Title: What should dental services for people with disabilities be like? The results of an Irish Delphi Panel survey.

1. Introduction

For many years research in Ireland has described poorer outcomes from oral diseases and their treatment among people with disabilities (Crowley et al., 2005, Costello, 1990, Holland and O'Mullane, 1990, Elliot et al., 2005, Mac Giolla Phadraig et al., 2014). Examples of poor outcomes include extraction rather than filling of decayed teeth, increased severity and extent of gum disease and a lack of functional replacement of lost teeth when people lose teeth or become edentulous. Possible contributing factors include a lack of appropriately designed service models (Elliot et al., 2005). A review of primary care dental services found inconsistent targeting of "Special Needs" groups across the country with great variability. This report suggested a need for evidence based service models for people with disabilities across Ireland (PA Consulting Group, 2010).

This project used a Delphi panel consensus process, as a first step to evidence based service models, to agree goals for dental services for people with disabilities. The term Delphi Method owes its origin to the fabled Oracle of Delphi. It is described as a structured group communication process that allows the production of information for decision-making (Adler and Ziglio, 1996). This allows an expert group to resolve complex problems with the goal of producing useful guidance and opinions for decision makers (Cramer et al., 2008). The Delphi method has been used in oral healthcare research for some time and is a popular and acceptable means of answering questions of clinical, educational and policy issues in oral health care (Cramer et al., 2008). According to Hsu and Sanford the Delphi technique is often designed for the purpose of goal setting, policy investigation, or predicting the occurrence of future events, attempting to address "what could/should be" (Hsu and Sandford, 2007). Jones et al. developed goals for disability specific services through a Delphi process in a residential care setting (Jones et al., 2000). The Delphi method has never been used to identify broader goals of oral health services for people with disabilities until now.

1.1 Aim

This study aimed to develop a prioritised set of goals for oral health services for people with disabilities in Ireland.

1.2 Research question

What is expert consensus on priorities for oral health services for people with disabilities, in an Irish setting?

2. Methods:

2.1 Design:

Modified three round e-Delphi method. Ethical approval was received.

2.2 Sampling and Participation:

Participants were mainly invited from the fields of Public Dental Services and Disability Advocacy in Ireland. Others joined via an online open access registration. Participants could also recommend colleagues, thus allowing an element of snowballing. Inclusion and exclusion criteria listed in Table 1.

Table 1: Inclusion and exclusion criteria

	Inclusion Criteria
1	Dental Service Users who have a sensory, mental, intellectual, neurological, medical, social or combined impairment that affects their oral health or access to oral health services.
2	Dental and non-dental service providers who support individuals fulfilling criterion 1 above
3	Advocates of individuals fulfilling criterion 1
4	People with experience in the delivery of dental services for people with disabilities
	Exclusion Criteria:
4	Inability to participate in Delphi Process despite reasonable accommodation*

2.3 Data Collection:

Consent and all 3 rounds were completed online using SurveyMonkey ™. The initial round asked: "*List what you think dental services for people with disabilities in Ireland should be like.*" Items for subsequent rounds were generated from responses to Round 1. Rounds two and three used 5 point Likert scales to rank these items by priority: "*Rank [the following] statements according to the level of priority that you think each should hold for dental services for people with disabilities, using the following 5*

point scale. The options included 1.No Priority; 2.Low Priority; 3.Not Sure; 4.High Priority and 5.Top Priority.

Items were grouped thematically allowing clustering prior to a consensus meeting (Efstathiou et al., 2011), carried out by two researchers independently (CM and AD). These statements and questions were discussed at a joint face-to-face and e-conference, leading to the production of 17 statements as an output of this process.

2.4 Statistics

Statistics for all 83 items include the median response and IQR. The ranked mean was used to rank items by relative priority. Consensus was measured by percentage of respondents giving either Top Priority or High Priority responses. Test-retest stability was assessed using Wilcoxin's ranked sum for each item. A p value below 0.05 indicated a statistically significant difference for items between Round 1 and 2, meaning poor stability between rounds (Kalaian and Kasim, 2012).

3.1 Results:

3.2 Participant Flow and sample:
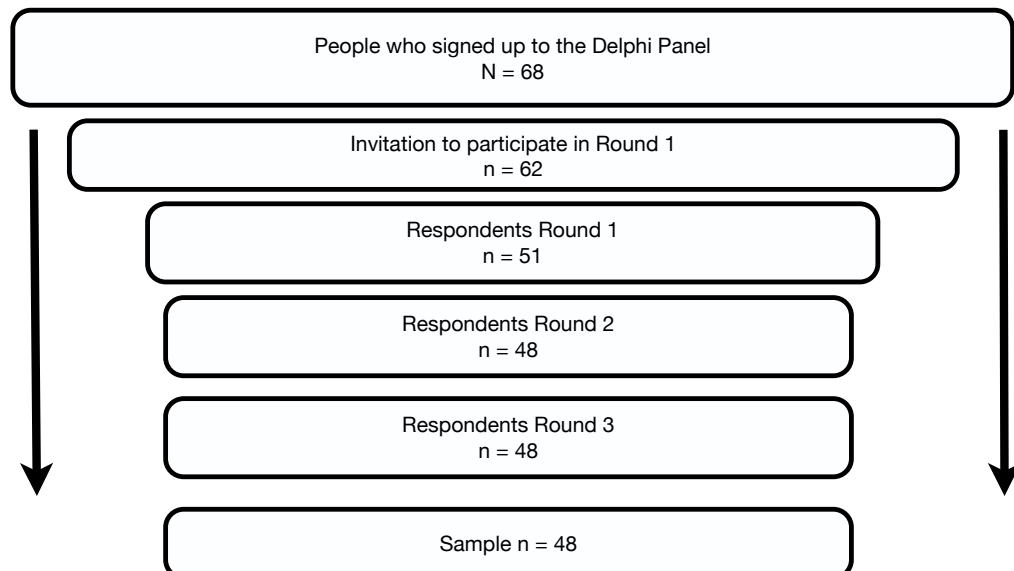
Figure 1: Participant Flow

Figure one demonstrates the flow of participants in this study. Eleven Panelists did not return a completed Round 1 questionnaire and were

therefore eliminated from further rounds. A further three panelists, invited onto Round 2 did not respond to this survey and were also removed from further analysis. This left 48 panelists to complete Round 2, 48 of whom completed the survey. This group consisted of 36 females and 12 males; twenty five participants (52.1%) were dental professionals and twenty three (47.9%) represented people with disabilities (Table 2).

Table 2: Professional profile of Panelists

|	Frequency	Percent
Total	48	100.0
Total Representing Dental Services	25	52.1
Dental Hygienist	2	4.2
Dental Nurse	4	8.3
General Dentist (mainly private)	4	8.3
General Dentist (mainly public)	9	18.8
Manager / Policy Maker	2	4.2
Specialist	4	8.3
Total Representing People with Disabilities	23	47.9
Disability Professional	14	29.2
Person/Parent	9	18.8

The panel represented a broad range of ages. Dental Service Panelists tended to be younger (median= 30-39 years) than those representing people with disabilities (median= 50-59 years; $p > 0.01$), but groups were otherwise similar. Geographically, participants from all four provinces of Ireland were included, though most were from Leinster, (n=33, 68.8%). Most participants were from urban settings (n = 37, 77.1%). The panel were associated with a broad range of disability types. Figure 2 summarises the responses from 27 respondents.

3.3 Data Collection:

Round 1: A total of 351 open-ended responses were collected from 51 respondents. Three researchers (CM, AD, SG) independently reduced

these items according to previously published methods (Dougall et al., 2013). Round 2: This process led to 83 distinct items, which were sent for ranking in Round 2. Consensus was achieved on many items at this stage: only 22 items had agreement at less than 80%. No items were considered Low or No Priority by the group after Round 2. Initial rankings are presented in Tables 3 and 4 in the appendices. Round 3: All experts from Round 2 completed Round 3. Thirty one items had 100% agreement while eleven had agreement at less than 80%. No items were considered Low or No Priority. Final Ranking: Table 3 demonstrates the final ten highest ranks and Table 4 demonstrates the final ten lowest ranks. These tables give a measure of consistency over rounds for the group as a whole. Table 5 lists the items, which showed the highest and lowest change over time (test-retest stability) within respondents is also available in the appendices.

Figure 2. Type of disability associated with panelists
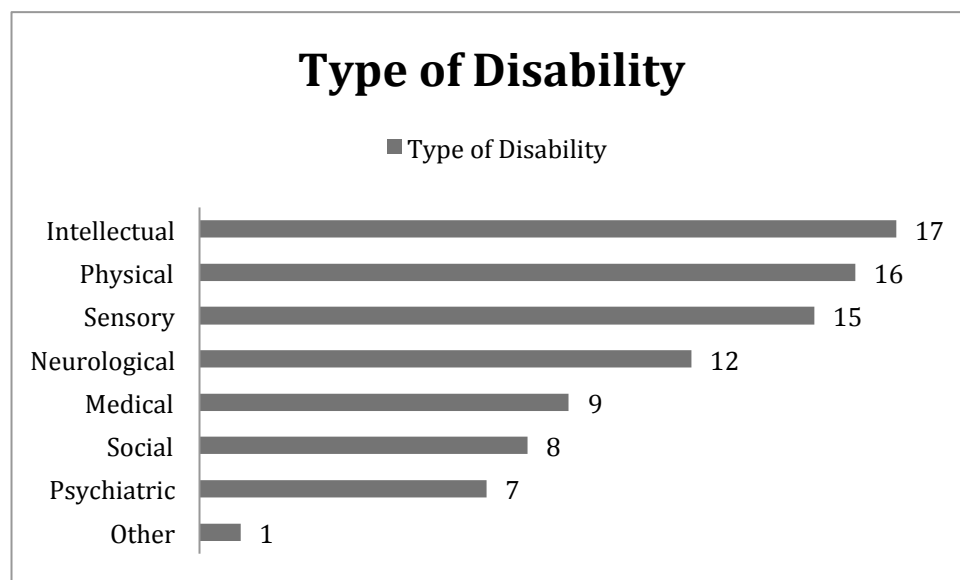
3.4 Consensus conference

All 83 items generated by the Delphi process were grouped thematically for review by the panel. Two researchers independently (CM AND AD) grouped items into themes generating 17 statements, reviewed by 21 panelists at a face-to-face conference. Table 6 represents the final ranking of statements generated by this round, along with the initial ranking, based on mean ranking of constituent items, number of items considered within each statement and the mean rank and mean level of agreement of constituent items.

4. Discussion:

4.1 Findings:

The aim of this study was to develop consensus amongst an expert panel regarding priorities for oral health services for people with disabilities using a Delphi survey design. This study achieved this aim by identifying 83 items which were of varying priority to dental service planners, users and their advocates. Further, this process generated 17 statements which can be used by researchers, practitioners and policy makers when asking: What should dental services for people with disabilities be like? This is a novel means of identifying goals for such services. Interestingly, Owens et al., using participatory approaches, to develop guidance on quality care for commissioners, found results similar to ours (Owens et al., 2010).

The list of items generated add to the evidence available for answering a fundamental service planning question, though the full utility of this list is yet to be explored. It is hoped that policy makers and commissioners can reference this list when planning services for this group of patients. The intention is that policy makers can reference the statements of interest and then explore the items within that domain that may give guidance as to the goals of the services which they may commisison. A measure of agreement and priority will enrich user understanding of these data. A full list of items is available at www.projectsmileireland.com.

4.2 Methodological issues

Retention and flow: The retention rate in this suvey was good at each stage. Most losses occurred in the initial round where 17.7% of those who had signed up and were selected to partake did not respond. Only a further 5.8% did not complete the succedent 2 rounds. This is a pleasing result as retention over rounds is a recognised problem in Delphi Panel research. It is felt that the use of email, and online data collection was a large part of this success. Additionally, the short timeframe between rounds was also felt to benefit the response rate. One challenge the team encountered was the need to generate Braille versions of rounds. Given the quick turnaround, this addition challenged both researchers and respondents causing challenge and delay, but doubtlessly enriched the data collected.

Table 6: Final statements generated by review of Delphi Panel Consensus following face-to-face meeting.

Final Rank	Statement	N included items	Mean rank of included items	Mean level of agreement
1	Oral health services should raise awareness of oral health among people with disabilities, their families, carers and non-dental, health professionals	2	3	100
2	Oral health services should be available and accessible	2	3	100
3	Oral health services should enable optimal outcomes for people with disabilities that meet individual need	4	9	99
4	Oral health services should be designed using defined care pathways.	4	11	99
5	Disability related training should be available to Dental Healthcare Professionals and students, appropriate to their need	6	13	96
6	Oral health services should be acceptable to people with disabilities	6	13	98
7	Oral health services should be structured to enable the targeting of specific groups and deliver care based on individual need	7	16	93
8	Oral healthcare should be available within an acceptable timeframe	2	20	96
9	Oral health training should be available for people, their families, carers and health professionals	5	20	99
10	Oral health services should be quality assured	4	20	86
11	Oral health services should be well resourced	4	22	93
12	A range of Oral health services including emergency, preventive, primary and secondary care, should be available as appropriate to individual need	8	23	90
13	Information and documentation should be accessible, and available in suitable formats where appropriate	4	26	91
14	Oral health services for people with disabilities should be integrated both with general oral health and non-Oral health services	7	27	94
15	Oral health services should be structured to enable frequency of care, appropriate to individual need	4	28	84
16	Care pathways should be developed that allow people to choose oral healthcare settings, appropriate to individual need	8	29	86
17	Novel funding models of oral health service for people with disabilities should be examined	3	41	52

Statements relate specifically to oral health services for people with disabilities. This is implied in most statements to reduce the burden in understanding items except where this phrase is needed to clarify the specific meaning of services.

Te statement: *Services should be accessible locally* (initial ranking 8, n=3, mean rank of included items = 17, mean level of agreement =94%) was removed during this consensus meeting and amalgamated with the Statement 2 as contributors felt that this represented needless repetition.

Face to face discussion: The face-to-face consensus meeting, which was well attended, led to the development of common themes among grouped items. This was done primarily to make it conceptually easier for participants (who were at this stage also knowledge users) to consider large sets of items concisely. The Face-to-Face consensus meeting enabled the group to clarify and agree meaning within statements and items.

At the outset, this study aimed to include 60 individuals in the sample, giving equal representation of disability and dental experts, to determine the full spectrum of opinion. This number was arbitrary as there is no clearly accepted guidance on sample sizes in Delphi Processes. As it happened, 48 individuals completed this study, including people with disabilities, their care givers/ parents / siblings and disability service providers/policy makers/ advocates as well as a range of dental healthcare professionals. This group was diverse and offered a broad range of opinions which contained some element of regularity across the sample.

4.3 Conclusion:

This Delphi Panel achieved its goal of achieving consensus on the question: What should dental services for people with disabilities be like? The items and statements generated by this Delphi Panel and summarised in this article represent an agreed set of priorities for dental services for people with disabilities in Ireland. This represents many challenges for the development of future policy, service development and research in this area of public health and special care dentistry. The pursuit of these goals will surely be engaging for those who wish to rise to this challenge.

4.4 Acknowledgements:

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6. Appendix

6.1 Table 3 Ten highest priorities (23 Items) as ranked by the panel after the third round around here

6.2 Table 4 Ten lowest priorities (14 Items) as ranked by the panel after the third round around here

6.3 Table 5 Test – Retest Stability: Items with the greatest and least variation in individual opinion between rounds

Table 3

Final Rank	Item	Initial Rank in Round 2	Round 3 level of consensus (% High or Top Priority)	Round 3 level of Consensus (% High or Top Priority)	Final Median Rating in Round 3	Reason For Disagreement
1	Dental services should be physically accessible	8	100	100	Top Priority	
1	Dental services should be person centred	6	100	100	Top Priority	
1	Dental services should be oriented towards prevention	8	100	100	Top Priority	
2	Carers and people with disabilities should be aware of the importance of oral health	3	100	100	Top Priority	
3	Dental services should be available	14	100	100	Top Priority	
3	All professionals should be aware of the importance of oral health for people with disabilities	7	100	100	Top Priority	
3	Dental care should be responsive to the individual needs of the person	11	100	100	Top Priority	
4	Dental services should be safe for patients	1	100	98	Top Priority	
4	Disability Training should be provided for dental students	6	96	100	Top Priority	
5	Dental services should be accessible	14	98	100	Top Priority	
5	Emergency access should be available for people in pain	4	98	100	Top Priority	
5	Dental services should enable people with disabilities, for example by maintaining the ability to eat and be comfortable	2	100	100	Top Priority	
5	Dental care should be individualised to cater for the individual needs of the person	11	100	100	Top Priority	

Final Rank	Item	Initial Rank in Round 2	Round 3 level of consensus (% High or Top Priority)	Round 3 level of Consensus (% High or Top Priority)	Final Median Rating in Round 3	Reason For Disagreement
6	Dental services should lead to quality oral health outcomes	5	100	100	Top Priority	
7	Facilities should be suitable for patients with disabilities	6	100	100	Top Priority	
8	Training should be provided for those involved in the oral care of people with disabilities	9	96	98	Top Priority	
9	Care Pathways should be developed that allow appropriate care based on individual need	10	98	100	Top Priority	
9	Care Pathways should be developed that allow people to access services early in life	4	98	100	Top Priority	
9	Dental care should be delivered by qualified care providers	18	91	100	Top Priority	
10	Dental services should be well resourced	15	100	100	Top Priority	
10	Oral Healthcare Training should be provided for people with disabilities	8	96	100	Top Priority	
10	Disability Training should be provided for dental care professionals such as hygienists and nurses	7	96	98	Top Priority	
10	Dental care professionals should be aware of disability issues	9	98	98	Top Priority	

Table 4

Final Rank	Item	Initial Rank in Round 2	Round 3 level of consensus (% High or Top Priority)	Round 3 level of Consensus (% High or Top Priority)	Final Median Rating in Round 3	Reason For Disagreement
34	Documents relating to specific impairments, such as epilepsy, should be available	29	78	81	High Priority	
35	Patients should have a choice of whether they use private or public dental services	34	63	83	High Priority	
36	Services should be structured to enable a choice of treatment options under general anaesthetic	33	65	77	High Priority	
36	Dental care should be coordinated with general healthcare, for example by using designated coordinators	31	76	85	High Priority	
37	Care Pathways should be developed that are lead by local dentists in primary care setting	37	70	79	High Priority	
37	Dental care should be only provided in hospital settings when necessary	42	57	77	High Priority	
38	Dental services should be structured to enable twice yearly review	33	70	70	High Priority	
38	Dental services should be structured to enable domiciliary care (home visits)	40	59	68	High Priority	
39	Dental services should be free, only for those who cannot pay	44	50	72	High Priority	
39	Dental services should be structured to enable	38	59	72	High Priority	

	yearly review				
40	Dental care should be dependent on the diagnosis of the individual	39	57	64	High Priority
41	Dental care should be dependent on clearly defined scope of service	41	48	49	Unsure
42	Dental services should be incentivised for private practitioners to encourage the treatment of people with disabilities	38	61	57	High Priority
43	Dental services should be totally free for all people with disabilities	43	46	28	Unsure