

Lives of Irish Adolescents who were born with a Cleft (LIA-Cleft)

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16th Annual Research Conference
9 October 2024

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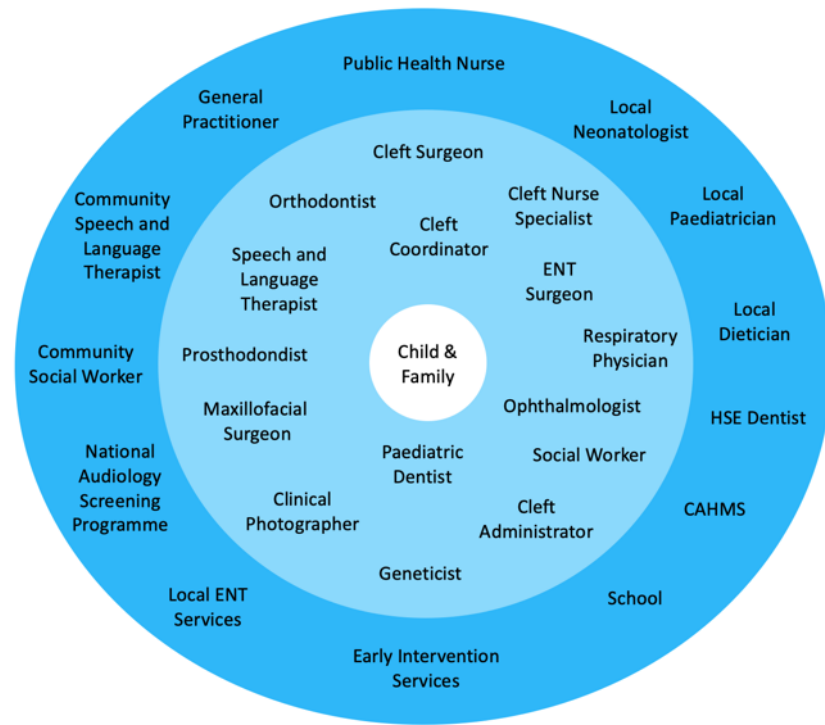
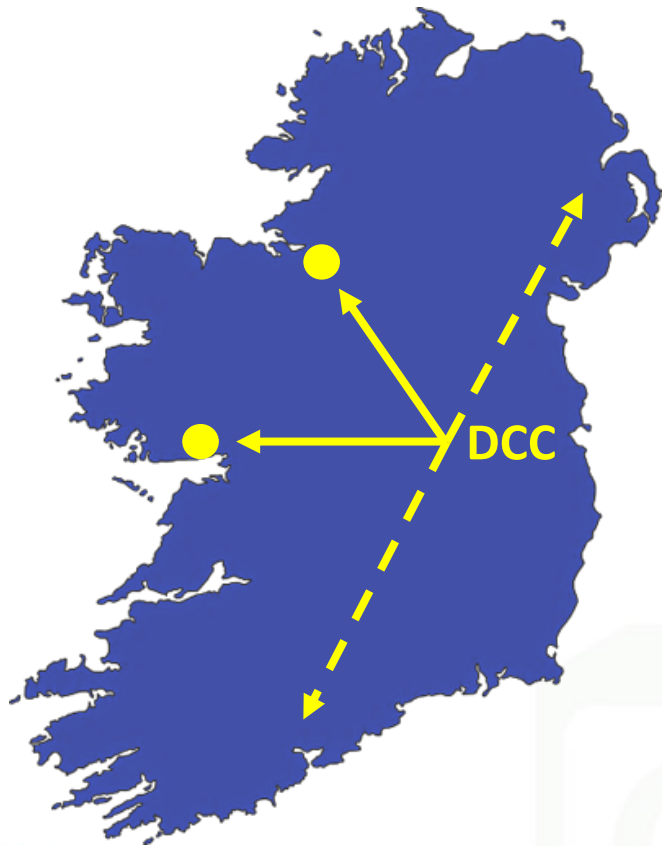
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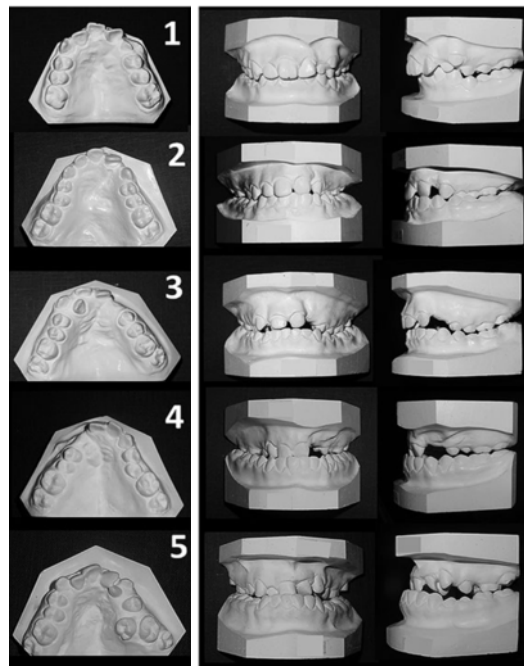


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Appendix 2 **Cleft Audit Protocol for Speech - Augmented**

Please rate all items. Omissions are ambiguous. Circle number '0' only if it is not possible to make a judgement

Name:		Date:	Audit No:
Date of Birth:	Age:	Centre:	
Male/Female:	First Language:	Therapist:	
Type of Cleft Structure:			
Background information (e.g. current URTI, Voice disorder)			

Insufficient speech sample to audit the case: 0

1. Intelligibility/Distinctiveness of speech

Rating	Description
0	None
1	Difficult from other children's speech, but not enough to cause concern
2	Difficult enough to provide concern, but possible to understand most speech
3	Only just intelligible to strangers
4	Incapable to understand

0

2. Voice

Rating	Voice Characteristics
0	Normal
1	Distinctive or abnormal voice quality

0

3. Resonance

3.1 Hypersensitivity

Rating	Description
0	Absent
1	Borderline - minimal
2	Mild - evident on close vowels e.g. egg, frog, up /u:/, /i:/
3	Moderate - evident on open and close vowels
4	Severe - evident on vowels and voiced consonants

0

3.2 Hypo-sensitivity

Rating	Description
0	Absent
1	Mild - partial demoralisation of nasal consonants and adjacent vowels
2	Moderate - demoralisation of nasal consonants - /m/, /n/, /ŋ/ and adjacent vowels

0

4. Nasal Airflow

4a Audible Nasal Emission

Rating	Description
0	Absent on pressure consonants
1	Occasionally heard on pressure consonants - < 3 examples on different sounds
2	Frequently heard on pressure consonants - > 3 examples on different sounds

0

4b Nasal Turbulence

Rating	Description
0	Absent on pressure consonants
1	Occasionally heard on pressure consonants - < 3 examples on different sounds
2	Frequently heard on pressure consonants - > 3 examples on different sounds

0



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Methodology

Lives of Irish Adolescents who were born with a Cleft

- ▶ GUI cohort '08 turned 13 in 2021, wave 6 data collection
- ▶ Cross-sectional cohort study, comparing 13-year olds who were born with a cleft to their peers in the general population
- ▶ Adapted **GUI Cohort '08** Age 13 questionnaires in partnership with PPI contributors
- ▶ Invited **DCC Cohort '07, '08 and '09** (n=271) to participate

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Results

Recruitment = 11%

- ▶ 30 participants – 9 female, 21 male
 - 15 Isolated cleft palate
 - 8 Unilateral cleft lip & palate
 - 6 Cleft lip only
 - 1 Bilateral cleft lip & palate

VS

- ▶ Wave 6, GUI Cohort '08
 - 6655 primary caregivers
 - 6375 young people

- ▶ *Non-responder analysis*
- ▶ *Power calculation*

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Results

Demographics

Variable	GUI	LIA-Cleft
<i>Respondents, n (%)</i>	<i>6655 (100)</i>	<i>30 (100)</i>
Sex, n (%)		
Male	3354 (50.3)	20 (66.67)
Female	3301 (49.6)	10 (33.33)
Age, years		
Median	13	14
Mean	13.05	13.63
Cleft type, n (%)		
Cleft lip only	.	1 (3.33)
Cleft lip and alveolus	.	5 (16.67)
SMCP	.	2 (6.67)
Cleft of soft palate only	.	8 (26.67)
Cleft of soft & hard palate	.	5 (16.67)
Unilateral cleft lip & palate	.	8 (26.67)
Bilateral cleft lip & palate	.	1 (3.33)
Syndrome diagnosis, n (%)	.	6 (20.0)

Results

Medical and dental health

Variable	GUI	LIA-Cleft	U	z	p
How would you describe your child's health ? (Scale 1-3, where 1=very healthy, 3=almost always unwell)			109023	2.052	0.04*
<i>Respondents, n</i>	6654	28			
Median	1	1			
Mean	1.28	1.46			
Range	0-3	0-3			
SD	0.51	0.576			
How would you rate the health of your child's teeth ? (Scale 1-5, where 1 = excellent, 5 = poor)			117393	2.13	0.033*
<i>Respondents, n</i>	6653	29			
Median	2	2			
Mean	2.02	2.55			
Range	1-5	1-5			
SD	0.944	1.298			

Results

Expected educational attainment

Variable	GUI	LIA-Cleft	U	z	p
How far parent expect child to go in education			98576	0.29	0.771
<i>Respondents</i>	6609 (100)	29 (100)			
Junior/Leaving cert or equivalent	343 (5.2)	3 (10.3)			
Apprenticeship or trade	410 (6.2)	1 (3.4)			
Diploma/Certificate	368 (5.6)	1 (3.4)			
<u>Degree</u>	<u>3452 (52.2)</u>	<u>14 (48.2)</u>			
Postgraduate/higher degree	1587 (24.0)	7 (24.1)			
Don't know	449 (7.0)	3 (10.3)			
How far child themselves expects to go in education			64996	-0.73	0.466
<i>Respondents</i>	5789 (100)	24 (100)			
Junior cert	59 (1.0)	0 (0)			
Leaving cert	617 (10.7)	1 (4.2)			
Certificate or diploma	711 (12.2)	7 (29.1)			
<u>Degree or higher degree</u>	<u>4402 (76.0)</u>	<u>16 (68.7)</u>			

Results

Psychological wellbeing

Variable	GUI	LIA-Cleft	U	z	p
Mental Health Inventory 5 (MHI-5) , child report (Scale 0-100, with higher score indicating good mental health)			67649.5	-1.07	0.284
<i>Respondents, n</i>	6173	25			
Min	28	40			
Max	100	100			
Mean	78.3029	75.84			
SD	14.88255	15.42638			
Short Mood and Feelings Questionnaire (SMFQ) , child report (Scale 0-26, with higher score indicating poorer mental health)			9568.5	-1.025	0.305
<i>Respondents, n</i>	3024	8			
Min	0	0			
Max	21	8			
Mean	6.1703	4			
SD	5.69779	3.8172			
Strengths and Difficulties Questionnaire , parent report (Scale 0-40, with 40 representing maximum difficulty)			113496.5	1.653	0.98
<i>Respondents, n</i>	6649	26			
Min	0	0			
Max	23	20			
Mean	6.975	8.7241			
SD	5.423	5.9455			

Results

Psychological wellbeing

Variable	GUI	LIA-Cleft	U	z	p
"How satisfied are you with your life these days?" (Scale, 1-10, with 10 being maximum satisfaction), child report			60727	-2.201	0.028*
<i>Respondents, n</i>	6173	26			
Min	0	0			
Max	10	10			
Mean	8.05	7.19			
SD	1.557	2.227			
Rosenberg self-esteem scale, summary score, child report (Scale 0-30, with higher score indicating higher self-esteem)			61689	-1.964	0.049*
<i>Respondents, n</i>	6096	26			
Min	5	4			
Max	18	18			
Mean	13.3159	11.96			
SD	2.91114	3.77869			

Results

Friendship

Variable	GUI	LIA-Cleft	U	z	p
Victim of bullying in last 3 months			100960	0.994	0.32
Respondents (PCQ)	6619 (100)	29 (100)			
Yes	572 (8.6)	1 (3.4)			
No	6047 (91.4)	28 (96.6)			
"I have made new friends"			68648	-1.116	0.264
Respondents (YPQ)	6186 (100)	25 (100)			
Strongly agree	2596 (42.0)	13 (52.0)			
Agree	3437 (55.6)	12 (48.0)			
Neither agree nor disagree	53 (0.85)	0 (0)			
Disagree/Strongly disagree	100 (1.6)	0 (0)			



Results

Activities

Variable	GUI	LIA-Cleft	U	z	p
Weekday time playing video games			88380	0.641	0.521
<i>Respondents (PCQ)</i>	<i>6360 (100)</i>	<i>26 (100)</i>			
None	2695 (42.4)	11 (42.3)			
Up to 1 hour	1097 (17.2)	5 (19.2)			
1 hour to less than 2 hours	1097 (17.2)	4 (15.4)			
2 hours to less than 3 hours	548 (8.6)	4 (15.4)			
3 hours to less than 4 hours	205 (3.2)	0 (0)			
4 hours to less than 5 hours	51 (0.8)	1 (3.8)			
5 Hours or more	31 (0.5)	1 (3.8)			
Physical activity for at least one hour over last 7 days			73274.5	-0.995	0.32
<i>Respondents (YPQ)</i>	<i>6342 (100)</i>	<i>26 (100)</i>			
None	208 (3.2)	1 (3.8)			
1 day	270 (4.3)	3 (11.5)			
2 days	598 (9.4)	1 (3.8)			
3 days	900 (14.1)	6 (23.1)			
4 days	1057 (16.7)	4 (15.3)			
5 days	1129 (17.8)	3 (11.5)			
6 days	663 (10.5)	3 (11.5)			
Every day	1517 (23.9)	5 (19.2)			
Have own social media profile			75582	-1.572	0.116
<i>Respondents (YPQ)</i>	<i>6367 (100)</i>	<i>26 (100)</i>			
Yes	5814 (91.3)	26 (100)			
No	553 (8.6)	0 (0)			

Summary

LIA-Cleft group

- ▶ Reported poorer medical and dental health
- ▶ Similar responses regarding friendship, bullying, physical activity, social media and screen time
- ▶ Less satisfied with their lives
- ▶ Lower self-esteem
- ▶ No difference in measures of mental health and wellbeing or socio-emotional wellbeing



Lessons learnt

and future opportunities

- ▶ Challenge of recruiting teenagers
- ▶ Broad nature of data collection in a national longitudinal study

- ▶ GUI Cohort '24
- ▶ Other congenital conditions

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FOUNDATION**

Crumlin • Temple Street • Tallaght • Connolly

Supporting Children's Health Ireland

♥ LIA-Cleft participants & PPI Contributors

Helena Scully
Aidan Beegan
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**RESEARCH
AND
INNOVATION**

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