this one time and she ended getting up even sicker because she had such a lowered immune system.</p>
<p style="text-align: center;">Oral care</p>	<p>Well I was pushing at the time because the only problem I had was her eye teeth, there was some decay in them and she has teeth layered behind each other but the dentist said that was normal. And just to put toothpaste on where these two things are. I was more worried about the staining and the shape of her teeth. But the lady doing the services with Enable Ireland gave me a tooth brush for her but the 3 pronged toothbrush was better because you get all the teeth at once but I've only been up the once yet and I haven't been called back.</p>
<p style="text-align: center;">Daily pressures and lack of support</p>	<p>I couldn't. It was just his attitude the way he went on and like. I felt it was my fault and I thought he was thinking that I wasn't feeding her, just all this stuff goes through your head. Then getting other services was difficult and we ended up fighting over silly things.</p>
<p style="text-align: center;">Information</p>	<p>I saw the lady through Enable Ireland and got more leaflets which were good but I knew a lot of the information already.</p>

Anne

<p style="text-align: center;">Diagnosis</p>	<p>Niamh was born with Down's syndrome, they diagnosed it at birth, she had a heart complaint and she had bowel surgery and so we are constantly, every so often in hospital and she has people prodding her and this that and the other, but you know, it's part of life now so</p>
<p style="text-align: center;">Learning resources and skills of parents</p>	<p>With the shock at the time, you are listening but you are not taking it in, and when we got home from the hospital and we had a feeding tube and whatever</p>
<p style="text-align: center;">Burden of care</p>	<p>I have other children so when Niamh was born it was difficult and a busy time, you know when she was born with medical problems and that [...] mum's have to do everything themselves, or train yourself on the internet, or whatever to help enable you to help your child.</p>
<p style="text-align: center;">Oral care</p>	<p>Up to now we haven't needed a huge amount of dental care needed, it's common sense really with the sugary drinks and things, we've tried, we're not holy Joe's by any means but she's doing pretty well now. She has sensory issues around her face and we've been better because speech therapy have done a lot with sensory toys and trying to get her used to having touch and things in her mouth so that has helped to be able to get the toothbrush in...</p>
<p style="text-align: center;">Daily pressures and lack of support</p>	<p>I've a busy life running backwards and forwards to the hospital with Niamh and looking after my other children, your whole life is calendared but it's not so bad [...] but you can't do anything but get on with it. Services aren't great in Ireland and that's an issue, there's huge gaps [...] You never stop fighting with them [...] And access can be difficult depending on where you live. [...] There's loads of things they do offer like coffee mornings, but I've no interest in going to them because life for me at the moment is too busy, I've 3 kids, I get in the car in the morning, I've the school run and then all the after school activities and the medical things and those kind of things are last on my list. [...] it's not the social things we want it's the hands on important things. [...] constantly every week I could come in here with a pile of letters come to a coffee morning or parent get together or play dates for children, that's fantastic but we need productive things to bring things on. [...] and we had a psychologist who was nice but I felt he was extremely negative, he told me not to encourage her and she was shape sorting and every time she got one right she would look at me and I'd say well done and he'd say stop that, nobody praises you in the real world when you do things right, you shouldn't be doing that. I just think</p>

	he used a medical model all the time.
Information	I use the net; the American sites are fantastic for information, much better than Ireland's. I've a couple of friends who send me information that helps.
Family life	Niamh is just the annoying little sister, she does everything that her brothers and sisters do, and their friends include her when they come round, she follows them everywhere and everyone greets her in the village when we are out, even the children, so she is not set apart from the family, she is very much a part of everything that we do.

Regina

Diagnosis	When the twins were born they were premature and the social worker referred them to every service going but it wasn't until they were 6 months old that they realised that there was something more
Learning resources and skills of parents	Alex didn't suck for a long time, he was 6 or 7 months old before he sucked and he has cause to have problems with his speech as well as well as having to have grommets, and he has had glue ear. Sorting out weaning and getting them to eat was a huge problem.
Burden of care	It's up to a mother to ask for services, it's your duty and your job
Oral care	The boys don't have any problems with their teeth, they have good teeth. I had to go and meet the oral health promoter and she gave me loads of information on the sugar in the food and when to give them treats and when not to give them treats and the types of sugar that could cause damage which was really interesting.
Daily pressures and lack of support	We seem to always get a bunch of appointments together, we see the doctor and Alex has an assessment every year to see how his speech is coming on and how he's progressing and then there's Temple Street for their eyes [...] which we visit every 6 months so that's that, but we don't have as much as we did a year ago. It took a long time to get the services they needed and a lot of phone calls. I think maybe years ago if the dentist had contacted me I'd have said no because there was too much to do [...]
Information	I work for the Health Board and a lot of information is readily available and I can always ask someone
Family life	You just want the best for your children; you want them to get on when they are older and have as normal and independent a life as possible. I work at making sure their lives are as similar as any other child in their age group.

3.3 Summary of parent's experiences

These four parents all identify the demands on their resources. Oral health care is a low priority for them because of these competing daily demands. Fighting for services so that they have a diagnosis and explanation of their child's delay in developing, then services that will enable their child to hear, speak, walk, and achieve some degree of independence for themselves and from their parents is initially of greater concern than their child's oral health. As these concerns are addressed, and the parents become more confident, the capacity to consider oral health becomes more apparent. Confidence appears to be an issue that may constrain parents from attendance, perhaps fears concerning devaluing of their personal experiences by other non-dental professionals.

What is apparent is that the early intervention services are addressing the medical and developmental needs of the child, albeit in a patchwork fashion, but the array of family support that is necessary when a disabled child is born remains a challenge. A large burden of care is placed on the mother, although these parents interviewed appeared to have supportive partners and a supportive family network. Unfortunately, some parents appeared surrounded by the pervasive negativity of some professionals. This disabling attitude on the part of some professionals gave parents little hope for their child's future, and this may further disable them and their children by affecting their willingness to engage with services.

In terms of support, there is no way to identify the importance of different types of support without asking the parents themselves. Many parents felt that support meant being given medical services to enable their child to become more independent, or to ameliorate a disability. However, this may change as daily life is never static and emotional support, support for siblings, financial support, or support for travelling takes precedence. The daily demands of caring for a child with disabilities means that most parents are tied to a day-to-day existence and the greater the level of impairment, the higher the number of demands. Some parents interviewed were performing the role of an intensive care nurse; giving intravenous injections, ventilating their child, using pulso-oximeters, dealing with double incontinence, dressing open areas, administering medication, waking

throughout the night to tend to their child. This was in addition to the almost secondary role of being a parent.

3.4 *Non-dental professional perceptions*

Professionals confirmed the burden of care and the lack of importance relating to oral health for parents.

Professional 7:

“It (oral health) is a very small part of their lives; it depends on level of disability and the stage that they are at. Of late, more parents are allowing me to make the referral in the early stages, when I do my first visit to all families I explain about the project, I give them the leaflet and say we could give the referral and offer it at an early stage and they might say not yet, there’s too much going on now and we just cannot cope with anything else, which is often the case.[...] Some children with complex needs go to hospitals that involves a day trip that usually starts at 5.30 in the morning with the kids in their pyjamas in the car, so some of the families are busy with those things and usually for a limited time period where things are really busy and it is only then 3-4 months later when things settle back into a pattern and they can think oral health, it’s so different for every family, it’s a lot of juggling for them. [...]”

Dental services were portrayed mostly as ‘fixers’ of teeth rather than promoters of oral health. Unfortunately, dental services have promoted this ideology because of the monopolistic position in relation to their patients which compartmentalises dentistry and the mouth, divorcing it from other disciplines (Lynch and Calnan 2003). This position is disabling because it is a result of the development of dental practices and policing that have moved the mouth away from a more holistic perspective to a need for treatment from the supply of dental care (Nettleton 1992). The way the dental profession is perceived obviously has repercussions for the profession as a whole; if the general public hands over control to the dental profession to ‘fix’ their teeth and the expectation is that this is what the profession does then this leaves little room for manoeuvre and for dental professionals to be recast as professionals who promote oral health and empower people to take

control of their oral health care. This is evident in some of the professional statements.

Professional 3:

“It’s a shame that parents don’t take oral hygiene more seriously because in terms of oral hygiene it’s aesthetics for children with special needs because if they have badly decayed teeth it makes them more disabled you know from a social point of view and maybe they might be more impaired and have lower functioning in terms of learning disability but if they have a lovely smile it’s going to draw you in more and want to make you make an effort to communicate.”

Professional 5:

“[...] let them know you are interested in seeing their teeth because often you come across decay and sometimes it awakens awareness in the parents by just looking at the children’s teeth [...]”

Professional 6:

“[...] you talk about their diet and how their kids will have poor teeth if they start into a poor diet and not good practices [...]”

Professional 7:

“[...] In some areas the staff are all new and I don’t know that oral health will be on their radar.”

This returns full circle to working collaboratively with other disciplines and implementing a ‘whole person’ approach, by educating other disciplines concerning syndromes and co-morbidity and their relationship with oral health. This emphasises the importance of oral health, and its influence on general health, particularly in relation to children with disabilities. It may be of more relevance to professionals to link syndromes and co-morbidities with oral health first, and then proceed to the impact of sugar, dental decay and gum health. It may also be useful for the dental profession to employ a social model approach and look at the disabling medical and social factors in relation to oral health and how a child may be disabled socially by poor oral health. Enabling non-dental professionals in this

way may enable parents to have a more holistic overview of how to care for every aspect of their child.

For example, children with metabolic disorders who may need many services but if their oral health management from birth contains a strong prevention focus it may assist in reducing unnecessary treatment under a general anaesthetic which, alongside poor oral health, may cause more management problems in relation to their general health. Poor oral health may also inhibit positive social interaction which socially marginalises the child. Likewise, children with chromosomal disorders may have cleft palate, delayed dental eruption, low birth weight, delayed growth, developmental heart disease, and altered facial structure amongst other co-morbidities. This may link in to feeding difficulties, weight maintenance, poor gum health, and the use of high calorie feeds which can adversely affect oral health and this in turn can affect general health and vice versa and social interaction.

Barriers and Oral Health

Chapter Summary

Oral health is struggling to be seen as part of general health and it is only when crisis situations occur with children with disabilities that services are frantically fire fighting to address the issues. The existing gap in dental service provision has widened with fluoridation not solving the oral health problems, particularly for children with more profound needs. Creating a specialist service for children with disabilities is creating its own problems with visits being duplicated and parents and children seeing different dental professionals, for the same procedures and becoming confused by the process. This may be a contributory factor for some parents refusing to engage with services.

There are many barriers related to procedures for accessing oral health services, and when a parent does manage to access the services a further barrier may occur in relation to delays in being seen. The independent assessment of individual need is already creating problems in areas where it has been implemented because of the length of time between assessment and receiving services. The restructuring of services is creating a burden upon non-dental staff already working above capacity and struggling with the demands of their work. Oral health has become relegated to a position of little importance and a whole child approach is not being taken by all services.

Budget constraints are affecting joint working because non-dental professionals are overstretched, feeling that they only had the capacity to carry out day-to-day work with parents and children rather than participate in networking meetings and further training in other areas such as dental.

4.1 Accessing and engaging with services

This section focuses on the barriers that parents may face when accessing or engaging with services. One aspect that many studies have identified for successful engagement of parents in services has been the relationship between front-line service providers and service users (Lee and Ayon 2004, Morris 2004, Katz et al. 2007). Trusting relationships that have built up rapport involve not only the front-line service providers with parents but also professionals from different disciplines with each other (Cooper et al. 2003).

Trusting relationships are only part of the picture. For example, in the case of implementing independent plans (IP) studies indicated that the slow rate of progress and uptake was directly related to the work load demands on front-line workers which were overbearing (Grant 1997). This is directly related to structural barriers in care provision. Structural barriers with services cannot be used in isolation from other barriers; i.e., procedural, or financial, that parents may encounter when trying to access and engage with services. This is in addition to the competing daily demands on a parent's energy and resources when caring for a child with disabilities which have been identified in the previous chapter.

The focus on this chapter centres entirely on service provision as a whole and how this then impacts on oral health and oral health promotion. This study presents the findings in this way because examining oral health in isolation from other services does not give a full picture into the oral health initiative, and the barriers to its implementation. Therefore, the first area to be examined will be structural barriers in terms of how the services are organised to meet the needs of the service users, this is followed by procedural barriers in terms of how procedural guidelines may affect service delivery, and then budgetary or how budgets shape, and constrain services. There are cross-over points with these three barriers and again they do not occur in isolation from each other; each process impacts on the other in terms of service delivery and accessibility for parents.

4.2 Structural barriers

The Disability Act (Government of Ireland 2005), aimed to make service provision for individuals with disabilities more equitable, person-centred, accessible, appropriate for the needs of the user, and more accountable. These ideals follow a social model of disability approach which has a rights based agenda. However, the very language used in the Act is conflicting when it comes to defining disability. Disability as defined under the Disability Act 2005 in relation to a person means; *“a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment”* (Government of Ireland 2005, p6, para. 2:1). This is very adult oriented and bears little relation to a child with disabilities. It is saying that if you are classified as disabled you will be restricted, as a result of your disability, from working, becoming a professional, and unable to participate socially and culturally. This is a medical model of disability which is in tension with a social model. Immediately within the Act there are contradictions which when translated into a service environment become open to interpretation and misinterpretation.

At present, the services are set up to allow for an assessment but for early intervention services to be offered alongside the assessment based on the need for more than one therapy. However, the independent assessment of individual need is now a more formalised process and health care resources will now be allocated by an independent assessor after using a range of measurement scales and questionnaires. Although this should in theory be an interactive task very often power differentials are forgotten, and bureaucratic processes take precedence, in the drive to gather information about a child with disabilities (Millar and Corby 2006).

Professional 7:

“[...] we equally see children with some developmental delay and equally see children who need some occupational input or speech and language input. Basically the criterion to access this service is that a child needs a team based

service, i.e., they need more than one therapy. If they only need speech and language therapy they go to community care services it is basically for those with more complex needs. We have tended to focus on some kids who you may not say have disabilities simply because there is nowhere else for them to access and by implementing an early intervention they would have a more positive outcome. If they had been referred to them we could have said no but we chose not to because they would have ended back up in the system somewhere. We are getting stricter because the legislation changed last year, the disability act came in and there's a very formal assessment of need process, similar to the UK statementing process [...] there is more a formal structure around assessment, it's easier in some counties, we have had the capacity to be able to do it. Technically we are supposed to do an assessment of need to stop any contact with the family and wait for as it were the statement to come back to us. We have chosen not to do that, we continue service because if we think and know that the child is going to be for us we don't stop services, we don't wait for someone to complete reports. [...] That's what the legislation is technically asking us to do, do the assessment of need and return all our reports to the assessment officer and then the assessment officer and liaison officer/key worker (who is not in post at the moment for this area) they are then supposed to review the reports etc., and do their reports and only at that point they make a decision around what would be an appropriate service for the child. We are lucky in this area and the team have taken a view that we are not happy to do that. We are going to be challenged on it some day soon, but for the moment our parents are not experiencing a huge break in service. They might not be getting all the services they want and that is never going to happen, but there isn't a huge 3, 4, 5, 6 month break waiting for the statement of need to be written and we are lucky at present not to be in the same situation. [...] How long we can continue to do it, time will tell. [...] Basically referrals came into us and in a way we still did exactly what we are doing now, but it is much more formal now and all referrals have to come through the assessment of need officer in the HSE. We have lost control over referrals coming to us. We cannot accept them directly anymore. In some ways it hasn't changed but families get a visit from the assessment of need officer before we make contact with them, she decides who they need to be assessed by. [...] In some areas it is still direct referral but because of waiting lists families are not being seen for a long time so the assessment

process here has not created a waiting list for families in our area, but it has in other areas. [...]”

This professional is arguing that the assessment of need process has not affected their area in Ireland. However, they are acutely aware of the difficulties in other areas when services are being constrained whilst a liaison officer decides on level of need and allocates to services accordingly. In other areas professionals are receiving families for ‘early intervention’ twelve to eighteen months after assessment because there are waiting lists being created by the assessment process. If a family does not enter the services until their child is three, or four and then has to wait another eighteen months for services then this process becomes problematic because the early intervention services finish at six years of age when community services take over. Where this leaves oral health is unknown at present, however, if the liaison officer decides that oral health is a low priority, then this creates further difficulties. Additionally, for a child to be referred to early intervention services then the requirement is two or more therapies, a child could be disabled, not need the magical two for referral and miss out on early oral health promotion and then experience further marginalisation when they experience the poor oral health – general health continuum.

In Ireland there is a gap in dental service provision and fluoridation was one way that the HSE sought to reduce the need for and burden on dental services (Nunn 2006). However, fluoridation alone is not an indicator for optimum oral health; therefore services and oral health promotion are still in demand.

Professional 6:

“[...] it is really difficult to get oral health appointments for a child in this country and parents are starting to pick up on it now and I say look this is your only opportunity to link in with the service [...]”

Professional 5:

“[...] the dental service for children has been curtailed here and they have to go privately. At present, for children with special needs we can refer directly to dental or Enable Ireland would make the referral, but how long that will go on for

I don't know. [...] The child is dependent on the parent, the parent is dependent on the health board, and the health board are not delivering the services; and the children are suffering as a result."

There is a deficit in relation to oral health services in Ireland and if these services remain as a low priority for the HSE then the oral health of children with disabilities may remain poor and marginalise them even further. Oral health for all children appears to be given a low priority by the HSE. This remains problematic for children with profound needs, leading to the inverse care law which states that those in greatest need of services being the least likely to receive them (Tudor Hart 1971). Whilst there are no easy answers to distribution of services, marginalising parents of children with profound needs does not appear to sit comfortably with the rights based approach of the disability act. Of even greater concern is the restructuring of the HSE to accommodate independent assessment of individual need. Control appears to be in the process of being wrestled from family social workers and community nurses who would have made the initial contact, and developed trusting relationships, with the parents. Previous studies have confirmed the importance of these initial relationships and attributed parental distrust of systems to power differentials, the process of assessment, and bureaucratic practices, with parents viewing assessment as an intrinsically negative process (Corby et al. 2002, Millar and Corby 2007). Without that trusted person making the initial approach to consider the child's health holistically then oral health may run the risk of once again being relegated to a position of little importance.

Parent 8:

"You can't take a child like him to an ordinary dentist because of his medical history, and I don't know where I am going to get treatment [...] if you have a child who needs a general anaesthetic you have to trek over to Dublin which is a two hour journey, sorting your children out, putting the others into childcare and if your child isn't well on the day it makes things even longer. So now he will see yet another dentist to do his treatment and I don't think he will care any less about my child BUT he's not my child's dentist and the dentist who has seen him all along is the one who has the relationship with him [...] I'm the parent and I don't

have a choice if my child is seeing someone I don't know and may not like [...] It just isn't organised at all and you can have all the health promotion in the world BUT if there's no services for children with profound needs [...] then how can you do the work? [...] The main problem is lack of dentists but they are not winning [...] dentistry has never really been important [...] if your child doesn't speak they get a speech therapist, but if your child has a bad tooth no-one bothers. People just don't see dentistry as a priority [...] we are all misled, or not informed whichever way you want to put it. [...] My child's health comes first, his teeth second. But ironically his teeth are now affecting his health. [...] Because of my child's problems I could lose him to a bad tooth. [...] You need to have confidence in a service that they can care for your child [...] it's no good training people to talk about oral health when there's no-one to sort a problem out when it occurs [...] treatment is sometimes necessary and they need to have a quick service so a child is not in pain for 6, 8 or 10 weeks."

This mum (Bernadette) typifies crisis situations that may occur with a child who has profound needs with additional treatment management difficulties. If this situation is not dealt with quickly then Bernadette is aware that her child could die. She has first hand knowledge of how important oral health is in relation to her child's general health. Unfortunately, the way services are structured at present means that her child is marginalised. Placing a priority on other health problems is part of the ideology of the medical model/system but in this instance it actually becomes disabling. Creating a specialist service also has its own problems because of the level of input required to cater for children with profound needs. Without adequate structuring and resources then these types of problems may escalate quite quickly.

4.3 Procedural barriers

There are usually three components within the process of being a service user; accessing/being referred to services, being assessed for services, and using the services.

4.3.1 *Procedures for Accessing Oral Health Services*

The first requisite that people need to access services is usually a certain degree of awareness that the service exists. When interviewed all non-dental professionals were aware of the health promotion initiative but admitted to problems discussing oral health care on a one-to-one basis with parents and with referral for children with disabilities. This was for a number of reasons which are presented below, and not in any order of importance.

- Large case loads and not enough time to discuss oral health
- Children coming to early intervention services too late for referral
- Children not receiving a diagnosis
- Lack of clear guidelines and procedures for referral
- Children not being followed up quickly after referral
- Needs of parents and children being too great to include oral health care
- Parents refusing referral
- Non-dental professionals feeling their oral health knowledge was ‘too basic’
- Seeing oral health as ‘having teeth fixed’ rather than employing a strong prevention focus
- Language barriers with parents
- Non-dental professionals feeling overwhelmed by the amount of information offered during the oral health training course
- Non-dental professionals feeling under confident in discussing oral health
- Not feeling oral health was relevant to their discipline
- Lack of cohesion and establishment of early intervention teams in all counties
- Feeling oral health is a very small part of parent’s lives
- Not following parents up after an initial refusal
- Not taking a ‘whole child’ approach

- Dental being reliant on other systems to inform them about children with disabilities

All these factors may result in parents not accessing oral health services, or receiving oral health care advice. This creates the first barrier. If a parent is referred with their child then a second barrier may become apparent through delays in receiving services.

4.3.2 Procedures for being assessed for services

In terms of being assessed for referral, most professionals could determine that parents should be referred. However, there was a tendency for parents from higher socio-economic groups to be referred and parents that were most in need were still not managing to access the services. Whether this lack of access was to do with individual level of disability, burden of care for parents or lack of other resources was unclear. What was clear was that children in some areas were receiving appointments to see the community dentist and then another appointment to see specialist dental services, becoming confused and then not engaging with either, or having duplicate appointments. This indicates problems with a 'specialist' service and duplication of appointments which could be undertaken by the community services, rather than by a 'specialist' dentist. This duplication of services may create unnecessary waiting lists and reduce accessibility for other parents.

Not involving all the professionals was evident in some counties where teams obviously did not work together and had a lack of understanding of one another's roles or how their working week was structured. This means that professionals within services are not speaking to one another and have a paucity of knowledge concerning other disciplines and their working procedures. The danger of not understanding the importance of roles led to more than one professional stating "*I have a hard time seeing where oral health fits into psychology*", and '*oral health is not even on the radar of some professionals*', which again returns to a medical model of care and exclusion of the 'whole child'.

4.4 Budgetary barriers

Budgets play a large part in shaping service delivery (an embargo on staff recruitment, coupled with staffing shortages, such as the shortages of liaison assessment officers, occupational therapists, dentists, psychologists and speech and language therapists means that there were delays in parents accessing services). The ways in which budgets are organised for these services may have major consequences. For example, it could influence the service provider's ability to make or respond to referrals which means that a child with disabilities is experiencing delays in receiving necessary services at a stage when they can be of most benefit.

Inconsistency in budgets may also constrain service delivery. It was obvious that budgets differed from county to county because there were variations in resources as to what service providers could offer. This led to very different experiences for children with disabilities from county to county. In one area there was no liaison assessment officer and staffing levels were optimum therefore children could be offered services without any formalised assessment process. In other areas there were assessment liaison officers in place, staff shortages, and children experiencing twelve to eighteen month waiting lists before any intervention services. This created increasing emphasis on existing resources and created more barriers. The end result is that oral health received even less priority on a more limited budget.

How much funding government allocates to services determines how much a service can deliver. One obvious victim of budgetary constraints was joint working. This was because service providers felt that they only had the capacity to carry out day-to-day work with parents and children rather than participate in networking meetings and further training in other areas such as dental.

4.5 How are barriers being addressed?

The oral health initiative has attempted to address some of the barriers to access by training non-dental professionals. However, this training in itself has been

subject to barriers which are largely beyond the control of the dental services. For some areas, the oral health promoters have been able to work alongside the multi-disciplinary teams and directly with parents on a one-to-one basis, but there is only one oral health promoter for each county, each of whom is working at capacity. Joint working where a key dental professional is included at the earliest stages of assessment is still not occurring unless the child has a facial anomaly, such as a cleft lip and palate, and requires multi-disciplinary surgical intervention. The dental team needs to become more integrated into the early intervention services as a whole, and needs to be supported financially in order to achieve integration. There also needs to be greater awareness throughout the whole of Ireland in relation to the importance of oral health and its impact on general health and vice versa. Schools would benefit from oral health education sessions; however, the burden may once again fall on the oral health educators and their role needs to become more prominent, and more integrated into multidisciplinary teams.

Conclusions and Recommendations

The evaluation of the oral health initiative did not consider oral health in isolation from the rest of the services within the HSE. Oral health is a part of general health and the WHO advocates a whole person approach to health, and additionally suggests that people should be empowered to take control and ownership of their health. This blanket statement is more difficult to implement in practice.

Chapter 2 identified that parents and non-dental professionals required appropriate information in order to make choices and decisions regarding the oral health of children with disabilities. When non-dental professionals were interviewed they disclosed that there was not enough tailored and appropriate information to meet their needs. In some instances non-dental professionals wanted more knowledge on syndromes and how oral health may be implicated. Therefore, careful attention needs to be paid to the taken-for-granted use of dental terminology which non-dental professionals may find intimidating and which leaves them feeling irritated and isolated. There needs to be greater availability of oral health educational materials for teaching purposes for non-dental professionals. An exploration needs to be made for the commercial production of more interactive sugar boards and cartoon style teaching aids to facilitate non-dental professionals working with children with disabilities.

Parents found the oral health instruction useful and gained a great deal from the one-to-one sessions with the oral health promoters. The favourable responses could be directly attributed to the oral health promoters, who exhibited the requisite personal qualities for working effectively with parents. However, some parents appeared confused indicating that information needed to be tailored to parent's needs, reinforcement provided where necessary, and the use of tick-box questionnaires used with discretion.

Chapter 3 identified that many parents were fighting and pleading for services which are not accessible, adequate, appropriate or equitable as promised in policy. The daily demands of caring for a child with disabilities meant that most parents were tied to a day-to-day existence and the greater the level of impairment, the higher the number of demands. The burden of care was placed squarely on the shoulders of parents, and depending on the level of their child's disability, they were performing the role of medical professionals (but without training) in addition to the often secondary but just as important, role of being a parent. The effect on family life was often stressful. This had an effect on oral health because parents are spending their energy and resources on accessing what they considered to be priority services to fulfil their child's immediate needs, leaving oral health a low priority.

Non-dental professionals displayed a more medicalised view of oral health and dentistry and rather than seeing the dental services as oral health promoters there is a tendency to see services as being in place to ameliorate dental decay. Therefore, more collaborative working and the provision of training is required in terms of syndromes and disorders, in relation to their link with oral health may assist other disciplines and non-dental professionals in acknowledging the importance of oral health and its relation to general health and vice versa. However, just introducing oral health promotion, without its biological and social origins and implications provides little impetus for non-dental professionals to view oral health as part of general health and vice versa.

Chapter 5 explored barriers in relation to structure, procedures and budget it found that oral health was struggling to be seen as part of general health and it is only when crisis situations occur with children with disabilities that services are frantically fire fighting to address the issues. The existing gap in dental service provision appears to have widened with fluoridation not solving the oral health problems, particularly for children with more profound needs. Creating a specialist service for children with disabilities appears to be creating its own problems with visits being duplicated and parents and children seeing different dental professionals, for the same procedures and becoming confused by the

process. This may be a contributory factor for some parents refusing to engage with services.

There are many barriers related to procedures for accessing oral health services, and when a parent does manage to access the services a further barrier may occur in relation to delays in being seen. In terms of delays then the independent assessment of individual need is already creating problems in areas where it has been implemented because of the length of time between assessment and receiving services. The independent assessment of need and the restructuring of services is creating a burden upon non-dental staff already working above capacity and struggling with the demands of their work. One casualty of these structural changes is that oral health has become relegated to a position of little importance. The structural changes further impact on the existing compartmentalisation of services with dental services being seen mainly for treatment of decay, not promoters of oral health. This perception is partly to do with how dental services and practices have developed over the past one hundred years, and partly related to structural changes which reinforce existing ways of working. These factors are coupled with evidence that suggests a whole child approach is not being taken by all services and a lack of collaboration between and within services is evident.

Not taking a whole child approach is implicated by budgetary constraints which affecting joint working because non-dental professionals are overstretched, feeling that they only had the capacity to carry out day-to-day work with parents and children rather than participate in networking meetings and further training in other areas such as dental. This further compartmentalises services and reduces the opportunities for integrating oral health promotion into day-to-day work with parents.

Attention to alleviating budgetary constraints is only part of the issue and there needs to be greater integration of the dental services as a whole with early intervention teams and the rest of the healthcare and social services. More oral health promoters and dentists need employing to address the deficit in services. Schools, nurseries, and homes need to be targeted as settings of oral health promotion. There needs to be an awareness campaign throughout the whole of

Ireland on the importance of oral health and its relationship with general health. A greater input into supporting parents with services, alongside oral health services creating relationships with parents from the birth of their first child may foster parent's engagement with oral health services.

The existing oral health initiative appears well conceptualised, and has made a difference for many parents. However, a lack of knowledge concerning the structural, procedural, and budgetary barriers coupled with insight into the daily demands on parents caring for children with disabilities perhaps meant that achieving the aims of the plan could not be a total success from the outset.

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